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On data discipline, citizen care records, and rehabilitation work

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Abstract Reporting from an ethnographic study on municipal welfare provision, we focus on care workers' "data discipline" when engaging in result-documentation within rehabilitation work. We show how the care workers' own approach to result-documentation is a different kind of "data discipline" than the one called for by municipal management and supplemented by the digital care record. To unfold the analysis we draw on insights from Science and Technology Studies and Computer Supported Cooperative Work. We conclude the paper arguing that "data discipline" is practiced by care workers, they, however, engage in a different kind of data discipline.

Introduction

"How data are created, shaped and acquire legitimacy is often closely intertwined with normative statements of what should become visible and granted importance" (Bossen et al., 2016, p. 511).

According to the Danish Social Services Law, the abilities, needs, and progression of citizens with cognitive and physical disabilities should continuously be accounted for by municipal authorities and service providers (Social- og Indenrigsministeriet, 2015; Socialstyrelsen, 2020). A tenet in the 2014 social supervisory reform is that result-documentation should be conducted by

case and care workers in an effort to render probable the "positive" effects of services on the rehabilitation of the citizen (Socialstyrelsen, 2016).[1]

Consistent with the national strategies (KL, 2017; Socialstyrelsen, 2016), the municipal management, within the present case, is concerned with obtaining data that makes visible and qualify how service providers (day care centers and residential homes) work with rehabilitation approaches and their effects on citizens' functionalities and well-being. The documentation of rehabilitation takes place in electronic citizen care records where authorities and providers of services report on the individual citizen's case[2]. However, in the municipal ambitions data is seen as crucial for rendering rehabilitation probable, and municipal managers voice concern that the documentation practices in the decentralized care units differ from one another and lack "data discipline" – i.e., as told during fieldwork, to systematically document the rehabilitation approaches used and their effects in electronic care records (field notes from observations and interviews).

The analysis presented here is situated on the centralized wish for "data discipline" by way of exploring documentation practices at a day care center. We shed light on care workers' systematic approach, qualifying the work they are doing and their sharing of knowledge about it. By unfolding the care workers' documentation of rehabilitation in and outside the care records, we show how they produce and interpret data by inventing categories, documents, and forms in order to learn from and optimize their methods and tailor the care of each individual user[3]. We argue that care workers create their own systematic approach for working in a data-informed way. However, as much of this work is invisible in the care record, their disciplined production and use of data differs from management's wishes.

Previous research in the field of welfare provision and IT have looked into the changing nature of work and the role of professional discretion in standardizing and automatizing decision-making (Boulus-Rødje, 2018; Høybye and Ernst, 2018; Pedersen and Wilkinson, 2018; Petersen et al., 2021). Further, research has looked into the rationalization of public welfare professionals' work, which has occurred from the evidence-culture of documenting, monitoring and measuring (Andersen, 2013; Jöhncke and Rod, 2015). Along similar lines, research in health care informatics has been concerned with new forms of "data work", as situated practices of and cooperative efforts going into the making, re-purposing and

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1 In an effort to obtain and share data about effects of social services, a national digitalization project called Fælles Faglige Begreber [Common Professional Terms in English] aims to make practices of result-documentation across Danish municipal actors more consistent and structured with new digital classifications (KL, 2017; Socialstyrelsen, 2020).

2 This includes: services, which a citizen has been approved, details about e.g. medicine, health, background, and daily documentation of efforts related to the citizen's rehabilitation according to goals, e.g. independence, structure, mental health, formulated by municipal authorities (field notes from observations and interviews in the citizen centre for disabilities).

3 Care workers refer to the people at the units as 'users' (field notes from observations at a day care center).

sharing of data in order to enable and integrate information infrastructures (Bjørnstad and Ellingsen, 2019; Bossen et al., 2016).

While such research focuses on the changing roles and tasks of welfare professionals in information technologies and infrastructures, this paper is concerned with unfolding the term "data discipline", which was encountered during fieldwork. With the paper, we show how care workers creatively relate to embedded political and normative categories in and outside the electronic care records. With this, we shed light on care workers' "data discipline" and how a systematic approach, developed by care workers, does not fit the centralized demands for documentation in the care record. Our analysis, in this way, engages with how various approaches to documentation interfer with each other by looking at relations between formal (infra-)structures and situated practices of "recording" citizens (Berg, 1996, 1997; Chawani et al., 2014; Star, 2007; Suchman, 1994). This is to say that categories and classifications, embedded in information systems, are political and have disciplining effects (Bossen et al., 2016; Suchman, 1994). Similarly, in drawing on Ribes & Jackson (2012), we could say that data is infused with decisions, evaluations, and values, which designate what is taken into account and what is left out. In an effort to explore exclusions in categories, we turn to Star and Bowker's (2007) concept 'residual categories', which refers to that which is left out in a classification system; the "none of the above" category, the dismissed or disbelieved lived experiences, something straining the technical capacities of the information system, or something falling between two stools (Star & Bowker, 2007).

We bring this theoretical orientation with us and situate our analysis on the local, decentralized data practices of care workers and their encounters with centralized and legal requirements, political goals, and structures in the technical set-up. Moreover, we look more carefully into the care workers' documentation practices as they creatively use the embedded categories in the care record to make room for data that allows for their own systematic approach. That is, while the embedded categories in the care record have a structuring effect on how rehabilitation and documentation work is organized at the day care center, the decentralized practices are restructuring the structure of the care record.

Thus, in unfolding the empirical term "data discipline" in tandem with the theory presented, we argue that care workers are data disciplined as they use data to qualify their rehabilitation approaches in a structured way. However, the data discipline they engage in is different from the one called for by municipal management and the electronic care record. Although different, the data disciplines share in common that they put recordings of rehabilitation and progression on a specific meaning bearing path.

Empirical setting and methods used

The paper is based on ethnographic fieldwork (Cook and Crang, 1995; Neyland, 2008) in a citizen centre for disabilities in a Danish municipality. The fieldwork was conducted during March to June 2019 by the first author who did observations and interviews at a day care center and at a residential facility for persons with cognitive and physical disabilities. The observations were conducted during care workers' staff meetings, their documentation practices in front of computers, when they filled out printed forms, and during various activities such as bike trips with users. Beyond observations, 6 professionals, including care workers, heads and coordinators of care units, and a volunteer coordinator, were interviewed. The interviews were semi-structured (Brinkmann and Kvale, 2015), conducted in Danish, and lasted on average around one hour. Transcripts and fieldnotes, presented in this paper, have been translated from Danish to English. Field material including national policy documents (KL, 2017; Socialstyrelsen, 2016, 2020), municipal policy papers, printed forms, and descriptions of the case management system have been analyzed using continuous situational mapping and memoing from situational analysis (Clarke, 2005; Clarke et al., 2018).

For this paper, we present data from one day of fieldwork at a day care center with focus on local care practices and documentation in the citizen's electronic care record. The record comes with standard tabs such as abilities assessments and action plans, which the authorities are required to fill out, and with pedagogical plans, which care workers are required to formulate and update; here, care workers report on the specific goals and initiatives that the authorities have formulated in the record.

For the project, a NDA was signed between the first author and the social services administration in the municipality. The involved participants were orally informed about the aim and scope of the study, guaranteed anonymization, and voluntarily participation.

Analysis

Care units are required to report on a citizen's rehabilitation, but in the citizen centre for disabilities, several citizens lack verbal language; some have none at all, while others can utter single words. Due to the lack of verbal language, care workers emphasize that their daily reporting in the electronic care record is likely to represent their best assessment of a citizen's well-being *and* positive effects of the rehabilitation approaches. As a result, the care workers at the day care center which we follow here have come up with a way to make the pedagogical plans more structured by developing (what we refer to as) an indicator: the "coping signal". In the following, we will see how they fill out forms and categorize data in excel sheets, which helps them interpret what leads users to act aggressively.

However, we will also see how the electronic care record does not readily allow this type of data production.

Inventing categories of coping signals

At the day of the fieldwork reported here, two care workers walk the first author through the documentation tasks they perform on a daily basis in the case management system. They access the care record of one of their users and navigate to the "pedagogical plan", where they explain how they have to "add an effort" for each goal that has been agreed upon between the authorities, the citizen, and the providers of social services. Common goals are "structure", "independence" and "mental well-being". "An effort" is the activity or strategy that care workers put in motion to work towards a goal. Every day they make notes on "an effort". In the record, they usually write notes in prose, answer multiple choice questions, or use drop down categories. The first author observes that there are 444 pages of documentation in the pedagogical plan for this user. One of the care workers explains that due to the difficulties extracting anything from the thread of notes, they have created their own indicator to qualify their work:

> *"We had a long chat back and forth: What should we do with documentation? We thought it was difficult to extract anything from just writing notes. Because it was just a long thread of notes. It was difficult to see if what we do has an effect. So we decided to make these pedagogical plans more structured, so it was better for us"* (Interview with Maria, care worker at a day care center)

In the pedagogical plan in the electronic care record, the care workers are supposed to write daily notes in prose in a text field. However, as this care worker explains to the first author, the care workers and their manager decided at a staff meeting to supplement the notes with a personalized Word document, in which they explain the jotted down notes in the electronic care record. Further she explains that they decided to upload these documents, whilst knowingly straining the capacities of the case management system. The Word document contains categorized descriptions of behaviour and prescriptions of various rehabilitation initiatives designed for each user. They call this document "a coping signal". Beyond making meaningful the notes jotted down, it also serves the purpose of indicating day to day well-being of a user through a traffic light signal:

> *"Here we describe when John is in green, then how does he behave when he is doing well, and what we will do with him or towards him? What can we do to sustain that (green behaviour)? And then a more problematic behaviour can occur. That's the yellow signal. There, we have also described how his behaviour is (in yellow) and what we can do to bring him back to green. Actions that will help him back to a good mood. And what we can do to avoid that it escalates to red. There (in red), we also have a description of how he is when he is in his most*

> *horrible state. And what we can do to bring him back. We have one of these (coping signal) for each user. (…) John's behaviour is very labile and he can be really unwell. Other users aren't aggressive like that. Then instead, we use this as a comfort signal… They can be in red without kicking and hitting and all that. They can still be unwell mentally. So we use this as a way to look at their behaviour and interpret how they are doing physically and mentally".* (Interview with Susan, care worker at a day care center)

Each user's coping signal is modified regularly at staff meetings, where care workers categorize each user's states of *being* into colour codes that indicate what could be done to improve or what could be the cause of a user's particular state of being. The coping signal allows for them to do the daily required notes, but, in their own systematic way, which qualifies their work with all that it entails – their experiences, neuropedagogical knowledge, and skilled attentive knowing of marginal changes in behaviour and surroundings. By themselves, the categories and fields for reporting embedded in the electronic care record do not leave room for this type of qualification. Thus, without knowing the language of the coping signal and without accessing the document uploaded, the notes in the electronic care record make little sense. As it is, the care workers' data production method for sharing knowledge and learning about the effects of rehabilitation work is somewhat invisible for others who access the electronic care record.

Counting and interpreting incidents of violence

In the development of these documentation practices, this day care center is inspired by neuropedagogical supervision and its use of risk assessments in order to prevent aggressive acts by users. Care units are legally required to report on violent incidents in standardized forms in the case management system, as the head of the day care center tells the first author. However, at this center care workers also attempt to count incidences and interpret the circumstances under which they surface. They combine the coping signal with forms and excel spread sheets to which they produce data about user-violence - which relates to anything from a slight push to more aggressive acts. In the day care center, they have designed a form with questions regarding the details of an incident. They have a pile of printed forms in their shared common rooms, so that a care worker quickly can grab one and fill it out, using a pen, right after the incident. The head of the day care facility gathers the filled-out forms and type the information in an excel sheet that can illustrate, over a period of a month, who was aggressive, towards whom, at what time, and so on. This allows the day care center to identify patterns, which they discuss at staff meetings. Alongside the coping signal, the excel sheet makes it possible for the care workers to interpret particular expressions of a user's behaviour. If John tends to be violent towards George three days a week, often between 12 and 13, the care workers can go back to their daily notes in the care record, check the colour code, and open the file to check

John's typical responses. With this reading of their data reporting, they attempt to see if any repetitive patterns were registered, such as e.g. poor sleep or changes in medication, or whether John only reacts in certain ways towards specific users or care workers.

This type of counting and interpretation of reported data helps the day care center coordinate their rehabilitating approach towards each user. We see how they reflect upon care workers' experiences with a user, numerical data from the excel sheet, behaviour coded in the coping signal, and daily notes in the care record. In this way, they mix different sources of data in a systematic and disciplined way. However, as we have shown, these systematically and disciplined ways of working and documenting rehabilitation are in part digitally unaccounted in the care record.

Concluding discussion

We have focused on care workers' "data discipline" and shown how they intersect centralized formal and legal requirements with local requirements by using their own indicator, the "coping signal", as new categories for producing and documenting data to qualify their work and for sharing knowledge. While both municipal management and care workers share a concern for "data discipline", the care workers' use of data differs from the municipal (governmental) ambition. Even though care workers have invented a way of working meaningfully with documentation, their efforts are not acknowledged by the case management system and are thus to a large extent invisible.

In following Suchman (1994), categories act with a certain type of control and disciplining effect over social relations. Similarly, in the care record, we see how categories and fields value particular types of documentation and how categories are constitutive in organizing a particular type of care. The political focus on rehabilitation and progression is evident from the care record where calls to locate goals are made as prompts for notes and answers. In this way, categories assign value to and make visible notes expressed in a specific form, whilst other ways of noting and reporting on rehabilitation are invisible and excluded. Care workers translate these categories and political goals into their everyday work, but by restructuring available structures and changing the content, they make room for something differently valuable, which officially, might be residual.

In our case, residual categories (Star and Bowker, 2007) make us attentive towards that which is not part of the standard, but we also turn it around to see how care workers take advantage of the plasticity of the set-up by bringing in data that strains the technical capacities, inventing categories that might have been dismissed technically/politically, and initiating a data discipline that is fitable to local work requirements. The embedded categories in electronic care records and the care workers' own categories are equally political; they also carry with them

different valuations of what is worth knowing and worth counting. Data discipline, in this way, is acknowledged and practiced by care workers, however, they engage in a different kind of data discipline in order to qualify their rehabilitating work.

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