

Seeing the Other

Using fiction in a social work reflection on perception, language, and ethics

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*The article explores how a work of fiction can contribute to a social work reflection on the helping process and the challenging task of seeing the Other. The article has an interdisciplinary purpose and aims at creating a dialogue between social work discourse and the language of fiction. Drawing on Moi, Felski and Tygstrup & Holm, an argument is made that narratives, language and ethics are intertwined and to some extent transcend boundaries between literature and social work discourse. The novel analyzed is *Tung tids tale* (Tale of Troubled Times, my translation) by the Norwegian author Olaug Nilssen. Selected passages from the novel are interpreted through a psychological as well as a systemic perspective, highlighting the importance of language and theoretical lenses for social work ethics. The concept of institutional identities is suggested as the most fruitful approach, attributing the professionals' conduct in the novel to systemic factors.*

Introduction

In the essay *Språk og oppmerksomhet*, the literary scholar Toril Moi (2024/2013) reflects upon the connection between language, attention, and ethics. When we pay attention to a situation or person, we are also doing something moral, she writes. Building on a concept of attention developed by the philosophers Charlotte Weil and Iris Murdoch, Moi suggests that language, insight, and judgement are fundamentally intertwined. Our moral assessment is conveyed through the words and concepts we use to describe what we see. An attentive language, Moi writes, seeks to bring words in accordance with reality (23). Moral action depends upon our ability to perceive the world and other subjectivities with a fair, compassionate gaze. Only if we see and acknowledge the other are we able to provide the form of help that is needed, and not the form that is shaped by our own preferences or quick assumptions (69). A similar call for attention can be found in the social work tenet “starting where the client is” (Marsh 2002), resonating with Søren Kierkegaard’s classic quote on the art of helping: to help, one must first and foremost find the Other where the other is, understand what the Other understands, and start from there.¹

Taken literally and to its fullest extent, seeing the Other through the prism of his own subjectivity is of course utopic. The road to reaching a clear comprehension of another is beset by a multitude of obstacles, filtered through language and narratives, which lead our attention in certain directions while ignoring others. Still, in social work practice, striving towards the Other, the endeavor to understand, is an invariably moral demand (Chambon 2013, 125). Social work ethics stress the importance of reflecting upon the complexities that are involved in fulfilling this obligation (Levin 2004, 76). Can some relationship be made between this ethos of social work and Moi’s take on the role of language in fostering our ability to perceive? This article contemplates this question. More specifically, I will explore how a novel can contribute to a social work reflection on the challenging task of seeing the Other.

Social work strongly identifies with a field of practice and gains much legitimacy from a social science knowledge base. A novel, on the other hand, is a cultural form associated with language and narratives. Can these two quite different epistemological sources of knowledge be bridged? In this article I argue that they can. The overall aim is to foster an interdisciplinary dialogue and reveal how a work of fiction can be a valuable contribution to social work discourse of helping

1. In this article, «Other» is used synonymous with «client» or «service user», i.e. a generalized term for a position within a professional helping relationship (see for instance Chambon 2013).

the Other. The novel chosen for analyses is *Tung tids tale* (2017) by the Norwegian author Olaug Nilssen (hereafter *Tale of Troubled Times*). Olaug, the novel's narrator, is the mother of Daniel – a young boy diagnosed with neurodevelopmental disorders. The story portrays the family's everyday life and thematizes what being parents to a disabled child can entail. The novel is the first in a trilogy where Nilssen explores the topics of disability, responsibility and family dynamics. For *Tale of Troubled Times*, Nilssen was awarded Brageprisen, a prestigious Norwegian literary award. The novel was praised for its nuanced and bold descriptions, and for highlighting the situation of informal caregivers (Fontene 2017). Dealing with various helpers and an institutionalized support system comes with the territory and is a recurring motif in the novel. It explores interactions between the welfare system's helpers and the recipients from the recipients' point of view.

Social work is one of several professions that provide help to individuals and families within the Norwegian state welfare apparatus. The help provided does not necessarily match the help needed: A common experience among parents of disabled children is that the heaviest burden is not having a child with extensive helping needs, but rather the interaction with the welfare system (Tøssebro and Wendelborg 2018). The system seems to incorporate certain "thresholds" that require parents to be persistent and not give up in the process of accessing help (214). This challenge is also depicted in *Tale of Troubled Times*. As will be elaborated and analyzed, the helpers' attempts to assist are often a source of frustration for Daniel's parents.

In the next section, I outline my theoretical background – the meeting between social work discourse and literary discourse. The second and main section is a literary analysis of how the encounters between Daniel's parents and the professional helpers are portrayed in the novel. The analysis will make use of different perspectives related to social work, casting different lights upon the interaction, thereby illustrating one of Moi's central points – that language is a form of attention. Through this, I hope to demonstrate the intimate relationship between language, attention and ethics.

Theoretical background – social work discourse and literary discourse

Social work discourse

According to Julkunen and Rauhala (2013), social work can be regarded as “a knowledge producer and professional activity that develops and delivers methods and strategies in organizing the care of people who in one way or another are defined as being outside of normative ways of living, especially of waged employment” (106). Traditionally, the notion of deviance has been connected to and is constitutive of social work, as responding to different forms of social deviance in some sense is what social work does (Ellingsen & Levin 2015, 52). Today, a more common theoretical frame for describing social work’s target groups is the concept of marginalization (Julkunen & Rauhala 2013). Approaches to studying marginalization tend to focus on situations and positions of disadvantaged groups, and incorporate concepts like social exclusion, deprivation and segregation (113). Poverty, crime, substance use disorders, mental health challenges, child neglect and disability are some of the conditions that social workers are involved with today.

In a Norwegian context, social workers are sometimes referred to as “the heart of the welfare state” (Fellesorganisasjonen 2022). Broadly embedded in its institutions and practices, the profession is often said to be situated in the space between help and control. Social workers are the welfare state’s door opener, and its gatekeeper (Levin 2015, 42). Being closely associated with the field of practice generates distinctive dilemmas. Social work is to work for the betterment of vulnerable groups and contribute to empowerment and inclusion, issues of ultimate importance to the profession. At the same time, social workers are responsible for administrating current social policy. Being part of the state apparatus, helpers are there to assist, but also to educate, regulate, and modify (Chambon 2013, 122). These conflicting considerations cause considerable tension in social work practice (Levin 2015). For many social work clients, declining welfare services is not an option; the social worker might have a legal mandate to interfere, or the service user might lack the resources to get by without the offered assistance (Levin 2015, 42). This structural element of power cannot be bypassed and adds a normative and ethical dimension to social work practice. Reflecting upon this situated side of social work is central, as the political discourses and institutional demands of a specific time and place are not necessarily in alignment with social work’s core values and principles (Askeland 2006).

A defining feature of social work, ethically and theoretically, is its strong commitment to foregrounding the role of societal conditions and structures in the unfolding of life. Acknowledging the impact of “the social” is central to the profession. The global guidelines emphasize social work as a discipline that recognizes historical, socioeconomical, cultural, political, and personal factors as being intertwined (IFSW 2014). As a multi-disciplinary profession, social work utilizes knowledge from different disciplines such as sociology, psychology, philosophy, law and social pedagogy (Kleppe 2015, 132). Although social work knowledge base contains a diversity of branches, perspectives, theories, and methods, social work tradition and discourse is characterized by a clear preference for contextual frames of interpretation as opposed to individualistic. The significance of taking structures and context into account is expressed in the discipline’s vocabulary through the terms “person in environment” and “holistic view” (Ellingsen & Lev-in 2015, 59). “Person in environment” is social work’s analytical unit and a guiding principle for practice, which mirrors the discipline’s comprehension of the problems as also having social and contextual prerequisites. Although the individual might be the “bearer” of the problem, the analysis must transcend the individual level. In seeking solutions and ways forwards, the practitioner should approach the situation in a holistic manner and consider the interplay between the client’s resources and limitations on the one hand, and the surrounding relations and social systems on the other. In stressing the importance of structural and social mechanisms, the Other in social work becomes the antithesis of the liberal subject – a subject that, as the American philosopher Martha Fineman (2008) makes clear, is conceptualized as self-sufficient, and free from vulnerability and circumstances beyond its control. In contrast, social work discourse highlights a subject that is immersed in social context and dependent upon a social structure. The central place of the terms “person in environment”, “holistic perspective” and “context” underscore social work’s insistence on seeing the social and structural aspects in the challenging task of seeing the Other.

Literary discourse - fiction and representation

Fiction can encompass insight into stratification, social life and subjectivity. In Moi’s view, fiction can assist us in seeing reality more clearly, as it is a genre through which an attentive language can be expressed. At its best, the attentive language of literature “forces us to open our eyes, to see language and reality as something important and concerning us, and as something we should reflect on” (18). In *Uses of Literature*, Rita Felski (2008) claims that literature – and the novel genre in

particular – creates distinctive configurations of knowledge about social reality and selves immersed in this reality, – about “how worlds create selves, but also of how selves perceive and react to worlds made by other selves” (91). The novel has a flexibility that enables it to capture and render the deep intersubjectivity and complexity of social interaction. The novel’s shifting attention between interiority and exteriority, the alternation of reading minds and portraying behavior, is the novel’s privilege and its strength (91). In Felski’s view, the novel doesn’t mirror reality but provides a “window” to see it anew: “Literary works rework the works of culture, redescribes that already described” (85). Through its redescrptions, literature can augment our understanding of how things are (86). While a mirror can only reflect, “window” points to the possibility of seeing something different, of gaining a new (in)sight.

How literature relates to society is also discussed in an article by Tygstrup and Holm (2007). In their perspective, literature is one of many practices which take part in public discourse where images of social reality are produced and circulated. Society constantly creates figurations of “how things are”, and of how we can and should relate to ourselves and others (150). Tygstrup and Holm state that this activity is inherently political, as constructing specific models of social reality simultaneously obscures other aspects of that reality (157). At the level of symbolic forms, literature is a practice of representation among others (159). What separates fiction’s representations from other representations circulating in the culture is as much a question of the position fiction occupies in society as it is of its specific “literariness”. Contrary to social work, literary discourses lack a clearly defined societal function. The discourse of fiction is not expected to deliver solutions beyond itself or to improve any aspect of reality. Fiction is without such a societal obligation. This non-pragmatic status that fiction holds, and the distance accompanying it, enables fiction to be attentive to marginalized aspects of social reality, and to produce figurations that diverge from, or exploit, the hegemonic representations in the surrounding culture (158). From its space of freedom, fiction holds the potential to contest and question “the order of things”.

In this article, *Tale of Troubled Times* and social work are both regarded as practices of representations that are involved in producing images of subjectivity, interaction, and social reality. Whether the issue at stake is helping someone in a practice field or narrating the subject matter in fiction, some form of meaning construction takes place. This common landscape between literature and social work is what this article seeks to explore and, in some way, construct. Sæther (2022) points out that an interdisciplinary approach must seek to achieve a certain balance, permitting both “parties” to premise the dialogue. In this, I’ve

been inspired by what the philosopher Hans Skjervheim (1976/1996) writes about the nature of dialogue and its prerequisite: Equality between two parties can be ensured by what he refers to as a “common third” – a shared focus for attention. The passages chosen from the novel depict the role of the informal caregiver, the issue of defining Daniel and the conduct of the helpers. In the literary analysis, I will make use of resources from social work discourse which seem relevant to the novel, as I attend to a topic at the heart of social work – the complicated task of seeing the Other.

Understanding the Other in a novelistic discourse

Parenting Daniel

It's been six weeks since I lost it at work. Was it tears, rage or fainting, I no longer remember, nor whether it was the fifth or tenth time. But I do remember catching a glimpse of myself in the mirror, seeing that I was wearing old sneakers, with pants that were too small, face looking harsh, hair being grey. (14)²

These words belong to Olaug, the narrator of *Tale of Troubled Times*. Daniel is her first-born child and is undergoing diagnostic assessment. In his first few years, he seemed to be a normal child, with linguistic skills above average. Or so his parents thought, until he suddenly began to lose his acquired language and motor skills and changed behaviour. Now, at nine years old, Daniel has been diagnosed with autism, and the parents are currently disputing another diagnosis, that of intellectual disability. As the quote illustrates, the novel leaves the reader in no doubt that Olaug's everyday life is challenging. Combining a professional life with the role of parenting Daniel comes with severe difficulties, pushing Olaug to her limit, again and again: “I often went to the doctor, always thinking that one sick leave would be enough, like a short rest to recover, but it wasn't, week after week, it wasn't” (19). After several attempts to stay in the workforce and with strong encouragement from her doctor, Olaug has applied for care allowance.

In the novel, we become well acquainted with how the parents have experienced the changes in Daniel, and how baffling it has been, trying to make sense of and reconciling with this unexpected reality. Accepting the diagnoses suggested by the psychiatric assessment has been –and still is – difficult. Olaug frequently returns to the issue of Daniel's identity and how she can understand what has happened. In some of these passages, Olaug explicitly addresses Daniel, as the novel's “you”:

2. All translations of quotations from the novel are my own.

“When you were small, you had a synthesizer in your room. You had a shelf, a desk with drawing materials, and a stair shelf filled with books. You fetched books yourself and asked to be read to” (43). Through her, at times scrutinizing, memories of the younger Daniel – often a stark contrast to his present being – the novel provides the reader a window to intimately access the parents’ experience of shock and despair.

Also portrayed in the novel is an aspect of parenting Daniel that can perhaps be described as “cultural loneliness”. That a child’s socialization, development, and life quality require resources beyond parenthood is captured in the well-known saying that it takes a village to raise a child (Reupert et al. 2020). To most parents in contemporary Nordic societies, a village is open, with its arsenal of resources, offering advice and guidance and access to sports, music, theatre, or whatever activity suits our child. As an effect of compliance with the norm, we often benefit from the surroundings without realizing it. When one’s child’s needs and behaviors deviate from those of the majority’s, being parents is a whole different ball game. *Tale of Troubled Times* portrays parenthood from outside the village, where everything around the child must be organized on completely different terms, without getting the support from, or finding rest in, the matrix of normality. Rather, in everyday situations, Olaug often brushes up against its standards and expectations. As a schoolboy, Daniel wears large nappies and generates much more weekly waste than the outdoor garbage can hold, which causes their neighbour to carefully guard his own (84). For safety reasons, the nursery’s furniture is kept to a minimum, as Daniel can tear down curtains and throw things out the window. Exposing family life to others is stressful to Olaug, as she is often painfully aware of how her coping strategies and ways of organizing might appear to those who are unfamiliar with Daniel:

I hesitate to show the room to others, it’s like an institution – it must be explained, and when I think about it, I always think about the case manager from the social services who visited us, standing there silently, with a stiff look on her face, and me, getting more and more frantic, apologizing, and explaining that your room wasn’t ugly. She didn’t say a word. (41)

Even to a professional helper, making a home visit to get acquainted with the family’s coping needs, Olaug feels the need not simply to describe and lay out the “matter of fact” but to justify and defend herself. Having internalized the normal gaze and the judgement it might contain, Olaug, understandably enough, interprets the case manager’s silence as a lack of validation.

In the role of the informal caregiver, Olaug finds herself in a double span (Simonhjell 2020, Warberg 2021). On the one hand, Olaug is oriented towards Daniel, trying to understand his needs and conditions of existence through other forms of communication than verbal and neurotypical. On the other hand, Olaug must continuously mediate between what she perceives as Daniel's needs and the broader surroundings, including the world of professional helpers. As the mother of a disabled child, Olaug is tasked with speaking about and for the child (Warberg 2021, 59). In Olaug's interactions with the welfare system, this task of "representing Daniel" is heightened. By virtue of being Daniel's mother, Olaug is not a client in her own right: rather, she represents what Lawrence Shulman within the context of social work discourse has termed "the second client": a person of vital importance with whom the system must cooperate to meet the actual client's needs (2003, 35).

As is often the case when power and help run together, Olaug's relationship to the system is ambivalent. At times exhausting, yet inevitable – to families with severely disabled children, the welfare apparatus can in a certain sense be thought of as the "village", as a potential source of non-parental resources, enabling the child to have a life and impulses outside the domestic sphere, as well as assisting the parents in helping their child. A prerequisite for cooperation in a helping process is that the helper succeeds in "contracting": between the parties, a somewhat united understanding must be reached, of the situation, the problem, and the road forward (Shulman 2003). For this to be obtained, the helper must actively search for areas where the client's challenges and the resources of the system coincide (157). In *Tale of Troubled Times*, such a joint understanding is hardly present. Often, interactions between Daniel's parents and the system are portrayed as an abyss between different perceptions, between the family's everyday life and an organized apparatus of support. Accessing the system's resources is anything but simple. The helping needs must be presented, conveyed, and documented. Olaug's continuous efforts at making Daniel and the situation visible to the system is a prominent theme in the novel. Portrayals of her encounters with various professional helpers often have a strong emotional charge. Time and again the impression is of a system which adds insults to injury; to an already demanding situation comes another layer of stress, resulting from interaction with professional helpers, which pushes Olaug to the limit of what she can endure. Despite recurring periods of sick leaves, the welfare administration gives her little hope of having her application for care allowance granted, as this benefit is not meant for situations when the one being cared for is one's own child (23). Somewhat ironically, the comprehensive amount of case papers, documents,

and letters of correspondence, which are dutifully sorted by Olaug in binders according to dates and years, speaks of “representing Daniel” as a continuous and time-consuming activity.

Defining Daniel

A dominant theme in the novel, which causes much friction between Olaug and the system, concerns the labelling of Daniel through diagnosis. That he needs extensive help is indisputable, both to the parents and the various helpers. The nature of his difficulties, on the other hand, seems to be less clear. To the parents, Daniel’s development is a puzzle. Faced with the diagnostic categories, Daniel long seems like an equation that does not quite add up. In their attempts to understand what has happened to him, and as a way of providing the system with documentation, the parents have filmed him in everyday situations, at various stages of his development, capturing both his loss of function and moments where he exhibits neurotypical demeanor, like playing and singing (57).

The novel narrates three diagnostic assessments of Daniel, of which the first concludes with a variant of autism. But due to his atypical development, neither the parents nor the special education teacher in the kindergarten feel comfortable with this diagnosis. Daniels regressive development is not compatible with the diagnostic criteria, and the special training he receives, targeted around this diagnosis, has not resulted in any progress – on the contrary, Daniel regresses despite the efforts made. Initiated by the special education teacher and in accordance with the parents, a new meeting with the diagnosticians takes place, where they call for a new assessment of Daniel’s condition. At the meeting, the diagnosticians strongly oppose this request:

-But it doesn’t work, we are not getting results, said the special education teacher.

-No, but as you know, you must keep trying it out, find out what motivates him, said the senior physician.

-But as I said in the presentation, nothing motivates. We can’t make it work. He has moved backwards. The parents have videos showing how huge the difference between then and now really is, it’s a gradual regression, said the special education teacher.

-I don’t doubt it, the senior consultant said, and added that he didn’t need to see them. He’d already risen and commanded us to follow him to draw a family tree, of mental disorders and diagnoses on both sides of the family. We went along, not knowing what else to do.

-Autism and depression occur frequently in families with many creative and intelligent members, he went on saying (...), and we took the bait, listed the mathematicians and artists in the family, speculated on the sanity of family members. The senior consultant nodded and took notes. (68-69).

The scene is illustrative of a recurring dynamic between Daniel's parents and the helpers. Interactions where "defining Daniel" come into play are often depicted as a clash between the parents' comprehension and that of a system, where only certain experiences and interpretations are recognized. The senior consultant's dismissive response to the parents' videos of Daniel is somewhat typical of the encounters involving various helpers in the novel; he does not need to see them, he says, clearly not regarding them as a potential source of enlightenment, as a gateway to Daniel's being in his everyday surroundings. Instead, the parents are steered towards an activity of speculation and interpretation, but from which nothing can possibly be gained except for confirmation of the diagnosis that has already been given.

The parents conform to the physician's redirection of the meeting and perform his instruction to interpret their family in psychiatric terms. But at night, Olaug is haunted by what happened: "I lie awake, thinking about the brutal dismissal, that I'm not the only one experiencing this, that this is how they do it. Dismiss. See the one that is now. Close their eyes to the one who was. Forcing the parents to do the same" (73). Olaug's behaviour at the meeting and its aftermath exemplify what Shulman (2003) calls an "illusion of work": the client conforms to the course that is staked out by the helper, but the agreement is only superficial (246). Without genuine ownership of the process, the client is not onboard. Olaug went along with the senior consultant's suggestion, but the truth is that she experienced the focus and direction of the meeting as forced. The parents are still grappling with the issue of "defining Daniel", which means that the nature of his being is a somewhat open question to them. But the power to define the situation lies with the diagnostician, and how Daniel is to be classified, is not up for negotiation. This case seems closed.

When power is unequally distributed, as is the case in professional helping relationships, the helper's power to define and determine relevance can take subtle forms and still be effective. In the novel, this aspect of power is also embodied: Daniel's father says that they have video clips of Daniel showing regression in several areas, but "no one asks about them" (79). In a conversation with the child psychologist, Olaug describes several episodes involving Daniels behaviour, of which some seem to undermine the criteria of the given diagnosis and others seem to confirm it. But only examples of the latter make the psychologist reach for her

pen: "It was only episodes like these that she wrote down. We wondered if we were lying. We had to prove that we were telling the truth" (52). Recounting Daniel's previous skills at meetings, silence is the response that the parents receive from the professional helpers. Their experiences and inputs are sometimes excluded from the minutes: "They didn't record anything" (57). In the novel, the examples are numerous: taking notes or not taking notes, silences, long pauses and averting gazes all become markers of a lack of recognition and of what is not considered valid – markers of micropower.

Referring to the videos appears to be an act of resistance, as the parents' attempt to oppose the diagnosis and argue against it. But when Daniel's being is on the agenda, inputs such as these are poorly received. The helpers often seem to have little room for curiosity, ambiguity, and uncertainty. Instead, the parents, in their broader comprehension of Daniel, are subjected to corrections and modification.

The portrayal of a multi-disciplinary meeting that takes place shortly after Daniel has started school provides a striking example of this. The school that he is attending is for children with severe learning disabilities. In their communication with the school staff, the parents are eager to convey Daniel's gradual regression and the skills he once had, in the hope that the school can be perceptive of this "broader" Daniel: "I repeated my phrases about what you could do, made a number of that we wanted the teachers and assistants to be aware of it, that also they looked for remainders of the one you once were (...)" (78). This approach to Daniel gains little sympathy from the professionals attending the meeting. As events unfold, the school principal takes charge and strongly implies that Daniel's neurodevelopmental disorder has been more encompassing from the start than the parents believe:

-But isn't it just the language? the principal asked.

-He hasn't really regressed in other areas beside that, he proceeded, and from the tone of his voice and how he asserted himself, from how the others sat there, silent, and stiff, I realized that they'd been talking about us (...) they thought we were crazy, living in a dream world. There and then I was silenced, primarily because my chest tightened, but also because, at that moment I couldn't remember. Was it true? Was it just the language? Have you, apart from that, been different since you were born? (...) In my brain and throat, a compressing sensation began to take hold (...). (78)

The intensity of Olaug's reaction plays tricks on her memory, leaving her in a state of silent impotence, tongue-tied, and unable to counter the argument with examples of Daniel's former skills. In yet another attempt to oppose the principal's

description, Daniel's father gives several examples of regression besides the language ("Previously, he ate sandwiches in a completely normal way") but is seemingly unable to influence the terms of the discussion. No remarks are made by the helpers to show any confirmation of, or interest in, this other Daniel. Bringing up the fact that they have videos, is of little use: "Everyone fell silent. The whole group sat still" (79).

Supported by the passivity of the other professionals, the principal undermines the parents as credible witnesses to Daniel's life and development. Their narrative of Daniel has its starting point in and can therefore include nuances of "the normal child". The principal's act of interpretation goes in the opposite direction and becomes retroactive as it takes the disorder as its point of departure, thereby downplaying any possible features of normalcy. In underlining the diagnostic category (and perhaps stretching it) as the most essential viewpoint, "the deviant Daniel" is foregrounded and becomes "the true Daniel" – the one he always was. Yet again, the parents' videos are not granted relevance. They are not used by the helpers as an opportunity to adjust their own outlook, to weigh their perceptions against another background or as a chance to see something else. Nor are they used as a gateway to understand what the parents are talking about, to try to see what they see –in other words, to empathize.

From the outlook of social work values, the novel's depictions of various interactions between the parents and the system are often disturbing, deviating from principles such as avoiding objectification, the importance of aligning oneself with the service user's perspective, using communication skills in creating a dialogue, and making room for the client's experience and comprehension of the situation. In facing the parents' understanding of who Daniel is, who he has been and who he perhaps can be, the helpers' lack of responses, and lack of attention, beyond the discourse of diagnosis is conspicuous. Little vocabulary and few horizons that would surpass "Daniel the diagnosis" emerge. In order to meet the obligation of creating a fruitful dialogue with the parents, one may also wonder why the helpers' responses are not more in line with: We're not sure, but this diagnosis is our best guess at this point; sometimes the diagnosis is wrong; a diagnosis is not a perfect description of someone; perhaps we need to reconsider; keep documenting Daniel's development; show us the videos, etc. Instead, a picture is drawn of professional conduct that appears to be reductionist, insensitive and at times manipulative, in their attempts to steer the parents' understanding of Daniel closer towards that of the system.

Posing the social work question: What is driving the helpers?

Do the novel's depictions of the relationship between the professionals and the informal caregivers give a believable account of the welfare state's helpers, outside the novel's domain? Is this really the state of affairs? Nilssen has openly declared that the novel is based on her own experiences as a mother of a disabled child, and that she hopes the novel will influence policy makers (see for instance Warberg 2021, Simonhjell 2020 and Nesby 2021). There are statements in the novel where Olaug seems to speak from an activist position that includes other caregivers in similar situations: "It is not any worse if I fall apart than if others fall apart. I don't have any more right not to fall apart, even if I can speak the cause" (24). The experiences are not just hers – it is challenging for them all and they are all barely holding it together, the narrator claims.

A work of fiction is not a piece of empirical evidence of reality. And yet, it is through its portrayals of what might have been and what might take place that the novel opens the door to social work reflection. According to Tygstrup and Holm (2007), concrete figurations in fiction can display the social matrix as well as what does not fall "naturally under" the current order of things. By typifying dominant ways of thinking, literature can make hegemonic representations visible and available for critical debate (160, 161). Let us therefore assume that the novel's portrayals of interactions between the parents and the helpers do pick up on something real; and as disturbing conduct calls for explanations, let us ask: How can we understand the behaviours of the professional helpers, and their lack of willingness to question their own interpretation of Daniel? In what follows, two hypotheses will be explored. The first one is grounded in an individualistic, psychological perspective and is congruent with how the helpers in the novel seem to perceive themselves. The second one is sociological and anchors the helpers' pattern of behaviour in institutional mechanisms. These two perspectives are both derived from social work knowledge base, and – as will become apparent – they give very different interpretations of the interaction.

"The parents are in denial"

Perhaps the issue at stake regarding Daniel's diagnosis is that the parents are simply wrong. In her understanding, Olaug herself sometimes alternates between viewpoints, of which one echoes the system's: Perhaps the helpers' approach is not too categorical, perhaps it is her own that is too broad? Perhaps blinded by

shock and grief, they as parents have not been able to face reality? Their attempts to solve the puzzle are nothing more than movements away from the truth, driven by wishful thinking and denial. Perhaps their wish to see normalcy has prevented them from seeing the autism that was always there?

Distance can sometimes be a prerequisite for seeing clearly; in searching for recognition and confirmation, we are easily drawn to idealized pictures, to the positive outlines (Felski 2008, 49). And as pointed out by Warberg in her analyses, Olaug is always on the lookout for presence and agency in Daniel, for him seeking her out and making contact, and for signs that are more in keeping with how he was before (2021, 70). As readers, we come to empathize with Olaug's sense of loss and her wish to make connections with her son. We understand how difficult it must be to witness him needing more and more help, the hope that arises, again and again, the long road to accepting that Daniel, as he was before, perhaps is gone. We also come to see that the emotional upheaval this causes is such that in facing the diagnosis, it can drive one to question it. It may be irrational, but nonetheless understandable. And perhaps a dialogical approach should be toned down by professionals facing situations like these, when it is not a matter of different but equal perspectives, but a matter of one being in grief and denial and the other, having a bit more distance, seeing more clearly. In situations like these, a dialogical approach only risks adding grist to the mill and feeding the denial. At one point, Olaug herself interprets the helpers' signals in this way: "(...) we had already understood, from the way they asked, that they looked for signs of the abnormal, and signs that we had also seen of what category you belonged to, right from the start (...)" (57). Although we do not have access to the minds of the helpers in the novel, it often appears as if this is how they fulfill their role – that the parents must be helped to face reality, be guided out of their self-deception, and firmly but subtly be led towards the truth that is presumably also held by them, beneath the layer of denial. In this light, the helpers' acts of silence become acts of patience, of waiting for the parents to come to terms with the truth about Daniel.

The dimension of denial and truth does have some affinity with social work's theoretical discourse. Following Shulman (2003), getting the client to accept the offered help is part of contracting, though it is not always easy. Getting to grips with a painful situation can take time, and the client may need the helper's support to face the realities and to acknowledge what is true (227). Some ambivalence and reluctance are to be expected along the way (197). Similar reasoning can be found in Prochaska and DiClemente, who thematize how, when confronted with needs for change, not acknowledging the problem and its aspects is a common psychological mechanism, and for some, difficult to overcome. In facing the

unknown, contradictory thoughts and emotions can keep the client locked in a state of paralysis, unable to take necessary steps forward (Prochaska & DiClemente 1982).

That some defense mechanisms are in play when life is turned upside down, surely seems sensible. But still, there is something unsatisfactory about how this level of explanation fails to cast light upon the dynamics of the social or address patterns of interaction. As readers, we are kept in suspense for a long time regarding the nature of Daniel's challenges. The parents continue to fight for a reassessment ("we didn't give up") and eventually succeed. This results in Daniel getting a more specified diagnosis within the autism spectrum. The new diagnose is more congruent with the parents' perception of Daniel's development, but which for a long time was not acknowledged by the helpers ("no one believed us"). To the extent a diagnosis holds some truth, the system turns out to be a bigger obstacle than the parents.

Seeing the Other through an individualistic psychological perspective always risks serving as a protective shield around the helper and the system as they are both left unquestioned. This is also the case here, as this framing does not take us any further than how the helpers seem to perceive themselves – that their insight, when it comes to Daniel, is a privileged insight. In reflecting on the professionals' conduct, I will therefore propose a second framing. A case can be made that the collision between the parents and the professionals is grounded in the phenomenon of "institutional identities".

Daniel – an institutional identity

The concept of institutional identities is derived from sociological research. It focuses on how institutions interact with so called "problematic identities", and how the organization of the system influences the interaction between the helper and those receiving help (Järvinen & Mik-Meyer 2003). In some sense, institutions can be regarded as "ideas in action" – as knowledge systems put to work. Like theories, they assume a structure and attribute resemblance through classification and diagnoses (Douglas 1986).

An institutional identity can be thought of as the premise on which the Other becomes visible to the system. Becoming a client also means becoming a "case" – a process in which the challenges are sorted, categorized, and assessed. To welfare institutions, "schizophrenia", "autism" and "substance use disorder" are not only labels meant to refer to specific beings in the empirical world; they also exist as institutional identities, as categories that are formed by and that function within

the systemic apparatus tasked with handling them (Järvinen & Mik-Meyer 2003, 11). Institutional identities can be viewed as systemic constructions that make it possible for institutions to act. No institution relates to “the whole person” or innumerable variations of the Other – characteristic of institutions is that they function by reducing complexity, by limiting the scope of interpretation (Borch 2011,7). The service user must be “translated” into a format that is compatible with the categories, diagnosis, routines, and directives of the welfare apparatus. If this is achieved, the client is assigned a “problematic identity” with which the system can interact. Based on assessments, documentation, and diagnostic mapping, a decision is made as to which institutional identity the client is ascribed to. In this process, the institution makes use of analogous reasoning; questions concerning what something “is” are subordinate to questions of “what fits with the problem categories” (Järvinen & Mik-Meyer 2003,17).

The assessment of what is to count as relevant aspects of the situation or problem occurs within an institutional framework, giving weight to the professional gaze. When helper and client have different understandings, the professional’s interpretation is considered “hyper real” compared to the client’s, because the former’s assessment is already intertwined with and stems from the institution’s range of action. For the welfare institutions, institutional identities are a pragmatic necessity in the sense that they reflect the system’s need of sorting: for it to implement measures, the problem description and suggested solutions must align with the system’s organization. Thus, receiving a certain diagnosis is not just about the person’s challenges being defined in a specific way. In an institutional context, diagnosing is far more exhaustive than a linguistic ordering of things, but is part of a larger system structure, where specific categories and resources are linked together. Hence, to the client, institutional identities come to play a crucial role as they are the “entry ticket” to the welfare institutions system of support.

That specific diagnoses are linked to the system’s possibilities for action is recognizable in *Tale of Troubled Times*, and is particularly evident when the parents apply for, and are granted, more days and nights at “Solgløtt” – a respite care facility where Daniel already spends time. But the implementation of this measure is dragging on. The funding that is involved is associated with the Agency for Intellectual Disability, but because the parents have refused to accept the diagnosis of intellectual disability, Daniel currently falls under the Agency for Children and Youths. This creates a “plug” in the systemic chain, which is not cleared until the parents go along with the system’s demand and accept diagnosing Daniel with

“unspecified intellectual disability”. This additional diagnosis is made without further assessment, but it speeds up Daniels “path” through the system, and results in the granted additional hours at Solgløtt eventually being executed (143).

When aligning with the professionals’ perspective opens doors to key services, power and interpretation come together. Despite being strongly encouraged by the helpers, the parents refuse for a long time to accept this diagnosis (“I understand that this is a small issue for you, but for us, it’s existential”, 118). When they eventually agree to it, it appears to be an act of resignation, as a trade-off to receive the necessary help. What this additional diagnosis adds to the helpers’ comprehension of Daniel seems unclear. However, increased or more adequate understanding does not seem to be the main point; embedded in the organization of resources, the diagnosis becomes a gateway which, if accepted, creates movement within the fabric of the system.

“Institutional identities” shed light on a systemic pivot, causing a pressure towards making a diagnosis, which, when defined, subsequently becomes preservative. The first autism diagnosis that Daniel receives turns out to be inaccurate, but efforts to get the system to reconsider are met with resistance and pressure to drop the issue – the diagnose seems to have a life of its own, relatively detached from Daniels actual being and what the parents have to say about his development. Encumbered with this quality of inertia, the threshold for changing the diagnosis is high.

Reading the novel through the concept of institutional identities makes the unarticulated premises of the interactions between the parents and the helpers visible. The perspective draws attention to the structural weight of definitional power and enables a reversal of the system’s self-understanding. Of course, it takes time to come to terms with one’s child’s loss of functions. But it is also the case that the diagnosis in an institutional context serves as a sorting mechanism, and as a lens through which the system acts. Once made, the diagnosis carries its own weight within the space of interactions. In this context, doubt and ambiguity become “noise” because they lack a systemic resonance. The unambiguity of Daniel’s diagnoses, communicated by the helpers as a privileged insight, is in fact a prerequisite, disclosed by what is excluded from the interactions, topics not being raised, questions not being asked, and the system’s resistance to reassessing Daniel.

In their interpretation of Daniel, the parents and the system have differing and partly colliding driving forces, which makes a fruitful collaboration difficult. Whilst the parents, faced with the first diagnosis of autism, seek to expand it,

as they are prepared to see Daniel as something else and something “more”, the system’s approach is oriented towards “peeling away”, towards making the diagnosis unambiguous. In this picture, the absence of recognition, the long pauses and silences, and the averted eyes, become expressions of the system’s limitation, where whatever or whomever does not fit the category simply falls through.

The social work tenet of “starting where the other is at” may give the notion of the helping process an ethical touch, but as a guideline in an institutional context it fails to provide it with a direction. The concept of institutional identities elucidates how diagnosis, as institutional categories, have indicative force and exert power in the client – helper interaction by guiding the helper’s gaze and interpretation. The perspective does not speak of a category’s “truth”, but of its function and performativity. It speaks of the professionals’ narrative and interpretation of the Other as conditioned by a systemic structure. In the novel, we observe how this institutional discourse influences the spaces of interaction, as the diagnosis constitutes a practical, thematical, and organizational force field.

Framing, ethics, and social work

The concept of institutional identities enables us to see the system’s presence in specific, embodied professional practice. One objection to this structural interpretative frame is that it reduces the professionals’ status to that of the system’s marionettes, without a psyche of their own. Admittedly, structurally oriented perspectives do not speak of individual differences, and they tend to miss nuances. And indeed, not all the helpers in the novel are portrayed as equally reductionist, but in the few exceptions that we do come across, the helpers are often apologetic about the system’s demands (147). Neither in the novel nor in the field of practice can the system be circumvented. The system will always take its toll.

Bringing attention to the structural dimensions of professional practice seems particularly important in these neoliberal times, where there are strong tendencies for “context” and “structure” being disparaged and downplayed in the locus of explanations (Degen et.al.2022, 3). Although social work tradition and values underscore the importance of a holistic approach and of highlighting societal factors, it is well-documented that the profession across the globe is subjected to neoliberal influences (Brockmann & Garrett 2022). The impact of neoliberalism is also evidenced in Norway by structural and contextual perspectives losing ground.

Increasingly, support and assistance are offered in the form of conversations, parental guidance, and the like – methods that are intended to mobilize change in the client (Kleppe 2016, 257), and that center the client and the professional around an individualized conceptual apparatus. Individualizing the “social” in social work is a challenge to the profession which can be attributed to neoliberalism – diminishing structural and systemic conditions is its mode of operation. In such a professional climate, calling forth aspects of reality that are not reducible to the client’s or the helper’s individual psyche, motivation, or choice is critical. Reading the novel through the perspective of institutional identities subverts neoliberal logic as it guides our attention towards a social, contextual layer of reality.

My analysis makes evident how *Tale of Troubled Times* both reflects and distances itself from prevailing representations in society. The institutional discourse, and particularly a language of medical diagnosis, is mimicked as well as questioned and complicated. Though often necessary in the process of helping, the novel highlights how the mapping of the Other can go hand in hand with the invalidation and suppression of divergent experiences. To the parents, navigating around the institutional categories holds an existential dimension to which the helpers in their conduct seem oblivious. The helpers seem unable to handle both a diagnostic frame of reference and the parents’ experiences. Revealing their absence of recognition, the novel highlights the close relationship between language, attention, and ethics. To professional helpers, the diagnosis is a working tool and a systemic requirement. But as the novel shows, this tool is anything but neutral, as it dominates the helpers’ outlook and makes them ill-prepared for responding or attending to other aspects of the situation or of Daniel. In this respect, the novel cautions us against the reductionism of diagnostic labels.

Based on the helpers’ conduct, we have no reason to believe that they are aware of what not being heard does to Olaug. If they did, their striving towards seeing what she sees would be greater, and the videos of Daniel would be less easily dismissed. In reading *Tale of Troubled Times*, we come to know Olaug’s inner world in a way the various helpers in the novel do not, as they only have access to her “outer layer” and social masks. As readers, we also have access to her motivation and what her behavior means; we know that Olaug’s silence is a paralysis and not a sign of tacit agreement with the helpers. We know that her silence at meetings conceals disagreement, resistance, and sometimes rage. Literature’s ability to “read minds” (Felski 2008, 89) makes us aware of this antagonism that is present in the interaction, and what it involves.

If it had only been the case that a diagnosis served to open doors, the question of which category one fitted into would primarily be a pragmatic one, and the

diagnosis could have been met with a shrug of indifference, or eagerly embraced to access help. But in the novel, the picture is more complex. The portrayal of the already described multi-disciplinary meeting shows how a category at the ground level becomes a frame for interpretation and for what is brought into focus. Even in an interdisciplinary meeting, where a diversity of perspectives could potentially have been highlighted in the interest of coordinating the efforts around Daniel (which is the purpose of such meetings), deviance from normality becomes the centre towards which the meeting gravitates. In this discourse, “Daniel the boy” seems to have no place. This opens a window to the dilemma and the discomfort that parents of disabled children may face: that a category that opens one door, also serves to close important other doors, that the child becomes mirrored and recognized only as a deviant, making the diagnose an encompassing identity.

Final words

As I hope to have demonstrated, a literary narrative can be a valuable contribution in a reflection on the challenging task of seeing the Other. In my analysis, *Tale of Troubled Times* heightens the reader’s sensitivity to the systemic forces at play. Although attention is an individual capability, its allocation is, at least partly, a matter of organization and systemic structure. In reflecting on the ethical dimension of social work, reclaiming the power of structure and context in shaping the professional gaze is a necessary step. The social worker will always represent some part of the welfare system. Reflecting on how practice is shaped, or undermined, by institutional demands is indispensable. It is also essential to be aware that the system can pose a challenge to clients and in some respects, even make the client’s situation worse.

As Felski argues, a novel can sometimes point towards insights through what is not explicitly portrayed: “To really see a thing may require an absence rather than an abundance of words (...) knowing is shaped as much by what is left out, as by what is kept in” (2008, 102). In many ways, the protagonist in *Tale of Troubled Times* is resourceful. Olaug belongs to the upper-middle class, is married, well-articulated, capable of “speaking the cause”, as she puts it, and can give detailed descriptions of the situation and of Daniel’s needs in the many applications she writes to the welfare administration. She possesses the resources that wrestling with the system seems to require. And yet, the battle is long and exhaustive. Even she becomes silent instead of speaking her mind. Challenging the authority of the professionals comes at a cost, even to her. Because Olaug is portrayed in the

way that she is, the novel gives rise to some essential questions, which reach far beyond the singularity of the novel and are of utmost importance for social work: What about other parents of disabled children, with fewer resources, and perhaps with additional burdens and challenges, but who also must interact with similar systems? Do they have the energy to contest a diagnosis that they feel is inaccurate, and that perhaps is in fact incorrect? Are they able to describe their needs in such a way that elicits (enough) help? Do they have the resources to carry out this continuous “work of visibility”? What are the prospects and life quality for those disabled children whose parents cannot advocate their rights and who, when called for, cannot challenge the system’s decisions? Because we understand what these struggles cost someone like Olaus, our attention is drawn towards the conclusion that class and verbal resources are related to the chances of receiving necessary assistance. We come to see that making vulnerability visible to the system – whether one’s own vulnerability or that of one’s child – is a highly demanding task. A task probably far too demanding for many of those living on the margins.

References

- Askeland, G. (2006). Kritisk reflekterende- mer enn å kritisere og reflektere. *Nordisk sosialt arbeid*, Vol.2:2, pp.123-135. <https://doi.org/10.18261/ISSN1504-3037-2006-02-04>
- Berg, B., Ellingsen, I.T., Levin, I., Kleppe, L.C. (2015). Hva er sosialt arbeid? I: Ellingsen, I.T., Levin, I., Berg, B., Kleppe, L.C. *Sosialt arbeid. En grunnbok*. Oslo: Universitetsforlaget
- Borch, C. (2011). *Niklas Luhmann*. Abingdon, Oxon: Routledge
- Brochmann, O., Garrett, M.G. (2022)). «People are responsible for their own individual actions: dominant ideologies within the Neoliberal Institutionalised Social Work Order. *European Journal of Social Work*, 25 (5), 880-893. doi: <https://doi.org/10.1080/13691457.2022.2040443>
- Chambon, A. (2013). *Recognizing the Other, understanding the Other: a brief history of social work and Otherness*. *Nordic Social Work Research* 3:2, 120-129. doi: <https://doi.org/10.1080/02156857X.2013.835137>
- DeFalco, A. (2016). *Imagining care: Responsibility, Dependency, and Canadian literature*. Toronto: University of Toronto Press
- Degen, J.L., Kleeberg Niepage, A., Bal, P.M (2022). Lost in Context? Critical Perspectives on Individualization. *Hu Arenas* 2022 Jun 15:1-6.
- Douglas, M. (1986). *How institutions think*. New York: Syracuse University Press
- Ellingsen, I.T., Levin, I. (2015). Det sosiale i sosialt arbeid. I: Ellingsen, I.T., Levin, I., Berg, B., Kleppe, L.C. *Sosialt arbeid. En grunnbok*. Oslo: Universitetsforlaget
- Fellesorganisasjonen. *Website*. 2022. Se filmer: Sosialarbeiderne er hjertet i velferdsstaten - FO - Din fagforening
- Felski, R. (2008). *Uses of Literature*. Oxford, UK: Blackwell Publishing

- Fineman, M.A. (2008). The Vulnerable Subject: Anchoring Equality in the Human Condition. *Yale Journal of Law & Feminism*, Vol 20, No.1, 2008. Available at SSRN: <https://ssrn.com/abstract=1131407>
- Fontene. *Website*. Brageprisen til Olaug Nilssen. 2017: Brageprisen til Olaug Nilssen | Fontene.no
- International federation of social workers (2014). *Global definition of social work*. <https://doi.org/10.18261/ISSN1504-3037-2006-02-04>
- Järvinen, M. & Mik-Meyer N. (2003) (red.) *At skape en klient. Institusjonelle identiteter i sosialt arbeid*. København: Hans Reitzels Forlag
- Julkunen, I., Rauhala, P. (2013). *Otherness, social welfare and social work-a Nordic perspective*. Nordic Social Work Research. <https://doi.org/10.1080/2156857X.2013.834266>
- Kleppe, L.C. (2015). Kunnskaps i sosialt arbeid. I: Ellingsen, I.T, Levin, I., Berg, B., Kleppe, L.C. (red.), *Sosialt arbeid. En grunnbok*. Oslo: Universitetsforlaget
- Kleppe, L.C. (2016). Helhetssyn – hva så? -Et honnørord med uklar betydning for profesjonell praksis i helse - og velferdsforskningen. *Tidsskrift for omsorgsforskning*, Vol 2, No 3:252-259. <https://doi.org/10.18261/issn.2387-5984-2016-03-11>
- Levin, I. (2004). Hva er sosialt arbeid. Oslo: Universitetsforlaget
- Levin, I. (2015). Sosialt arbeid som spenningsfelt. I: Ellingsen, I.T, Levin, I., Berg, B., Kleppe, L.C. (red.), *Sosialt arbeid. En grunnbok*. Oslo: Universitetsforlaget
- Nesby, L. (2021). *Skjønne og stygge sykdomsskildringer*. Scandinavian University Press, 61-102. doi: <https://doi.org/10.18261/9788215045122-2021-02>
- Nilssen, O. (2017). *Tung tids tale*. Oslo: Det Norske Samlaget
- Prochaska, J.O & DiClemente, C.C. (1982). Transtheoretical therapy. Toward a more integrative model of change. *Psychotherapy: Theory, research and practice*, 19 (3): 276-288. <https://psycnet.apa.org/doi/10.1037/h0088437>
- Reupert, A., Straussner, S.L., Weimand, B., Maybery, D. (2022) It takes a village to raise a child. Understanding and expanding the concept of the “Village”. *Front. Public Health*, Vol 10:756066. <https://doi.org/10.3389/fpubh.2022.756066>
- Shulman, L. (2003). *Kunsten å hjelpe individer og familier*. Oslo: Gyldendal Akademisk
- Simönhjell, N. (2020). Å fortelje eller bli fortald. Ein analyse av Olaug Nilssens Tung tids tale (2017). In: Lid, I.M., Solevåg, A.B. *Religiøs medborgerskap*. Oslo: Cappelen Damm Akademisk, doi:10.23865/noasp.100.ch8
- Skjervheim, H. (1999). *Deltakar og tilskodar og andre essays*. Oslo: Aschehoug
- Sæther, K. (2022). Når forskningskulturer møtes: Noen prinsipielle avklaringer av interdisiplinær forskning. I: Kleive, H.V., Lillebø, J.G., Sæther, K. (red.), *Møter og mangfold. Religion og kultur i historie, samtid og skole*. <http://doi.org/10.23865/noasp.156>
- Tøssebro, T & Wendelborg, C. (2018). Idealer og realiteter- perspektiv og eksempel fra forskning om funksjonshemming. I: Berg, B., Haugen, G. M. D., Elvegård, K., Kermit, K. (red.) *Marginalitet, sårbarhet, mestring. Metodiske utfordringer i praksisnær forskning*. Oslo: Universitetsforlaget
- Warberg, S.H. (2021). Apostrofere den levende. Den pårørendes vitnemål om autisme i Olaug Nilssens Tung tids tale. *K&K: Kultur og Klasse*. Vol.49 (131: Sygdom),59-80. <https://doi.org/10.7146/kok.v49i131.127483>