

Shadow categorizations – Children with 'special needs' and the ethical work of parenting: minding the gap!

Bjørg Kjær¹ 

^{A1} *Danish School of Education, Aarhus University, Tuborgvej 164, 2400 Copenhagen NV,
Denmark.*

Drawing on analyses of how, during the 20th century, explicit processes of social distinction morphed into languages of niceness and, further, into various categories of pathology (Löfgren, 1991; Conrad, 2007; Horwitz, 2002; Brinkmann, 2014), I explore some of the contemporary consequences of this transformation in a Danish context. Focusing on everyday experiences of parents of children with so-called special needs, I highlight their concerns and hopes, analysing what happens when they encounter those who work in welfare state institutions. Inspired by anthropology of policy (Wright, 2017), I view these parents' actions, efforts, and negotiations as a form of micro-policymaking, with an analytical emphasis on what Mattingly (2013) describes as everyday ethical work. Interactions with welfare state professionals such as early childhood educators and schoolteachers are part and parcel of parenting, especially in a Nordic context. In this ethical work, the parents face different gaps they need to handle.

Keywords: Parenting children with special needs, Early Childhood Education and Care, ECEC, shadow categorization, everyday life perspective, anthropology of diagnoses, ideals and realities

Introduction

The origins of contemporary parenting ideals in Denmark and its neighbouring countries can be traced back as far as the emergence of the modern nation state and subsequent transformation into welfare states and, some have argued, competition states (Pedersen, 2011). As Nikolas Rose has shown, ideals of motherhood became firmly established as defining feminine traits from the 1800s (Rose, 1999). The increasing institutionalization of children's lives during the 20th century, especially in Scandinavian countries, has not diminished social and cultural imaginaries concerning the importance of parents in

general and mothers in particular – leading some to coin the term parental determinism (Furedi, 2002; Lee et al., 2014). Thus, ideals and practices of parenting and mothering have been and remain intertwined with cultural and societal discourses. The ethnologist Orvar Löfgren (1991) has analysed changes in lines of social distinction over time in his native Sweden, outlining how an implicit discourse focused on whether or not people are “nice” became dominant. This change followed the emergence of the Swedish welfare state, known as “the people’s home” (*folkhemmet*). Within this narrative, distinctions were drawn along lines of “niceness”, with groups who were previously categorized as “dangerous”, “improper” or “wrong” now referred to using terms related to being less nice (ibid.). This made it possible to maintain social boundaries while at the same time promoting a narrative of equality. In her text *Egalitarian individualism*, Norwegian anthropologist Marianne Gullestad (1992) analyses a Scandinavian cultural trait whereby equality is understood as intrinsically linked to homogeneity and sameness. Hence, it becomes difficult to deal with difference. Gullestad shows how divides are established through increasingly subtle processes of building and maintaining what she calls symbolic fences that blur the delineation through a focus on polite communication that seemingly transgresses distinctions. However, these symbolic fences are never crossed; despite the narrative of equality and inclusivity, some groups remain excluded from the homogeneous, white, middle-class community, which is characterized by ideals of consensus, informal positivity, and “niceness” (ibid.; Löfgren, 1991). These implicit cultural distinctions, focused on personality traits such as niceness, raise the question of how differences are handled and understood when they emanate from bodily and/or (neuro)psychiatric difference. In this regard, many have argued that society has become “medicalized” (Conrad, 2007, 2006; Hacking, 1998), that the 20th (and 21st) century has witnessed a process of “pathologization” (Horwitz, 2002; Rosenberg, 2007), and that the contemporary discourses represent a “diagnostic culture” (Brinkmann, 2017; Rose, 2015). This medicalization or pathologization can be seen as building on and expanding the niceness-no-class imaginary.

In the following, I explore some contemporary examples of what happens when parents of children defined as having special needs approach staff in Danish kindergartens to ask them to apply their professional expertise to help their child. I examine how

communicative norms and roles are applied and handled in relationships between parents and ECEC educators.

Ethics at work

To analyse what is at stake for these parents, I draw inspiration from the anthropologist Cheryl Mattingly (2012), who offers an everyday perspective on moral and ethical work. Describing mundane daily routines as a moral laboratory where ethics are understood not as an intellectual activity, but as embedded in everyday actions – a form of practical philosophy – Mattingly characterizes this laboratory as:

...a metaphorical realm in which experiments are done in all kinds of places and in which the participants are not objects of study so much as researchers or experimenters of their own lives... (Mattingly, 2012: 309).

Such ethical experimentation is part of most parents' everyday practice, but according to Mattingly, it is particularly accentuated among marginalized groups that are dealing with issues of stigmatization and problematization (ibid.). When a child is diagnosed as having "special needs", it plunges the parents into an unknown social and cultural landscape at the margins of or outside "normality" (Davis, 1997). Mattingly's analytical gaze highlights processes of experimentation that are seemingly necessary for parents to get their bearings and act in response to these new and unfamiliar circumstances – mainstream logics and experience do not suffice. It is these exploratory practices and the moral labour related to social and cultural agents that are my focus. As this perspective insists on striving to understand people's agency, I find it both analytically rewarding and ethically sound.

Methodology

The research was conducted by a group of researchers, who produced an extensive body of empirical material through joint ethnographic fieldwork conducted 2016-17¹. This

¹ The cases presented here emanated from the research project Ready Children – imaginaries and practice between family and ECEC. This project was placed at the Danish Center for Research in Early Childhood Education and Care (CeDiF) and focused on relations, meaning-making processes

fieldwork was conducted in three kindergartens, all of which worked with children whose ages range from six months to five years. The fieldwork focused on the times of day when parents drop off and pick up their children. This focus was chosen to explore the interactions between staff and parents. In Denmark, parents are expected to help their children remove their shoes and any outer garments and, before leaving, to ensure the child has made contact with a member of staff and/or some of the other children.

The fieldwork also included observations of specific activities aimed at preparing the oldest children for school. Qualitative interviews were conducted with parents and early childhood educators (in all 62 persons), and two workshops were held with the educators employed at the participating kindergartens. Observations were also conducted during a series of so-called school readiness conferences, where parents and teachers met to talk about the child in preparation for the transition to school. Additionally, a series of qualitative interviews were conducted with parents of children with special needs and with the educators (Danish: *pædagoger*) working with these children.

In this article, I draw upon those parts of the empirical material that concern children with special needs and the interactions and communication between adults concerning these children. This material comprises transcripts from separate interviews with ECEC educators and parents, meetings where both parents and educators participated, and field notes from observations of their interactions during meetings and as part of everyday practice. I view these interactions as the locus of negotiations concerning children's school readiness in particular, and parenthood and normality in general. The examples in this article are chosen to illustrate different parenting strategies that the parents sought to apply in their encounters with ECEC, focusing on the parents' roles, experiences, and positions. This focus was chosen out of a sense of ethical responsibility to give the parents of children with special needs a voice – a group that is often “othered” (Spivak, 1985; Jensen, 2011). Most research on educator–parent relations implicitly or explicitly takes the professionals' perspective, with parents' experiences often perceived to some extent as a disruption that educators need to handle (Jahreie,

and interactions connected to pedagogues' and parents' assessments of children's school readiness. A detailed description of the theoretical and methodological approach can be found in Bach et al., 2020, chapters 1 and 10.

2022). Children with ‘special needs’ are particularly dependent on the educators that they meet in ECEC, their parents, *and* the collaborative and communicative interaction between these parties. It is therefore important to highlight these processes, and the experiences and reflections of both educators and parents, even though this raises ethical dilemmas regarding how to handle findings that may be opposed to prevailing norms and ideals. I consider it important to present the parents’ own voices to avoid perpetuating such norms and ideals, which tend to downplay and thereby reproduce systemic marginalization and stigmatization. In order to balance this ethical dilemma, I have chosen to moderate the descriptions of specific situations and to consider all actors’ intentions and rationales while maintaining the parent perspective.

The Danish context

My interest here is focused on the parents of the minority of children who are not considered ready for school – children who are in marginalized positions, who are problematized and seen as being different from most other children, and, consequently, where various diagnoses are considered. Since 2009, it has been mandatory for all children in Denmark to attend a so-called kindergarten class in preparation for primary education from the year they turn six. Before this reform, parents could decide to postpone their child’s school start, whether because they considered the child to be immature, as having general or specific issues, or for ideological reasons. After the reform, most municipalities only allow a child’s school start to be postponed following some kind of psychological, medical or psychiatric examination.

The current situation seems to have strengthened the aforementioned tendency towards pathologization (Horwitz, 2002). The Danish psychologist and philosopher Svend Brinkmann argues that we live in a society characterized by “diagnostic cultures” (Brinkmann, 2017) in the sense that more and more aspects of human suffering are perceived as pathological conditions – as diseases (often in the brain) that can be identified and diagnosed. In my earlier research focusing on everyday life perspectives and experiences, I developed the concept of ‘shadow diagnoses’ to describe the phenomenon ‘shadow categorization’ when analysing everyday dimensions of such diagnostic cultures, as they were omnipresent and played a crucial role in day-to-day practices (Kjær et al., 2020; cf. Bruner, 1990). Shadow diagnoses and categorization thus

refer to the everyday use of psychiatric concepts and diagnoses in contrast to ‘authorized’ medical use (Kjær et al., 2020).

Findings

Diagnoses in everyday interaction

Among both the educators and parents in this study, the context outlined above seemed to have instilled an awareness of the possibility that a child might “have” some kind of diagnosis. It is striking that the majority of parents and educators alike perceived a diagnosis as something a child “has” and that is discovered or revealed through various tests. In the kindergartens, psychiatric diagnoses had permeated everyday language, where they were used to understand and interpret the children’s actions and behaviour (Kjær et al., 2020; Ohlsson, 2011); i.e., diagnoses were used as shadow categories. In the following example, this terminology was used during a conversation between educators and parents at one of the kindergartens. One of the educators had spoken to a mother on the telephone about their concern for her four-year-old son. During the conversation, both the educator and the mother referred more or less intentionally to the category of autism. At first this caused conflict. The educator explained:

ECEC educator: It was about... Well, was it the educator who had said that the child was on the autism spectrum? Or was it the mother who had put the words in the educator’s mouth, because she [the educator] had talked a lot about how we saw the child. And there were doubts. It kind of drew a clear battle line between us. Because this happened during a phone call, and the words exchanged there... The mother thought my colleague had said: “it’s almost autistic sometimes”. And my colleague basically thought that the mother had said: “I hear you describe it as if it almost becomes autistic sometimes”.

Björg: Yes...

Educator: And the issue is that we are not allowed to use that word about a child here

The conflict came about because educators are not authorized to diagnose children, but only to describe the child’s behaviour and present any concerns they might have to the

parents and to the municipality's psychological consultancy unit. The example illustrates how early childhood educators are expected to be aware of the various diagnostic categories and thereby ensure that any issues are identified (and diagnosed) at an early stage, but they are not considered to have the necessary expertise to make such judgements and must therefore also avoid using the categories when discussing the children in their care.

The example also illustrates that both educators and parents are aware of these categories, which affects how they observe, describe, and assess the child. For both parties, these categories were so self-evident that it was unclear who actually mentioned autism. The key issue here is not who said the a-word (that it sometimes almost becomes autistic). It is striking, however, that it seemed so natural to compare the child's behaviour to a neuropsychiatric diagnosis that, at first, nobody perceived it as anything other than the mundane use of categories and terms originating from psychology and psychiatry. Like when someone says: I am so depressed to indicate that they are in a bad mood. Or when someone tidies up and excuses themselves by saying: "It's my OCD".

The words became significant and a cause of conflict precisely because they were uttered in a conversation between an educator and a parent. In this situation, the educator has a specific role as a representative of the kindergarten and her profession. The conflict emanated from a situation where the child was being problematized in such a way that a comparison with a particular diagnostic category was perceived as relevant and obvious.

The fact that only child psychiatrists (and specially trained clinical psychologists) are authorized to diagnose children with autism was used by the mother as a critique of the educators. In Denmark, ECEC educators can describe children and, with parental consent, request a psychological assessment. The psychologist can then ask for further psychiatric assessment at a child psychiatric unit. Despite this strict and hierarchical division of professional roles and responsibilities, parents and educators in this and many other examples refer to the child's situation in ways that draw on signs, symptoms, and concepts from the world of psychiatry. This can be seen as an expression of a diagnostic culture, resulting in the mundane use of diagnostic categories, whether implicitly or explicitly in the form of *shadow categorizations*.

This normalization of psychiatric knowledge and use of shadow categories can be understood as part of what are considered "good", legitimate, and well-informed

parenting practices. Parents (as well as educators) are expected to be aware of signs of “dysfunctions” and “deviant development”, and this mother demonstrated a detailed conceptual apparatus concerning what constitutes normal child development and what might be cause for concern. In this regard, she performed “good”, almost “ideal”, parenting during her casual conversation with the educators. This approach had proven advantageous up until the point when her son’s behaviour was identified as especially concerning. A considerable part of her everyday ethical work involved dialogue with the staff at her child’s kindergarten, where she demonstrated that she was well-informed and acted as a reasonable and “nice” partner in the collaboration between kindergarten and home by acknowledging and affirming the authority and competence of the educators. The educators saw her as a very loving, caring, and considerate mother with whom they had a good relationship. Meanwhile, when the conflict began, this all changed. The mother’s ethical work in the form of her concern about the risk of stigmatization associated with diagnostic categories was now seen as a sign of disrespect and criticism of the educators. The pivotal moment was when she emphasized the legal or formal division of labour and associated roles and responsibilities that is embedded in the organizational structure at the municipal level. By doing so, she rejected dominant ideals for the enactment of the relationship between parents and educators, breaking the spell of informal, consensus-seeking, “nice” and “friendly” communication (cf. Kjær, 2003; Löfgren, 1991; Gullestad, 1992).

Negotiating normality

When shadow categories and official diagnoses are at stake, a need to negotiate the boundaries between normality and deviance (in a broad sense) emerges, as evident in the empirical material. As categories of deviance or “not normal” are often implicit for various reasons, ECEC educators and parents are able to describe their concerns with regard to a particular child in ways that point either towards a diagnostic category or in the direction of factors in the child’s social context. In cases where the educators have serious and long-term concerns about the child, parents engage in different forms of negotiations and/or conflicts about how to interpret their child’s situation or difficulties. A recurring theme in these negotiations are the parents’ efforts to maintain a degree of humanity and normality. Such negotiations should be seen as parents’ attempts to ensure

that educators consider their child's unique personality and personal history rather than reducing them to a particular shadow category or diagnosis. When educators' concerns regarding a child turn to an understanding of that child as a problem requiring diagnosis, urgent questions arise regarding the risk of stigmatization. In some cases, however, diagnoses are unavoidable due to the obviousness of the child's difficulties. The five-year-old girl Noor provides one such example.

Maintaining a degree of normality and humanity

Noor's mother Hala highlighted the ways in which Noor is normal, using an approach in which she tried to negotiate the extent of the scope and consequences of her syndrome. Hala explained how shocked and unhappy she became when staff at her daughter's kindergarten said she was intellectually disabled because of a congenital syndrome and suggested that she ought to attend an institution for children with special needs. Hala argued that the severity can vary among children with this syndrome, and that Noor was a late developer due to the number of surgeries she had undergone but was not intellectually disabled:

Hala: Of course, she was a bit behind in her development, but a lot of kids are. Some are behind with speaking, because they just are, some are a bit behind with words... It's not necessarily because there is SOMETHING WRONG. So, I became quite upset, and a bit nervous... when they said: "So, we think she is a bit behind". I told them: "Come on, she has been through so much! I think she has done very well to come this far. I think she is very strong, and she is doing great".

Björg: How do you feel about how they see her now?

Hala: Well, the new group she's in [gives a thumbs up]... It was in the nursery that I felt that they did not feel secure in having her there, and they had labelled her, that she was not like the other kids.

Björg: How did that show itself?

Hala: ...I had told her [the educator] the name of the syndrome, and then she googled it. And the syndrome Noor has, some of the kids have mental retardation, but Noor just didn't have all the symptoms. But she just said: "I can read here, online, that it says they are mentally

disabled”. Then I became pretty angry. Because, if the doctors have said that Noor is well functioning, and she is developing well... It is quite obvious because she talks and thinks normally. So, I got really angry, actually, because she is diagnosing my daughter. And then, because she had read it on the internet, then she [Noor] must be mentally disabled.

The educator, who had no training in working with children with special needs, seemed to have a rather categorical understanding of disability as something lifelong and static (cf. Danneskiold-Samsøe & Kjær, 2023). Lacking knowledge about special needs or (dis)ability, she turned to shadow diagnoses informed by her own online research. She was offered no qualified guidance or supervision and, in her powerlessness, did what most people would do in the situation. Likely feeling that she was at the limits of her professional competence, and probably with the best intentions, she recommended that the mother apply for a place at an institution for children with special needs. However, Noor’s mother was far more focused on her daughter’s potential for development, life circumstances, and individual particularities. This focus can be seen as an integral part of her hopeful and optimistic parenting practice – as finding ways to improve Noor’s life, both here and now and in a longer-term perspective – or in Mattingly’s terms, as everyday ethical experimentation. Hala’s experiences with her daughter and with various doctors, hospitals, assessments, prognoses etc. seemed to have given her a well-informed and far more nuanced understanding of what disability means.

Noor’s mother saw how the educator diagnosed her daughter using shadow categories and, moreover, how she regarded this diagnosis not only as the cause of Noor’s difficulties but as static and totalizing. Thus, the diagnosis was perceived as comprehensively defining and characterizing Noor. Variations in the scope and level of difficulties facing individual children were not part of how the educator understood Noor and the diagnosis. Noor and the diagnosis became identical when she was shadow categorized.

Hala described her fight to make the educators view her daughter as an individual instead of letting the diagnosis box her in. Hala’s experience points to a problem related to how certain ways of understanding and dealing with specific diagnosed issues (in a child’s social environment) can initiate processes that become self-fulfilling prophecies

(Hertz, 2014; Rose, 1999). In that sense, she was fighting against reductionist, simplistic and stereotyped notions of disability, as well as a cultural tendency to coalesce diagnostic categories with social identity (Jenkins, 1996). Noor's mother instead focused on what Noor could do and on how she had developed. She emphasized Noor's victories and successes, leading to optimism and a desire to support and encourage Noor's development, whereas the educator placed the emphasis on Noor's symptoms, leading to a sense of professional impotence and a need to pass the baton to others with expertise in supporting children with special needs. This example illustrates the strong social power and effect of shadow diagnoses.

Hala was confronted with a situation where a diagnostic category with centripetal force drew most meaning-making processes regarding her daughter into the realm of medicine – at least, medicine as it is understood and interpreted in everyday, non-medical contexts – shadow medicine, so to speak. This is a process with serious and drastic consequences, affecting understandings and interpretations of what it means to be human (Goodley, 2016; Davis, 1997). The impact of diagnostic thinking has been analysed in many different contexts, including self-help groups (Ohlsson, 2011), disability advocacy and activism (Goodley, 2016), and (dis)ability identity politics (Broderick & Ne'eman, 2008). I view Hala's efforts to resist diagnostic thinking as a manifestation of how she "does" her everyday ethical work, whenever and wherever necessary. Clearly, Hala considered the ECEC educator's impotence and frustration in response to her daughter as part of a hostile and uncomprehending cultural environment that without empathy distanced itself from her as a mother and her child (cf. Scheper-Hughes, 1990). She felt the pressure and symbolic burden of being othered as a mother of a 'problematic' child. This form of positioning is highly stressful and the emotional and social consequences should not be underestimated (Douglas et al., 2021). Hala's ethical experimentation took the form of a search for other professionals open to a more nuanced and optimistic view of Noor, and who were willing to embark on a quest for solutions that could support Noor's development and include her in the kindergarten's social tapestry. This search meant that she could not avoid the possibility of conflict due to her disagreement with the educator. Ethical experimentation of this kind was perilous for Hala as she risked being labelled a "difficult" or "demanding" mother (Kjær, 2023). Nevertheless, she found it

necessary to attempt to improve Noor's situation and chose not to conform to the ideals governing collaboration between kindergarten and home.

The example also calls attention to the fact that a diagnosis not only changes the child's identity and social conditions, but also the situation and social identity of the parents. The educator's reaction can be interpreted as an expression of insecurity and impotence when faced with having to work with a child who in some ways differs from other children. Another consequence of the trend towards diagnostic cultures, as well as historically institutionalized conceptualizations of children with special needs, was apparent in how the educator viewed "syndrome children" such as Noor to be beyond her field of competence, making it a legitimate and responsible decision to refuse to work with her. She was informed by long traditions for specialization in all fields, including education. According to these traditions and the associated professional rationales, it would have been unprofessional of her to take on a task for which she was not qualified. As a result, the ideal of inclusive education was not achieved in this situation (or even considered relevant), clashing with existing everyday imaginaries of diagnoses, special needs, mainstream ECEC and professional identities. This creates a huge gap between ideals and realities. Recent agendas to introduce more inclusive practices within ECEC seem to conflict with the logics of specialization and expertise. In a broader perspective, this example raises questions of how to implement inclusive education and develop both mainstream and "special needs" education in ways that benefit children. Clearly, this is a field rife with conflict, and Hala found herself straddling the fault line in her efforts to support and enhance her child's opportunities in life under the given conditions.

Hala tried in different ways to relativize her daughter's otherness and soften the associated stigma. Drawing on Goffman (1963), this can be understood as her attempts to let her daughter "pass" by highlighting those aspects that were ordinary and normal while maintaining that, even if Noor was not at the same level as most children her age, she was still developing and should not be considered mentally disabled. Hala's argument was that long periods of hospitalization and several surgical procedures had delayed Noor's development. Her practical ethics drove her to fight for her daughter's right to develop and learn like other children, even if she did so at a different pace than most children and was therefore considered "developmentally delayed". In a Goffmanian perspective, we must assume that the associated stigma and strategies for managing this

stigma had an impact on the social identities of both Noor and Hala. Hala seemed to resist the danger of what Goffman (1963) calls spoiled identity, even though she was affected by the stigma power (Tyler, 2020) of her daughter's condition and her own proactive and yet diplomatic and dialogue-seeking endeavours (cf. Douglas et al., 2021).

Fighting stigma and diagnoses

Eliza chose a quite different strategy regarding her son, Philip, rejecting diagnoses but realizing that her son needed help. Still, she did not want him to be diagnosed due to the risk of stigmatization (cf. Goffman, 1963); she did not want Philip to be labelled (cf. Becker, 1963). Meanwhile, the educators at Philip's kindergarten thought that he should be assessed and diagnosed because then he could get access to the help he needed, both in the form of special expertise and extra resources. This had been a source of conflict between Eliza and the kindergarten for more than a year. During this time, the educators had tried to persuade Philip's parents to have him assessed and diagnosed. With Philip due to start school in six months, the educators' concerns were increasingly articulated in terms of a fear for how the other pupils would perceive him and react to his behaviour. The parents had now agreed to have him examined by a psychologist, and the ECEC staff hoped that the psychological assessment would motivate Philip's parents to have him examined by a psychiatrist. The educators saw both the psychological assessment and the psychiatric diagnosis as necessary if they, and later the school, were to do their job in a professional and proper manner; they (too) considered Philip's issues to be of such a magnitude and character that they exceeded what could be accommodated and supported within the framework of mainstream ECEC, with the professional expertise and conditions it provides.

A diagnostic gaze

I attended a meeting between Philip's parents, the ECEC educators, the ECEC manager and the psychologist. The psychologist had bad news, proceeding with great care and caution as she was aware of the conflict. She was not authorized to provide an official medical diagnosis.

Psychologist: ...His cognitive level is ... at the lower end of what is normal. ...and his language... He had difficulties reproducing

information and explaining what he thought about things ...and seeing similarities. His thinking was very concrete, very literal. So, he couldn't see ... If I asked him about a banana and an apple, for instance, he couldn't see that both of them are pieces of fruit. He could see that the banana is long and the apple is round ... So, he sticks to the concreteness of what it is.

Psychologist: I'm a bit worried about his attention span, and that might affect how much he can learn and how much he can show what 'he's learned... So ... umm ... I can see that he has some traits ... that could be considered autistic if they prove to be difficult. He really needs his routines. ... But it's also not so difficult that ... well, he definitely seems to have a few signs that could point in that direction [in a test]. So, I think the best thing I can do is to recommend that he be referred to the child psychiatrist ... Because then they can ... with much more certainty than I ' I'm not allowed to decide... But they can see – well, he either is or he isn't. And you would get an answer that way, right?

Here, the psychologist's expertise was brought in to solve the conflict, and hereby the educators' vague and uncategorized 'shadow' concern was turned into an articulated suspicion regarding a specific diagnosis. The psychologist was careful and considerate, meticulously outlining her specific concerns. She described Philip's cognitive level as being at the lower end of what is normal, which indicates that he is not developmentally disabled. Furthermore, she described his language as good, but emphasized that he could not use language actively to talk about a subject, reproduce information, explain what he meant or form an opinion. His different linguistic style was described as a sign that his thinking was very concrete, and not abstract or metaphorical, and that he was not capable of identifying linguistic patterns or of understanding that things can be divided into related categories using broader concepts. Through these examples, the psychologist described Philip's linguistic competences and highlighted several features that clearly pointed in a certain direction. She explicitly mentioned the diagnosis autism and recommended referral to a child psychiatric ward.

Eliza again made it clear that Philip was not going to the psychiatrist to be labelled and put in a box for the rest of his life. She then addressed the educators and told them that despite all their disagreements and conflicts, she had the utmost confidence in them and trusted them 150 per cent. She thought they did lots of good things for Philip and wanted them to continue doing so. This mother's ethical work took the form of a fight to avoid her son being stigmatized by a diagnosis, while still trying to get him the help and support he needed. This meant fighting against a system that distributes sparse and declining resources based on difficulties that are often defined using diagnoses. She was also fighting against strong societal forces related to social stigma and labelling. With a professional background as a social worker, she was familiar with theories of stigmatization and was well aware of her child's rights as set out in the legislation concerning special education and support. At the same time, she addressed ideals concerning the collaborative relations between parents and ECEC staff by performing an elaborate display of recognition, respect and good relations aimed at the educators. This enabled her to counter the narrative of conflict with expressions of positivity and gratitude, and to make it clear that her fight was not against the educators but against a broader danger to her son – that he be labelled with a diagnostically defined spoiled social identity as a consequence of popular imaginaries and organizationally defined rationales.

The ethical practices that motivated these parents' fight were about avoiding the stigma of diagnoses while ensuring that their son was perceived and treated as a human being with a unique personality and that he received the help and support he needed without being labelled. In the process, parents and educators alike grappled with the fundamental dilemma that is embedded in the tension between a human being's individuality and the category (or categories) in which they can be placed. The parents assessed that a diagnostic classification of their son would have so many unwanted side effects that it should be avoided, while the ECEC staff saw such a classification as giving access to rights and possibilities in the form of resources sought by both parties. From an analytical perspective and based on what we know from a large body of research, both parties had strong arguments and were right in each their way. This dilemma and the question of how a diagnosis affects the formation of human identities are the core issue, highlighting an intricate web of possibilities and barriers, recognition and condemnation, freedom and constraints (Drakos, 2011).

Conclusions

I have illustrated the everyday experiences and ethical work done by parents of children who are understood as having special needs when they meet and interact with ECEC. These specific ethical practices are performed in a cultural landscape of ideals of inclusion, good parenting, parent–educator collaboration etc. – ideals that affect how the parents’ actions are interpreted and responded to and how these parents navigate such interpretations and responses.

I have given examples of parents whose knowledge and efforts did not count as valid when meeting with ECEC staff. Instead, the parents, and particularly the mothers, ran the risk of being blamed and labelled unreasonable, demanding, annoying, and stigmatized accordingly (cf. Douglas et al., 2021). As a result, they were forced to fundamentally redefine their parenthood. It was no longer sufficient or possible to live up to the dominant ideals for good parenting with their focus on consensus and downplaying of any disagreement in their interactions with early childhood educators. It was not sufficient because the situation demanded something else, something more than ECEC professionals generally expect of parents. It was not possible because the actions they had to take to protect their children’s interests challenged prevailing norms and ideals about informal and consensus-oriented encounters. Among other things, these parents took it upon themselves to act as fighters and lawyers for their children in kindergarten and school; educators at home; mediators and coordinators who must always appear friendly, respectful, constructive, and cooperative, no matter what breakdowns, ignorance, perplexity, bewilderment etc. they encounter in welfare state institutions.

When taking it upon themselves to do ethical work within the contexts of their everyday life encounters with welfare professionals, these parents identified gaps between the ideals of inclusive education and the competences and mindsets of ECEC educators – gaps that fail children daily and deprive them of learning opportunities, social inclusion, human rights, and due process. At the same time, their ethical work conflicted with another set of ideals concerning a frictionless, informal, equal, and positive collaboration between parents and kindergarten characterized by “niceness” and “sameness”. Unable to avoid conflict and friction, they found themselves on the wrong side of the gap between these ideals and the realities of their situation as parents to a child deemed as having special needs – rather than practising niceness and sameness, they were

labelled difficult and different. This is parallel to what Douglas et al. (2021) have identified across contexts in the UK and Canada regarding the blaming and shaming of mothers of disabled children, whose fight is considered unreasonable, even mad.

I have shown how everyday experiences related to children's problems are influenced by available official and shadow categories and how imaginaries and ideals affect the possibilities, as well as the impossibilities, that emerge and establish a framework setting out which paths and options are available to the children and their parents – and which paths and options are closed off. In these processes, everyday shadow diagnoses and categories play important roles.

Strong ideals about consensus and equality (as sameness) dominate the collaboration between parents and ECEC staff (Kjær, 2003; Dannesboe et al., 2018), but conflicts, disagreements, and fights primarily unfold when children experience difficulties. It is in precisely those cases where the need for a well-functioning collaboration and a high level of professional expertise is greatest that the limitations of these ideals are revealed. Nevertheless, public narratives about so-called curling parents, overly demanding parents, difficult parents contribute to placing parents of children with disabilities/diagnoses in a particularly difficult position when trying to perform everyday ethical work. This positioning transforms parents of children who are different into parents who are different.

These conditions have a fundamental effect on parents' lives. The time-consuming investments in trying to get educators, administrators, teachers etc. to understand their child's needs and the strain of this kind of parenting, including coordination and advocacy, are burdens in themselves. But in addition, they also need to deal with cultural stigmatization and see their best efforts to be a good parent problematized. In this sense, this represents a Danish parallel to the phenomenon of public shaming of disabled families, as argued by Katherine Runswick-Cole et al. (2016). Exploring the consequences of these forms of stigma power (cf. Tyler, 2020) is an important avenue for future research.

References

- Bach, D., Dannesboe, K. I., Ellegaard, T., Kjær, B., Kryger, N. & Westerling, A. (2020). *Parate børn – forestillinger og praksis i mødet mellem familie og daginstitution*. Frederiksberg: Frydenlund Academic.
- Becker, H. S. (1963). *Outsiders: Studies in the Sociology of Deviance*. The Free Press, Simon & Schuster.
- Brinkmann, S. (2014). Languages of Suffering. In: *Theory & Psychology*, 24(5):630-648. DOI: 10.1177/0959354314531523
- Brinkmann, S. (2017). Perspectives on diagnosed suffering. In: *Nordic Psychology*, 69(1): 1-4. DOI: 10.1080/19012276.2016.1270404
- Broderick, A. A. & Ne'eman, A. (2008). Autism as metaphor: narrative and counter-narrative. In: *International Journal of Inclusive Education*, 12(5-6): 459-476. <https://doi.org/10.1080/13603110802377490>
- Bruner, J. (1990). *Acts of meaning*. Harvard: Harvard University Press.
- Conrad, P. (2006). *Identifying Hyperactive Children. The Medicalization of Deviant Behavior*. Aldershot: Ashgate Publishing.
- Conrad, P. (2007). *The Medicalization of Society. The Transformation of Human Conditions into Treatable Disorders*. Baltimore: The Johns Hopkins University Press.
- Dannesboe, K. I., Kjær, B., Palludan, C., Bach, D. (2018). Parents of the welfare state: pedagogues as parenting guides. In: *Social Policy and Society*, Vol 17 (3): 467-480. DOI: <https://doi.org/10.1017/S1474746417000562>
- Danneskiold-Samsøe, I. & Kjær, B. (2023). Aflæsning og praksis - specialpædagogisk arbejde med børnehavebørn med autisme. I: *Forskning i Pædagogers Profession og Uddannelse*, 7(1): 23-32. DOI: <https://doi.org/10.7146/fppu.v7i1.136705>
- Davis, L. (1997). Constructing Normalcy. The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century. In: Davis, L. (ed.). *The Disability Studies Reader*. New York: Psychology Press.

- Douglas, P., Runswick-Cole, K., Ryan, S. & Fogg, P. (2021). Mad mothering: learning from the intersections of madness, mothering, and disability. *Journal of Literary and Cultural Disability Studies*, 15 (1): 39-56. <https://doi.org/10.3828/jlcds.2021.3>
- Drakos, G. (2011). Diagnos i en läkares dialog med sin patient. In: Drakos, G. & Hydén, L.-C. (eds). *Diagnos och identitet* (pp. 50-77). Stockholm: Gothia Förlag.
- Furedi, F. (2002): *Paranoid Parenting. Why Ignoring the Experts may be the Best for your Child*. Chicago: Chicago Review Press.
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Touchstone: Simon & Schuster.
- Goodley, D. (2016). Autism and the human. In: Runswick-Cole, K., Mallett, R. & Timimi, S. (eds.) *Re-thinking Autism. Diagnosis, Identity and Equality*. London & Philadelphia: Jessica Kingsley Publishers.
- Gullestad, M. (1992). Egalitarian Individualism. In: Gullestad, M. (ed.) *The Art of Social Relations. Essays on Culture, Social Action and Everyday Life in Modern Norway* (pp. 183-200). Oslo: Scandinavian University Press.
- Hacking, I. (1998). *Mad Travellers. Reflections on the Reality of Transient Mental Illnesses*. London: Free Association Books.
- Hertz, S. (2014). *Børne- og ungdomspsykiatri: nye perspektiver og uanede muligheder*. København: Akademisk Forlag.
- Horwitz, A. V. (2002). *Creating Mental Illness*. Chicago: Chicago University Press.
- Jahreie, J. (2022). *Constructing the School-Ready Child – A study of ECEC Teachers' Experiences of Preparing Children for School*. PhD Dissertation. Oslo: Oslo Metropolitan University.
- Jenkins, R. (1996). *Social Identity*. London: Taylor & Francis.
- Jensen, S.Q. (2011). Othering, identity formation and agency. In: *Qualitative Studies*, 2(2): 63-78. DOI: <https://doi.org/10.7146/qs.v2i2.5510>
- Kjær, B. (2003). Forældre og forældresamarbejde – hvordan omtales forældre og hvordan udtaler de sig? I: *Udvikling og perspektiver. Socialministeriets evaluering af*

formålsbestemmelsen om dagtilbud til børn i Lov om Social Service. (pp. 105-123)
Rapport 3. CASA, Højvangseminariet og Roskilde University

Kjær, B., Bach, D., Dannesboe, K. I. & Kryger, N. (2020). Det ikke-parate barn: når risiko-, optimerings-, og diagnosetænkning mødes. In: Bach, D., Dannesboe, Ellegaard, T., K. I., Kjær, B. & Kryger, N. *Parate børn: forestillinger og praksis i mødet mellem familie og daginstitution.* Frederiksberg: Frydenlund Academic.

Kjær, B. (2023). Voicing the silenced: one million voices and the Danish disability experience. In: *Social Work and Society*, 20(2). <https://ejournals.bib.uni-wuppertal.de/index.php/sws/article/view/807/1391>

Lee, E., J. Bristow, C. Faircloth & J. Macvarish (eds.) (2014): *Parenting Culture Studies.* Basingstoke and New York: University of California Press.

Löfgren, O. (1991). Learning to Remember and Learning to Forget: Class and Memory in Modern Sweden. In: Bönisch-Brednich, B. & Gerndt, H. (eds.), *Erinnern und Vergessen.* (pp. 145-161). Göttingen: Verlag Schermer

Mattingly, C. (2012). Two virtue ethics and the anthropology of morality. In: *Anthropological Theory* 12(2), pp. 161-184. DOI: 10.1177/1463499612455284

Mattingly, C. (2013). Moral Selves and Moral Scenes: Narrative Experiments in Everyday Life, *Ethnos*, 78(3): 301-327. DOI: 10.1080/00141844.2012.691523

Ohlsson, R. (2011). Diagnosens roll i vardagligt meningsskapande - om psykisk ohälsa. In Drakos, G. & Hydén, L-C. (eds), *Diagnos och identitet.* Stockholm: Gothia Förlag.

Pedersen, O. K. (2011). *Konkurrencestaten.* Copenhagen: Hans Reitzels Forlag.

Rose, N. (1999). *Governing the Soul: The shaping of the Private Self.* London & New York: Free Association books.

Rosenberg, C. (2007). *Our Present Complaint. American Medicine, Then and Now.* Baltimore: The Johns Hopkins University Press.

Runswick-Cole, K., Lawton, R. & Goodley, D. (2016). The trouble with 'hard working families'. In: *Community, Work & Family* 19(2):257-260. <https://doi.org/10.1080/13668803.2016.1134153>

Spivak G. C. (1985). The Rani of Sirmur: an essay in reading the archives. *History and Theory*, 24(3), 247-272. <https://doi.org/10.2307/2505169>

Schepher-Hughes, N. (1990). Mother Love and Child Death in Northeast Brazil. In: J.W. Stigler, R.A. Shweder & G. Herdt (eds), *Cultural Psychology. Essays on comparative human development* (pp. 542-565). Cambridge: Cambridge University Press.

Tyler, I. (2020). *Stigma: The Machinery of Inequality*. London: Zed Books.

Wright, S. (2017). Policy – magtfulde begreber. In: Gulløv, E., Nielsen, G. B. & Winther, I. W. eds. *Pædagogisk Antropologi: tilgange og begreber*. Copenhagen: Hans Reitzels Forlag.

About the author:

Björg Kjær, PhD, is Associate Professor of Educational Anthropology at the Danish School of Education, Aarhus University, Copenhagen, Denmark. Her research is particularly concerned with ethical and moral issues related to ‘special needs’ and (dis)ability in educational, societal and familial contexts. In recent years she has been studying social and cultural aspects related to diagnosed children, their families and professionals. Especially she has been interested in children diagnosed with Autism Spectrum Disorder, ASD, and the consequences of everyday interpretations of what it means to be autistic.