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Development of a standardized social service pathway for children with complex cerebral palsy: The social production of disability

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Abstract

From a cultural-historical perspective, the impairments of a child with a condition like cerebral palsy (CP) have biological origins, but the disability evolves from the mismatch between the child and his/her social conditions for development (Vygotsky, 1993). One example of this dialectical production of disability can be seen in the challenge of the 21st-century welfare state: How to provide economically feasible health and educational services anchored in evidence-based methods and practices. Standardized social service pathways for children with CP illustrates an attempt to address this challenge and moderate the mismatch by acting in the intersection between impairment and society. The aim of the article is to analyze challenges in the practice of connecting research and practice-based knowledge with societal practices in order to diminish the disability of the child. A multidisciplinary group assembled by the Danish National Board of Social Services engaged in a

practice of developing a guideline for a social service pathway. Agendas and minutes from their series of meetings provide insight into how the work evolved through conflictual discussions. Rather than a neutral transformation of knowledge into practice, the practice revealed itself as a value-laden process in which the needs of the child and family were at times decentred and the focus shifted to how social services could be realised in complex, structured social practices. While the group managed to overcome several conflicts and agree on a social service pathway, a socio-economic analysis was unable to argue for the comprehensive social service pathway as an economic sound choice for municipal decision-makers. The conflict between the welfare ideology and economic feasibility remains unresolved and can be expected to limit the extent that impairments can be remedied and the mismatch decreased. Overcoming or diminishing the mismatch might never become economic worthwhile. As the political pendulum oscillates between welfare and economic concerns, the experience of disability will likewise diminish or expand.

Keywords: Social services pathways, welfare, cerebral palsy, standardization, disability, social organization

Introduction

The Nordic welfare societies are based on a common ideology about enhancing individual autonomy while ensuring equal opportunities for all citizens to participate in society. Central to the welfare idea is that health care and education should be free for all and that social services and financial compensation should be available for those with temporary or permanent illness or impairments. In practice, all kinds of medical interventions, educational services and social services are delivered within a historically developed and socially structured setting. Despite a high rate of taxation relative to other European and Western countries, in Nordic welfare countries currently, the welfare ideology is realized by balancing a comprehensive public responsibility to support citizens' needs on the one hand and restricted economic resources on the other. In addition to economic constraints, the 21st-

century welfare state also faces the challenge of how to ensure high-quality health and educational services anchored in evidence-based methods and practices. Based in a Vygotskian view of disability, the aim of this paper is to analyze challenges associated with turning multidisciplinary best knowledge into a comprehensive and orchestrated practice for children and youth with disability within a historically developed welfare society structure. As such, the paper will discuss the challenge of how to connect research- and practice-based best knowledge about disabilities with social and societal practices in order to address the social barriers associated with life with a disability.

This paper will focus on children and youth with cerebral palsy (CP). CP is an umbrella term for a condition caused by a congenital or early acquired brain lesion. The main symptom of CP is motor impairments that affect posture, balance and control of the body and the muscles. In addition, people with cerebral palsy often, but not always, have associated impairments in sensation, perception, cognition, communication and/or social functioning (Bax et al., 2005). Studies have also shown that children with CP are more likely to develop psychological and psychiatric problems than their peers (Bjorgaas et al., 2012; Rackauskaite et al., 2016). The severity of CP symptoms – both motor impairments and associated problems – varies considerably from person to person; some have mild CP with discrete aberrations in the functioning of one hand, while others have severe CP with no control over their posture or their upper and lower limbs, no verbal language, and substantial psychological and social challenges in their daily lives. People with CP are therefore a good example of a diverse group of people with disabilities for whom the welfare state has an obligation to develop services.

Disability as a dialectical concept

In order to analyze and discuss how to connect research- and practice-based best knowledge about disabilities with social and societal practices, we need to explicate how we

understand disability. In scholarly work on disability and society, social-contextual model approaches have been dominant (Shakespeare, 2006). Proponents of social-contextual models accentuate a sociological approach that focuses on social factors that cause barriers to equal social participation for people with disabilities. Biological differences are mainly seen as part of a continuum of biological differences shared by all of us (Reindal, 2008). Recently social-contextual models have been criticised for being too focused on the social oppression of people with disabilities while ignoring other aspects of disability, and different writers have proposed ways to approach disability that seeks to embrace the reduced function of the individual along with the social barriers to participation (e.g. Shakespeare, 2006). Although the dialectical approach to disability was formulated long before this debate, it provides a useful solution to the problem of how to connect individual and social aspects of disability.

The dialectical understanding of disability departs in the central idea in cultural-historical thinking that all aspects of human development arise from shared activity in historically and culturally developed practices (Vygotsky, 1993). The dialectical approach acknowledges and includes social barriers to participation in its analyses (Böttcher and Dammeyer, 2016); however, the central contribution of Vygotsky's dialectical approach lies in his understanding of the role of biological differences. A single child's development takes place within socio-cultural activity in which the child's participation is enabled, transformed and constrained by shared activities and social support. Expectations regarding what a child is able to accomplish with and without support are often based on the age and often the gender of the child as well as cultural values and conceptualizations about childhood and socio-biological maturation. For example, in Denmark, activities in first grade (age 6) will be short, concrete and often play-based according to culturally widespread conceptualizations about the young schoolchild's cognitive maturation.

This building of socio-cultural expectations and social support is based on the most widespread forms of participation and therefore on individuals whose psychophysical constitutions fall within the most typical range (Vygotsky, 1993). The often difficult development of children with disabilities, such as those with severe CP, can be seen as the result of a *mismatch* between the biological and physical development of the child on the one hand and the structure of cultural forms in which the child is living on the other (Vygotsky, 1993). Mainstream cultural-historical institutions do not support and accommodate the development of children with atypical psychophysical constitutions as well as they support those with typical psychophysical constitutions (Vygotsky, 1993). Due to the way CP affects motor and cognitive functioning, a child with severe CP will often find it difficult to participate in mainstream learning activities without support. From the dialectical vantage point, the most crucial difference between children with and without disability lies in their access to active participation in social areas that support children's learning and development and how this access affects the development and developmental opportunities for the child over time. The *impairments* of a child with a condition like CP have biological origins, but the *disability* evolves from the mismatch between the child and his/her social conditions for development. For children with disabilities and their families, the aim is not only to remove social barriers in the here-and-now but also to support the child's developing physical functioning and learning of skills through treatments and supportive social and educational services that acknowledge and address the condition in itself. Thus, knowledge about individual, biologically based challenges functions as a prerequisite for providing relevant physical treatment and social and educational services. By basing our analysis in Vygotsky's dialectical approach to disability, we open up the possibility to discuss the challenges of turning multidisciplinary best knowledge into a supportive practice for children with severe CP in an attempt to moderate the mismatch.

Historical background: why it was necessary to develop a new national practice for children and youth with complex cerebral palsy

The need for a new practice of support for children and youth with severe CP arose out of a particular historical and structural situation. Welfare delivery in Denmark had historically been organized in three organizational layers: the state, the counties (13) and the municipalities (271). All children with CP received health care from the hospitals organized by the counties. Children with severe CP also received more specialized services, such as consultations with a speech and language pathologist or a special school placement, organized at county level. The county-level institutions were able to specialize and uphold their level of expertise in complex or rare types of disabilities such as severe CP, due to more specialized work tasks, being confronted with a certain quantity of children with complex or rare conditions, and forming professional groups with expertise in specialized areas. Children who required less specialized social and educational services, such as children with mild CP and their families, were served by the municipalities.

In 2007, this organization was restructured and the counties were abolished. Some of their activities, mainly hospital-based health care, were transferred to five new regions. However, most of their activities were transferred to the municipalities. Smaller municipalities merged to create a larger base for their operations, resulting in 98 municipalities across Denmark.

At the time of this national organizational reform, a *National Counselling Service* was set up, which was organized under the *National Board of Social Services* at state level and was part of the Social Ministry. The municipalities could request counselling free of charge from the National Counselling Service on questions related to social work, such as educational and welfare services for children and adults with disabilities, in particular in relation to complicated cases (Ministry of Welfare and Ministry of Education, 2009).

In the years after the reform, user organizations reported that the quality of welfare services for people with disabilities deteriorated (Den Offentlige, 2017). An evaluation of the National Counselling Service revealed that the referral process was too bureaucratic. Municipal social workers more often sought knowledge in their local professional network rather than from the National Counselling Service, even in complicated cases (Rieper et al., 2008). Furthermore, many municipalities sought to solve their welfare tasks locally rather than buy services from specialized institutions (if these institutions now belonged to another municipality). The declining demand for services from specialized institutions (such as special schools or housing services) undermined their economic foundation and, in some instances, their continued existence. While this decline in demand paralleled a general societal move towards the inclusion of children and adults with disabilities in mainstream settings, the concern was raised that this change in social service provision could lead to a loss of specialized knowledge and experience about relevant social and educational support for groups with rare or complex conditions (Ministry of Finance and Domestic, 2013). Social workers, teachers and other professionals at the municipal level would come across the rare and complex cases too seldom to build a knowledge base on which to ground decisions about relevant and necessary social and educational services. To counter this concern, a new law instituted the *National Coordination* in 2014, organized as part of the National Board of Social Services (Retsinformation, 2014). The aim of the new National Coordination was to gather up-to-date knowledge of effective methods and best practices within the field of social work in relation to its target group and distribute this knowledge as guidelines to ensure its use. Target groups cover rare and complex conditions calling for an orchestrated practice between professionals with highly specialized knowledge in the particular area. The National Coordination immediately began work collecting up-to-date knowledge about different rare

and complex conditions and making this easily available to the municipalities as *guidelines for social service pathways*¹. All guidelines are available online free of charge.

Service pathways as standardizations

Service pathways are already known from the health sector as *care pathways*. Care pathways are defined as “a complex intervention for the mutual decision-making and organization of care processes for a well-defined group of patients during a well-defined period” (Vanhaecht et al., 2007 in Schrijvers et al., 2012). Care pathways are professional tools that introduce a standardization for health care, including treatment goals, treatment practices, work divisions and optimal sequencing of different parts of the treatment. They were originally imported from production management theories and developed within the health sector to enhance the quality of care across the involved professionals, improve patient outcomes, promote patient safety, increase patient satisfaction and optimize the use of resources (Vanhaecht et al., 2007 in Schrijvers et al., 2012). They were also used to induce evidence-based treatments and practices throughout local practices and improve inter-professional coordination within or across care settings or health sectors (Hunter & Segrott, 2008). As mentioned above, cerebral palsy is often associated with a wide range of impairments that will affect the social participation of the child and his/her family. In a welfare society like Denmark, this produces a substantial need for both social services and health services. The guidelines for social service pathways from the National Coordination were intended to help municipal leaders identify needs for specialist services in the social and

¹ In 2014, the National Board of Social Services published its first two guidelines for social service pathways for children with children and youth with congenital deafness or loss of hearing, and children and youth with severe visual impairments. Since then, the National Board of Social Services has developed guidelines for children and youth with verbal dyspraxia (2017) and rare disabilities (2019), among others.

educational area, allocate resources and coordinate social services for citizens with rarer or more complex conditions, possibly across municipalities, through cooperation or by buying into each other's services (Ministry of Finance and Domestic, 2013). In this regard, the social service pathways can be seen as a way to approach the dilemma of how to provide an economically efficient service that also addresses social and educational needs with evidence-based methods and best practices. Thus, the guidelines for a social service pathway were intended to become a tool that shapes how municipal leaders think about their social and educational service for children with severe CP and their families.

Development of guidelines for a social service pathway for children and youth with complex CP

The task for the National Board of Social Services and the National Coordination was to collect up-to-date knowledge about identified target groups and transform it into suggestions for social service practices. However, the employees were all generalists without expert knowledge of CP or any of the other disabilities and conditions for which they assigned the task of developing national guidelines. The National Board of Social Services therefore invited participants with particular knowledge and/or a particular position within the social service organization across Denmark to participate in the development of the guidelines. The tasks of the participants was to both provide scientific and practice knowledge and transform it into suggestions for a standardized social service pathway.

The National Coordination identified children and youth with severe CP as a relevant target group for a guideline for a social service pathway. Participants were invited to a workgroup or a reference group. For a *workgroup* of this kind, the National Board of Social Services usually invites people from The Municipal National Organization and Danish Regions. The Danish Health Authority and the Ministry of Education are invited when the

target group requires services across the health and social sector and requires special needs education services (National Board of Social Services, 2018), as was the case with children with severe CP. Other invited participants are those with expert knowledge about the target group. The workgroup developing the guideline for children with severe CP consisted of eighteen people and included professionals from various special institutions (special daycare institutions, special schools, and special youth education and habilitation units), representatives from the Danish Neuropediatric Society and the Danish Neuropsychological Society, and various other people with expert knowledge about CP from research or practice. Thus, a wide range of relevant professionals were represented (including pediatricians, psychologists, physiotherapists and music therapists) but not every relevant profession was represented (occupational therapists and speech- and language pathologists were not represented). The work group participants had their travel costs refunded but received no other compensation for their time. The *reference group* usually includes patient groups and user groups. In the present example, the reference group consisted of nine people and included participants from the CP user organization CP Denmark and ISAAC Denmark (the International Society for Augmented and Assistive Communication). In addition, representatives from municipal school support offices, a consultant from the national counselling service (under the National Board of Social Services), and a researcher in CP and social participation participated in the reference group. Members of the reference group received no compensation for their time either.

A practice for how to construct the guidelines had already been developed through work with previous guidelines. A generic structure for the guideline existed, based on the already finished guidelines. The workgroup participants were invited to four day-long meetings, led by representatives from the National Board of Social Services, with pre-defined tasks designed to generate and further develop content for a particular part of the guideline.

Since these tasks stimulated discussions and conflicts, a fifth meeting became necessary to refine both the content and structure of the guidelines. Meeting agendas and minutes from the meetings were drawn up by the participants from the National Board of Social Services.

Between meetings, employees at the National Board of Social Services transformed discussions from the workgroup meetings into text and sent out the draft guidelines to both work and reference group members, who read and commented on the text between meetings.

We present the practice of constructing the guideline through condensed descriptions of the agendas and minutes from the five workgroup meetings. In the analysis, we consider how the practice of drawing up a guideline for a social service pathway for children with complex CP evolved through different kinds of conflicts and contradictions. Conflicts are identified in the agendas and minutes as prolonged discussions (e.g. the same item is carried through several meetings until a solution is reached) and unresolved issues (e.g. the theme might be present in one meeting only, but the solution does not resolve the contradiction).

Condensed content and discussions at the work group meetings

First work group meeting. The three main items on the agenda were (1) what is a guideline for a social service pathway (2) a clear definition of the guideline's target group and (3) a refinement of the literature review.

The initial literature search and subsequent literature review were completed by employees from the National Board of Social Services, but in order to ensure the completeness of the guidelines' knowledge base, the workgroup was asked to help refine the search terms. However, the main discussion in the minutes regarded how to delineate 'severe CP'. Initially, the target group was labeled "severe CP", but a demarcation was required to make it clear when children and youth with CP crossed the line into severe CP. In research as well as everyday common sense understandings, the severity of CP is frequently collapsed with the severity of the motor symptoms. Thus, children with a Gross Motor Function

Classification Scale (GMFCS) score of IV or V (<https://cerebralpalsy.org.au/our-research/about-cerebral-palsy/what-is-cerebral-palsy/severity-of-cerebral-palsy/gross-motor-function-classification-system/>) can be considered as belonging to the group of children with severe CP. However, this way of classifying CP severity is based in a mainly medical approach to CP. The medical approach to severity might be meaningful when evaluating the need for physical treatment such as physiotherapy, but was considered less useful by the work group participants when evaluating the need for social and educational services. Workgroups at the meeting discussed how to delineate the target group in a more useful way.

Second work group meeting. The agenda had two main items: (1) a follow-up discussion of how to define the target group and (2) ideas about what would constitute a good social service pathway for the target group. This item was commenced by the question; *What types of social services are needed for the target group and when?*

The minutes reveal that the discussion about how to delineate the target group was continued into the second meeting, addressing further refinement in the definition such as how to include comorbidity between CP and other impairments and whether impairments in social participation belonged in the definition of the target group or later in relation to need for social services. The employees at the National Board of Social Services would rework the definition in preparation of the third meeting.

In the second part of the meeting the participants brainstormed about which social services the target group would need either continuously or at specific developmental time points (e.g. prior to school start). The brain storm produced a very extensive list of social services – at the meeting with post-its on a large time line on the wall, but in the minutes each suggestion was placed in a table (either with a specific timeline e.g. ‘Youth period age 16-17’ or ‘Continuous social services through childhood and adolescence’) and two columns added asking “Which professionals will be involved?” and “What is the effect of the service for the

child (and its family)?”, and thus anticipating the content of the third meeting. As a final comment, it was added that it is important that the work group participants aim only to include social services and methods that are agreed upon among their professional specialist group as efficient and applicable in a Danish context.

Third work group meeting. Three main items were on the agenda. (1) the delineation of the target group, (2) the demography of the target group and the type and amount of social services they typically receive (e.g. special education) and (3) how to organize and coordinate all the different services and social interventions deemed central at the previous meeting.

The representatives from the National Board of Social Services had agreed that ‘severe CP’ was inaccurate to delineate the target group. The guideline in process was renamed ‘guidelines for a social service pathway for children and youth with complex consequences of CP’ (in this article shorthanded to complex CP) and, while the GMFSC was retained in the description of the group, the GMFSC scores were not used to delineate the target group. The definition of the target group had now been written up as qualitative descriptions, stressing the complexity of the constellation of impairments and the impact of social participation, next to the globally accepted definition of the whole CP group. Further discussion at the third meeting addressed smaller refinements in the wording.

The qualitative delineation of the target group created problems for the next item; a demographic description of needs regarding of social and educational services. The limited data typically regarded the whole CP group with possibilities for breaking down into the different GMFCS groups. Furthermore, data existed only on a very limited scope of social and educational services. Thus, it was only possible to sketch the amount of social and educational resources needed by the target group.

The third item regarded how service initiatives could be implemented in the structured welfare system. The previous meeting had generated a proliferation of (suggestions for)

social service efforts necessary to secure thorough social and educational services for children with complex CP and their families. Such a proliferation was not surprising – it motivated the development of guidelines in the first place – and, whilst continuing to generate ideas for relevant social and educational services, the discussion focused on how to organize the different professionals and activities within the current institutional bureaucracy of the Danish welfare society. Some of the recommended services would cut across sectors. For example, the cost of providing aids could fall into the regional health sector or the municipal social sector, and disputes sometimes arose and delayed the provision of the aid. The division of health and social services and the layered structure of the welfare system raised questions about how to resolve problems arising in the interface between different sectors, e.g. the regionally organized health sector and the municipally organized social sector. This complex structure also raised the issue of who should coordinate the different services and how the various professionals involved could integrate their contribution within the entirety of the social service provision. Discussion also stressed the need for the municipality to coordinate efforts to ensure services were efficient and that someone was in charge of identifying new needs when children with complex CP transitioned from one (institutionalized) life period to the next, such as evaluating need of educational support when children transitioned from kindergarten to school. Thus, while the discussion about the good social service pathway was rooted in the participants' professional knowledge about what the child and his/her family would need in different life periods, a lot of the meeting time became devoted to how different parts of the social service would be organized and who would be responsible for which task.

Fourth meeting. The draft version of the guideline generated three items on the agenda: (1) the complexity of service delivery within the welfare system discussed at the previous meeting had generated a long list of questions regarding conflictual responsibility

and mutual coordination and integration, (2) a discussion of what kind of competences professionals would need to be able to deliver adequate services in this specialized area and (3) how to illustrate the social service pathway visually.

The long list of the questions and the discussion of the visual illustration both regarded how to address the interface with health services, even though the guideline was aimed at describing social and educational services. During the second item, the work group split up in groups of different professionals who worked at specific part of the guideline text that described either what professional competences were needed to be able to provide the specialized services needed by this group or a more detailed description of the specialized service itself.

Fifth meeting. The main item on the agenda was to present and discuss an economic scenario analysis to conclude the guideline. The aim of economic scenario analysis is to help leaders formulate strategic goals. The National Board of Social Services and the workgroup wanted to argue that early and timely interventions, even if costly, might be economically worthwhile when considered on a long-term basis. To support municipal leaders in the decision to grant extensive and expensive social services early on, the work group had helped gather information on two real cases of people with complex CP: one who had not received timely support and one who had. An economist at the National Board of Social Services subjected the two cases to socio-economic scenario analysis. The costs of each case scenario were calculated on the basis of available information, e.g. information given by the parents about what type and amount of social and educational services they and their children had received. Thus, the comparison between the two cases was subject to several limitations, such as the parents' ability to remember and describe past life experiences. Unfortunately (in relation to the argument for early investment), the scenario with timely support came out as more expensive than the scenario in which support was provided very late, around the entry

to adulthood. Discussions about how to interpret and present the socio-economic scenario analysis took up the meeting.

Following the fifth meeting, the National Board of Social Services finished the guideline text, shared it with the work group member with invitation to comment before a deadline, after which the guideline was published on the National Board of Social Services homepage (National Board of Social Services, 2019).

Analysis: Drawing up a guideline for a Social Service Pathway for children with complex CP evolving as a conflictual practice

Before the first meeting took place, the National Board of Social Services had already developed a practice for how to construct social service guidelines, even though they needed the specific knowledge of the work group participants fill in content in the (1) definition of the target group, (2) the types of social practices that would be necessary to ensure a ‘good’ life for children with complex CP and their families and (3) how to realize the assembly of social services in the structured welfare system. While this work plan is fairly straightforward, conflicts did arise and had to be solved before the construction process could move forward. In a dialectical perspective, the conflicts are windows to understand more about the mismatch that produces disability and thus the analysis will look closer at central conflicts in the construction process and how they were resolved.

Defining the target group. The definition of the target group was planned as an item mainly for the first work group meeting, but turned out to be conflictual and generated extended discussions into the second and third meeting.

The National Coordination was instituted to develop welfare services for citizens receiving support from the highly specialized social area and the *highly specialized* special needs education area (National Board of Social Services, 2018). Since not all children with CP would be in need of *highly specialized* social and educational services, the workgroup’s

first task was to formulate a definition that could delineate the target group from the larger group of children with CP. However, the mainly medical understanding of severity was considered incongruent in the allocation of social and educational services. One or more of the so-called ‘accompanying’ impairments – such as impairments in cognition, communication or perception, should also be taken into account when considering severity. In addition, several work group members tried to argue for a much more inclusive approach than allowed by the National Board for Social Service and its commission. A more inclusive definition of target group was seen as an opportunity to stress the need of a wider set of social services for as many children with CP (and their families) as possible and thus an opportunity to better adjust the mismatch between children with CP and their families’ needs for social services and their current level of services experienced by the work group participants in their various social positions. The tension in how to define the target group affected the construction practice in the continued discussions of the definition beyond the first meeting. The representatives from the National Board of Social Services was adamant on their practice being only for those in need of the ‘highly specialized’, this being based in the law. The conflict was resolved in the sense that the work group members accepted the narrow nature of the target group, but were successful in including their knowledge about the complexity of CP and changing the title of the guideline (from ‘severe’ to ‘complex consequences of’). Further, the impact of social participation became included in the definition of the target group, thus moving the definition from a medical to a more social and developmental approach.

Imparting knowledge or reifying professional standards and standpoints. The aim of the guideline construction practice was to gather the best up-to-date knowledge and structure it in an easy-to-access and easy-to-use way. To do so, the development of the guideline went beyond the neutral transformation of knowledge into development of practice

recommendations from the second meeting and onwards. However, the participants in the workgroup brought with them both knowledge-based and value-infused ideas about what type of efforts could potentially diminish the mismatch and support better life conditions for children with complex CP. The discussions about what types of social services ought to be recommended, commenced at the second meeting, produced conflicts between professional standards. Firstly, the workgroup included health sector professionals with a (natural) science background and social and educational sector professionals with a social science background. These two broad groups among the work group participants had different standards for a ‘service’ and what type of ‘evidence’ would be needed to argue that a service was well-founded and ought to be included in the guideline. Secondly, the professional specialists at the workgroup each brought with them particular standpoints on controversies within their field. The psychologists argued that the content of the recommendation for a psychological evaluation needed to be explicated to ensure a particular type and level of psychological evaluation. The physiotherapist likewise felt that a physiological evaluation of function and needs for intervention would require a particularly thorough assessment. Similarly, the pediatrician argued it was essential to include multiple assessment points for evaluation, as the consequences of the non-progressive brain lesion is known to change over time. The guidelines were thus also treated by the work group participants as an opportunity to reify professional values and potentially influence how fellow professionals, such as psychologists or physiotherapists, would carry out the recommended tasks. From the point of view of the employees at the National Board of Social Services, extensive text about professional standards could potentially lengthen the guideline and run counter to the aim of providing an easy-to-use tool. At the fourth meeting the representatives from the National Board of Social Services asked the work group member to consider and discuss the required level of description rather than the description of particular professional standpoints. Furthermore,

recommendations of particular professional practices or methods were to be justified preferably by scientific literature. Thus the conflict was partially resolved by all participants agreeing on the inclusion of more general descriptions of the content of the services provided by different professionals, while specific methods, tools and level of professional skill was left out. The conflict between science-based and social-science based recommendations for services were not resolved. Instead, the different types of services figure side by side in the finished guideline, a point we will revisit in the discussion. Furthermore, a new conflict arose between the agreed-upon definition of target group and research being based in medical definitions, thus making it difficult to argue for services using research.

The conflict between a user- and a system focus. Even though the target for the guideline was children with complex CP and their families, many considerations and discussions from the second meeting and onwards regarded the social system and relegated the children and their families to the background. From the vantage point of the dialectical disability approach, this shift in perspective is inevitable because children with complex CP and their families have to act in a society that is primarily adapted to children with typical psychophysical constitutions. The guidelines for a social service pathway is a top-down initiative designed to repair the mismatch associated with a rare and complex condition. The mismatch probably existed before but became exacerbated by the particular cultural-historical situation; the municipal re-structuring reform. However, it is not only the families of children with complex CP who have to act in social institutions not designed for them. As the workgroup discussion about interfacing problems at the third meeting revealed, the system seemed structured towards more straightforward tasks than the very complex needs of families in need of the most specialized services across sectors. The municipal restructuring was designed to bring social services closer to their users, but social services mainly became tailored to more frequent social and educational needs and challenges. The mismatch

experienced by children with complex CP and their families regards both the *interaction between different impairments*, e.g. it requires specialized knowledge to psychologically assess a child without verbal language and with extensive upper motor impairments, and the *interaction between different professionals organized in different practices* in the welfare system. The practice of creating a social service pathway separate from health services was only grounded in the fact that the health sector and social sector were separately organized and nationally organized under different ministries. The mismatch is thus also produced by section interfaces, institutional transitions and lack of clarity in the division of responsibility. Professionals working within the system are repeatedly caught in conflicts about who is responsible for services and expenses. The attempt of the participants to ensure inscription of particular professional standards in the guideline reflects their frustration with the mismatch between the child's needs and the current state of affairs where children and families lack essential services, are offered services by professionals without sufficiently specialized knowledge and services are un-coordinated. In a dialectical perspective, the problem addressed by the social service pathway guidelines is that rare types of disabilities and conditions fail to influence and shape the system in a bottom-up process in which the constant pressure of particular problems force a system change. The problems – and perhaps sub-optimal solutions – experienced by 1-2 families per year do not strain the municipality sufficiently for them to acknowledge the children's and families' more complex needs for comprehensive early intervention and services. The construction of guidelines for social service pathways for complex CP and other rare conditions represents an attempt to short-circuit a much-needed system change in the direction of a smaller mismatch. The task of the guideline for a social service pathway is to reconnect the needs of a child with complex CP and his/her family with a highly structured and often bureaucratic system by a top-down initiative because the bottom-up pressures do not work with rare conditions.

The conflict between economic and humanistic arguments for 'investing' in the early life of the child with complex CP. The suggested social service pathway, which featured a comprehensive set of social services throughout childhood, would be expensive for the municipalities. However, the social service pathway is only a guideline, and the National Board of Social Services does not have authority to direct municipalities to follow it. The municipalities are only obligated to adhere to the relevant laws, which are less specific and comprehensive as to which social and educational services should be offered to children with complex CP and their families. Practical experience suggests that municipal decision-makers may prefer cheaper short-term decisions and postpone more expensive solutions, though this experience is not supported by documentation. Thus the socio-economic scenario analysis in the final chapter of the guideline was intended as an economic incentive to provide the child and the family with extensive support early on.

The two real-life cases both regarded a child with extensive motor impairments, no verbal language, need for augmentative and alternative communication (AAC), and no intellectual disability. In scenario 1, the child had not received a proper psychological evaluation. He was wrongly assumed to be intellectually disabled and placed in a special school. He did not receive any support in AAC development at school. It was only once he finished compulsory school that a psychological evaluation revealed he had much higher intellectual potential than was previously thought and, through an intensive intervention, the now young man learned to express himself by AAC and began to read and engage in many more activities. However, he needed therapy to cope with mental health problems that seemed associated with his former social seclusion. In scenario 2, the child received an AAC solution and support in how to use it from an early age. The child went to a mainstream kindergarten (with practical assistance) and planned to go to a mainstream school and high school (the child in this scenario was about to begin school and the scenario was extrapolated

from the educational trajectory followed by other, somewhat older children with similar impairments). The age difference between the two children in these scenarios meant that they had grown up in different versions of the Danish welfare society. For example, over time, other parents' efforts in procuring the gaze-controlled Tobii computer for their children with severe CP opened up this opportunity for other and younger children with severe CP (Böttcher, 2019), such as the child in scenario 2. Thus, rather than being directly comparable, the two case scenarios were illustrative of late versus early social and educational support.

Unfortunately in relation to the economic argument for early investment, scenario 2 came out as more expensive. Expenses in the two scenarios were distributed differently, with more expenses in the early years in scenario 2 and more expenses later on in scenario 1. The economic analysis thus underlined the point that, considered across the whole of childhood, the difference in expenses would even out, provided the early intervention had the desired effect. However, a conflict was still obvious between the type and level of service deemed necessary by the work group from a welfare perspective and the reality of restricted economic resources.

The representatives from the National Board for Social Services and the work group members were united in their frustration about the conflict between their welfare intent and the outcome of the economic scenario analysis. Subsequent discussions at the fifth meeting regarded alternative arguments for the expensive social service pathway. Going back to previous meetings, arguments for services had mainly been along the line of physical, psychological and social well-being and development for the child and support of the family as a whole. Thus, the whole endeavor to argue in economic terms was in conflict with the concept of welfare, whose main aim is not to generate economic value but to ensure equal opportunities for all citizens to participate in society. The extensive nature of the impairments of children and youth with complex CP precludes a completely self-sustained adult life no

matter what social and educational services are provided in childhood and youth. Still, the social and educational services were thought to generate values beyond what can be measured in economic analyses. The welfare-informed argument for early interventions (such as support using ACC) will be that early development of AAC skills have subsequent positive repercussions for quality of life. Thus, even though the aim of the socio-economic analysis was to argue for social services in economic terms, the work group ended backing up in a humanistic position, arguing for quality of life as a value in itself. This conflict was thus handled, but could not be resolved.

Discussion: How a standardized social service pathway feeds into the social production of disability

The practice of drawing up guidelines for a social service pathway can only be understood when considered within the wider socio-cultural and historic situation. The National Coordination and the practice of drawing up guidelines for social service pathways emerged in answer to a historical situation following the Danish structure reform that increased the mismatch between children with complex or rarer types of disabilities and the forms of social support. The lack of specialized knowledge at the municipal level made it difficult for the decision makers and service providers in the municipalities to fulfill the welfare tasks they became responsible for. The National Coordination and the practice of drawing up social service guidelines was developed in order to repair the new mismatch between locally provided welfare and the need for specialized knowledge. The willingness of the workgroup participants to devote their time to the task (without monetary compensation) and the discussions during the meetings revealed that the participants were motivated by the idea of providing children with CP and their families with better developmental support, each from their particular professional position. Thus the employees at the National Board of

Social Services and the work group participants were aligned in regard of the goal of the practice of drawing up the guideline.

Based in this wider socio-cultural situation, the aim of the guidelines was to ensure the social practice as a whole and the specific social services became more founded in specialized knowledge, ideally backed by research literature. However, the analysis revealed that the translation of ‘best knowledge’ into social practice also evolved from productive conflicts of various kinds. In this conflictual practice, the literature review and familiarity with the body of research knowledge in relation to CP was indispensable, but the knowledge base was mediated through the subjective perspectives of the participants, who all contributed as particular, positioned professionals. In addition to their scholarly and/or professional specialized knowledge about complex CP, the work group members each provided (partial) knowledge about current structures and practice known from their particular social positions, knowledge that was indispensable in putting together an orchestrated social service pathway. The complexity of CP and the welfare structure called for a practice of sequential discussions during which the work group as a whole created an overview of what social and educational services would be needed, when and provided by which professionals. The organization of the process – multiple meetings, agenda items carried over from one meeting to the next - was designed with the purpose of generating discussions as they were considered productive to the process of piecing the knowledge of all the participants together. Some conflicts were resolved, others were only partly solved.

The conflict that emerged as part of the task of defining the target group reveals a truly dialectical process in which the solution to one conflict or contradiction bring forth new contradictions. Work group members strived for an inclusive target group description that was at odds with the overall purpose of the national coordination. While this conflict was solved by the change of focus of the target group from severe physical symptoms to overall

complexity and barriers to social participation (while keeping the narrow definition of children and youth in need of highly specialized social and educational services), the re-definition of the target group created new conflicts. The original definition of ‘severe cerebral palsy’ based on severity of motor impairments departs in a medical approach to CP. This approach was deemed unfeasible for the provision of social and educational services and an alternative definition of complexity written into the guideline. However, the redefinition created a new conflict at subsequent meetings as research had to be found that supported particular methods and services and research typically uses the GMFSC or type of motor symptoms to delineate groups. Thus the creation of a socially and educationally more meaningful description of the target group made it difficult to connect research with recommendations. The partial resolution of this new conflict was to accept that research backing social and educational services precisely for the target group was non-existent and instead include research in the literature review for the whole CP group or subgroups based in medical divisions incongruent with the target group.

Service pathways have been characterized as hybrid constructions of evidence-based standardization and features from local situated practices within the implicated institutional systems (Hunter & Segrott, 2008). This hybrid nature can also be recognized in the practice of developing the social service pathway. Furthermore, the practice of discussions gathered the knowledge and former experiences of ‘good practices’ along with visions about how things ought to be (e.g. the discussion about particular professional standards of service provided by psychologists, physiotherapists and pediatricians at meeting four). The value-infused and constructive nature of the social service pathway suggests that social service pathways can be hybrids between research evidence, knowledge of current best practices and professional values, merged as a possible ideal(ized) social service pathway. The suggested new best social service pathway might never have occurred this way previously. Stenner

(2016, p.147) writes that “standards mediate values, and in doing so aim to generalize them”. The subjective refraction of knowledge influenced what knowledge was deemed important and how research results should and could be translated into social and educational efforts that would constitute a ‘good’ social service pathway and create a ‘good’ life for children with complex CP and their families. The social service pathway suggests when and why to conduct specific work tasks and thus contains relatively specific reified values about what would constitute a good social and educational service delivered by professionals (Nissen et al., 2016). The standardization regards municipal leaders in particular, but to some extent it also regards the wide array of other professionals involved in the different social and educational services. The guidelines for a comprehensive social service pathway propose how professionals ought to act and how society ought to act to minimize the impact of impairments and create as good conditions for social participation for the children and their families as possible.

In the construction process, the conflict between nature-science based and social-science based services was never solved and the different services figure side-by-side in the finished guidelines. Thus, the social service pathway guidelines offer no advice regarding decisions about priority. This omission could be considered as a weakness in the construction process. A discussion about priority would have given rise to serious conflicts about whose professional role/intervention was more important in relation to other services and professions. However, another line of argument would suggest that children with complex CP are a heterogeneous group and that how to solve the mismatch of a particular child/family cannot be standardized. Research suggests that it is difficult to develop standardized pathways for groups with great variation and complexity (Hunter & Segrott, 2008). In cases of target group with variable conditions service guidelines do well in providing suggestions about how to exercise professional judgement rather than adhering to a strict directional

approach (Allen et al., 2009). For the social service guideline for children with complex CP, it will be a matter of professional judgement whether children with CP belong to the target group because the medical categorical approach was replaced by the emphasis on a qualitative evaluation of the compound of impairments and the complexity of interactions between several impairments. In this regard, the workgroup and the practice of the workgroup contributed to a new construction of the disability group by the shift from a definition of the target group based in motor impairments to a definition highlighting multiple impairments and complexity as barriers to social and educational participation.

The construction of the social service pathways as a system-focused and service-agency-based approach is a top-down approach (King & Meyer, 2006), even when the developmental practice involve the professionals and open up for bottom-up feedback as in the current example. A standardized service pathway as a top-down approach collides with another trend within social services: to work in a child- or family-centered way. In the construction process, the needs of the child and his/her family were often decentered and the focus shifted to how the disability was embedded in complex, structured social practices. The family-centered approach features mainly as a recommendation to support the family holistically rather than just focusing on the child; for example, by supporting parents to participate in parent-to-parent networks or to master being the parent of child with substantive impairments. A true family-centered approach would build the intervention bottom-up from the aims and concerns expressed by the family (King & Chiarello, 2014). Although the recommendations in the guidelines were based on the participants' extensive experience with many families with children with complex CP, these recommendations are still perceived and formulated from the professionals' perspectives. No parents participated in the workgroup or reference group. An argument against a mainly top-down standardized social service pathway could be that social and educational efforts might not address

problems and challenges deemed central by the family and the child. The counter-argument from the dialectic disability approach would be that the family-centered bottom-up approach loses sight of how the disability is produced by the mismatch with the structured welfare system rather than ‘owned’ by the family (also Ward, 2011). From their bottom-up perspective, the family may not have enough insight into the system to be able to suggest the systemic change actually required to ameliorate the problem. The guidelines represent an attempt at such a systemic change. However, the family have unique insight in the mismatch experienced in everyday settings and thus their perspective could very well contribute relevantly to the practice of developing social service pathways. This critical conflict between top-down and bottom-up perspectives on how to diminish the mismatch did not arise in practice of developing the guidelines as families were not included in the workgroup. Research in the area of neurodevelopmental disorders found the families preferred services to be centered about the child and family rather than deficits and impairments (McAllister et al., 2018). Thus the inclusion of families could potentially have opened up productive conflicts that might have moved the guideline for a social service pathway in a different direction. The inclusion of families might also have generated new points of view on the unresolved conflict regarding priority between different services. At least research suggest that parents are crucial links between service delivery processes and child outcome (Dempsey & Keen, 2008) and that the involvement of parents in decisions about health care and social services are associated with higher satisfaction about the received services (King et al., 2004). Thus the unresolved conflict of prioritization might benefit from discussion and description of how to include the family in the decision process and thus base decisions about priority on the concrete family situation.

In a Vygotskian perspective, the aim of the idealized pathway is to minimize the mismatch as much as possible by creating the best possible developmental opportunities for

the child. The guidelines suggest ways to spend municipal economic resources to ensure the best standard of social service, but the comprehensive service offer is still expensive and a new conflict arose as the suggested social service pathway could not be argued to be ‘a better investment’ than a lower social service standard, at least not in a strict economic sense. The partial solution suggested that the comprehensive service pathway is still an investment in the quality of life. The crucial nature of early and timely social support for life-long quality of life resonates with other research in the area (Bjarnason, 2002). Municipal leaders and other professional agents may very well be persuaded by the argument about investing in quality of life. However, even a humanistic-minded municipal director may be forced to consider which types or levels of service are economically feasible.

The contradiction between quality of life and economic feasibility is perhaps the most salient example of how conflicts arising in the practice mirrored conflicts or contradictions in the wider welfare system. Thus, the conflict about how to define the target group will also be present in the welfare system, as professionals in the social and educational sectors experience that medical designations and categorizations are not useful for their purposes or do not lead them to all children in need of social and educational services. The unresolved conflict about welfare versus economic resources and how to prioritize between different services when economic resources are limited are conflicts present in the everyday lives of both professionals and families outside of the social service path construction practice. The unresolved conflict within the workgroup mirrors the balancing of the welfare state itself between undertaking the comprehensive public responsibility to support citizens’ needs on the one hand and considering the restricted economic resources on the other. Remembering the main point of the dialectical approach that disability evolves from mismatch, the ongoing balancing between welfare and economic considerations will affect how the disability of the child evolves. The guideline is aimed at municipal decision-makers, because they have a

gatekeeping function in the allocation of resources for educational and social services due to their economic responsibilities (King & Meyer, 2006). However, the conflict between the welfare ideology and economic feasibility remains unresolved and can be expected to limit the extent that impairments can be remedied and the mismatch decreased. Overcoming or diminishing the mismatch might never become economic worthwhile. As the political pendulum oscillates between welfare and economic concerns, the experience of disability will likewise diminish or expand.

Conclusion

According to the dialectical approach, disability arises from a mismatch between individual biologically based impairments and conditions for participation in social settings. This mismatch is not stable, but changes over time in response to variations in social support. In the present example, a particular historical and social situation set off by a large-scale municipal restructuring had changed how social support for individuals with disabilities were provided. Both professionals and user organizations described a deterioration in support and thus a situation of increased mismatch between impairment-based need of support and the social services that were provided, with possible long-term repercussions on the child's developmental opportunities. A report had interpreted the problem as 'lack of specialized knowledge' and a new practice of knowledge distribution was created with the National Coordination and their development of guidelines for standardized social service pathways. A standardized social service pathway is society's way of entering a value-laden ethical space based on the welfare idea. In this paper, our aim was to outline the challenges associated with turning multidisciplinary best knowledge into a comprehensive and orchestrated practice for children and youth with disability within a historically developed welfare society structure. The practice of constructing a social service pathway called for extensive and sometimes conflictual discussions about how to define a 'severe' disability group in terms relevant to

social and educational service provision and how to ensure an orchestrated and professionally acceptable social service practice for children with complex CP and their families. The ideal(ized) social service pathway created in the process can be seen as a reification of societal and professional subjective values about the ‘good’ life and professional standards for services and is an example of how sociality – by setting up the National Coordination - produces and transforms what disability is and what it can become. The development of a tool such as guidelines for a social service pathway operates in the space between disability as an individually carried condition and disability as a social position mediated by social support and opportunities. Societal ideas and professional practices related to particular impairments or conditions feed into this mismatch and potentially alter how impairments are transformed into disabilities. If the social service pathway is successful, opportunities for active participation in educational activities potentially decrease the disability, as the child gains new competences. However, if it is unsuccessful, insufficient support of the child or the family will continue to constrain their social participation and amplify the disability both in the short and long term. Resolved conflicts, e.g. the definition of the target group, may have positive repercussions on social and educational service allocation because they help service providers understand their task more clearly. Unresolved conflicts; e.g. welfare versus economic considerations and how to prioritize between different services, on the other hand may continue to preserve or increase the mismatch. Prospectively, the practice of developing social service pathways ought to supplement the top-down approach with bottom-up input directly from the concerned target group: the children with complex CP and their families.

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Declaration of interest

All of the authors of this paper were involved in the development of the guidelines for a social service pathway for children with complex CP.

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