

How to consult with people with mental disabilities: A conceptual ground clearing¹

Part I.: The question of ascribing sense²

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Summary

In my research in a "care homes for persons with disabilities", I try to follow Bruno Latour's maxim that to do good ethnography means to "speak well to someone about something that really matters to that person". But what exactly does this mean in a setting where many of the important actors could not voice their matters of concern and whose actions, according to many others around them, make no sense at all? While one possible way out of this problem might lead through investigating physiological and behavioural features considered easy to understand and common to all (as displays of pleasure and discomfort or irregularities of heartbeat), an interpretative ethnographer is faced with a question what sense could he/she ascribe to and discuss with people whose life projects are commonly thought of as interpretable only through their irrationality and radical otherness. The paper presents an example of author's encounters with disabled-identified people and discusses some options how to make sense of these encounters, how to write about them and how to present interpretations back to the actors.

Writing ~~mental disability~~ under erasure

I want to tell stories about people living in "care home for persons with disabilities".³ Quoting from the *Public commitment* of the institution to which I come to collect my "little narratives" (Lyotard 1984), its "target group" consists of "men and women with mental disability and mental disability combined with physical disability" and could not include "persons without mental disability". Something called "mental disability" seems to be the reason why heroes of my stories live where they do and why they are objects of institutionalized, state controlled and state sponsored care. Mental disability is the main organizing category shaping communities in which they spend most of their time,⁴ the basis for special treatment and education they receive, and, as I will try to show in this text, the key according to which their needs, thoughts and actions are usually interpreted and retold. Thus, from a certain point of view, in certain times and certain situations,

¹ This text, as almost every text, is a result of collaborative effort. The "author" wishes to thank for their extremely valuable comments to Zdeněk Konopásek, Ingunn Moser, Kristine Asdal and to students of Zdeněk Konopásek's doctoral seminars and participants of "Politics and Practices of Methods" PhD course at TIK Centre for Technology, Innovation and Culture of University of Oslo. I would also like to express my gratitude to the inhabitants and the employees of the care home where my research for this article took place.

² I will deal with the problem of consulting with people ~~with mental disabilities~~ in three steps, that is by answering three closely related questions. First, the question of ascribing sense, second, the question of giving voice, and third, the question of communicating without words. *Part 1.: The question of ascribing sense* has been developed as a contribution to the seminar in sociology of medicine at the Faculty of social sciences of the Masaryk University, led by Iva Šmídová, Eva Šlesingerová and Lenka Slepíčková.

³ The phrase in the quotation marks is the official name of the social service offered by the institution. The care home is located in the South Moravian Region of the Czech Republic.

⁴ In the care home, clients live in "groups" organized according to "degrees" of their mental disability (mild, moderate, severe and profound), or, in the newer paradigm, according to the "extent of support" they need (low, medium and high). About these subcategories, see also Carlson 2010: 7.

mental disability is important, for the people themselves, for me and for our encounters as well. But in other situations, in other times and places, it is not important at all.

As I mostly come into the care home to talk about food, in the framework of a quality improvement programme and a research project concerned with dining, many of the experiences I have with people with mental disabilities – many of the experiences we have together – take place on a common plain so universally important, that inclusion of some of the actors into this category seems hardly relevant. When somebody promises to make me a potato pancake, because I have made a marble cake for him, I do not take it as manifestation of mental disability and interpret it simply as a show of gratitude. And when I try to feed a man, I have to fully concentrate on his abilities to eat and his reactions to my words and gestures, on his mouth, his tongue, his eyes and his expression and have no time to contemplate his score on an IQ scale. In both these situations – and in many others – I deal with a person, not with a person with mental disability, and I want to keep the same attitude in the stories I tell. But as soon as I step outside the immediate framework of these encounters, the mental disability crops up. And this incessant cropping up of mental disability in the situations I try to describe has to be included – or so I think – in my stories as well.

So, when I write my stories about inhabitants of the care home I write mental disability *sous rature*, under erasure: ~~mental disability~~; which, according to Gyatri Chakravorty Spivak means “to write a word, cross it out, and then print both word and deletion” (Spivak 1997: xiv). “Since the word [~~mental disability~~] is inaccurate, it is crossed out. Since it is necessary, it remains legible” (Spivak 1997: xiv). By using this “strategically important practice” pioneered by Martin Heidegger and Jacques Derrida, I’m hoping to make uncertain and in the same time to highlight certain view of the world and of language, which has been un-problematically excepted as a correct one, and by doing so, to open it to examination. “In examining familiar things we come to such unfamiliar conclusions that our very language is twisted and bent even as it guides us. Writing ‘under erasure’ is the mark of this contortion” (Spivak 1997: xiv). My central hypothesis, as far as the general category of mental disability is concerned, is that *stories about people with mental disabilities make more sense and have more positive impact on the lives of the protagonists, if mental disability – as a central interpretative grid inserted between the experience and the story’s retelling – is put under erasure.*

But what exactly is being crossed out by writing the category of mental disability under erasure and how do I want to record its persistent re-appearances? What is being deleted and what is being left to analyse? And isn’t this strategy of crossing out all too easy and therefore largely ineffective to rid my experiences with inhabitants of the care home of this seemingly natural, matter of course interpretative key, which intrusively offers itself for use whenever I broaden the framework of the face to face encounters?

In the “care homes for persons with disabilities”, the actors are divided into two groups by almost impermeable borderline drawn by the diagnosis of mental disability. Some of the actors are said to be mentally disabled, some of them are not, and this hierarchical order has profound implications for the way actions of members of these two groups are interpreted. While the later are granted full human agency and accorded with the full range of psychological and social motives, the former are understood as primarily and most importantly mentally disabled, their life being often explained as a “reflection of syndrome” (Goodley 2001: 224). So, firstly, it is this “abstract universality of disease”, as Michael Foucault called it, and the silence it establishes between the members of the two groups (2006: x), which I want to attack with writing ~~mental disability~~ *sous rature*.⁵

⁵ „In the serene world of mental illness, modern man no longer communicates with the madman: on one hand, the man of reason delegates the physician to madness, thereby authorizing a relation only through the abstract universality of disease; on the other, the man of madness communicates with society only by the intermediary of an equally abstract reason which is order, physical and moral constraint, the anonymous pressure of the group, the requirements of conformity” (Foucault 2006: x). Deconstruction of the seemingly self-evident dividing line between disabled and non-disabled could be also attempted, on a textual plane, by a different strategic practice, i.e. by putting a slash between the preposition *dis* and the

Secondly, disability, in my view, is not a property of the physically/mentally other, situated in his or her body/mind and revealed as a natural fact by the medical diagnosis. The concept of disability denotes general arrangement of social life, hierarchical relations of many human and non-human actors, and it “pervades all aspects of culture: its structuring institutions, social identities, cultural practices, political positions, historical communities, and the shared human experience of embodiment” (Garland-Thomson 2002: 4). In my research in the care homes for people ~~with mental disabilities~~, I draw on the denaturalised view of disability, cultivated in the constructivist and post-structuralist (critical) disability studies (see e.g. Shildrick 2012; Goodley 2011). My main interest lies in the *modes of ordering disability*, which means that “disability is not something a person *is*, but something a person *becomes*” (Moser 2005: 668).⁶

Thirdly, if denaturalised and re-distributed, mental disability is not a unified, homogenous object. Poststructuralist disability studies often understand disability as “powerful, normalizing discourse that is often traced back to medical science, and sometimes also a wider spectre of ordering efforts or interests to do with the regulation and government of bodies”, assuming that this discourse “works to order disability as well as society in a unified and coherent way” (Moser 2005: 668). But the detailed studies of practices of institutional care reveal instead of one hegemonic omnipotent discourse a variety of different and often incompatible *modes of ordering disability* (Moser 2005; Pols 2006), which leads us to questions about their origin, socio-materiality, mechanisms of enactment in everyday life, authority and interactions (Moser 2005; about modes of ordering generally see Law 1994: 20-22, 73-93; 2003). Thus, I find inspiration in two interconnected streams of recent sociological thought: material semiotics (e.g. Mol 2002; Pols 2004) and actor-network theory (e.g. Law 1994; Latour 2005). These disciplines enhance Foucauldian definition of discourse as a strategy in materials (Foucault 1981: 94–95; Law 1994: 105–110) with the following accents: 1. emphasis on material heterogeneity of the conditioning arrangements; 2. cognizance of the emergent, precarious and recursive process of ordering; 3. modesty in empirical scope and claim; and 4. basic assumption of the multiplicity of and relations between arrangements, productions and settings (Moser 2005: 669).

To summarize the answer to the question what is being deleted and what is being left by writing ~~mental disability~~ under erasure, I could say that I want to bracket out the universality, naturalness, homogeneity, and matter-of-factness of this central interpretative category, together with its silencing and dominating effects, which marginalize inhabitants of the care home.⁷ This does not mean – and it would be very naive to think so – that by this textual strategy the naturalising, universalising discourse of mental disability could be simply put aside, switched off, or that the stories of people ~~with mental disabilities~~ could be convincingly told without making references to its genealogy, materiality and power. Crossing out is not deletion. It is not weapon of destruction, nor it is tool for description – it is a sign of initial distrust, a somewhat theatrical disrespectful gesture, opening – or so I hope – the way to exploration. The strategy of writing ~~mental disability~~ *sous rature* only opens way for analysing this discourse as multiple, materially heterogeneous and conditioned modes of

adjective *able*, as it has been done e.g. by Ingunn Moser and John Law (1999), and lately by Dan Goodley (2014). As Zdeněk Konopásek writes in his note on the use of the term *dis/ability*, “[t]he term *dis/ability* here used is closely related to the notion that it does not make sense to divide people by one thick line to ‚healthy‘ and ‚disabled‘; and that is necessary to be constantly aware of the fact that we all are – in various respects and situations – ‚healthy‘ and ‚disabled‘. The difference between ability and disability is in fact always defined contextually, with respect to specific conditions” (Moser, Law 1998: n. 3; emphasis Konopásek; translation from Czech is mine). On deconstructing the general category of disability see also Shakespeare: 2014: 56–68.

⁶ Emphasis by Moser.

⁷ I tend to agree with Margrit Shildrick, when she writes that “[d]isabled people continue to be the targets of widespread discrimination, oppression and alienation, not so much for their differences (both visible and hidden), but because their performativity of embodied selfhood lays bare the psychological imaginary that sustains modernist understanding of what it is to be properly human” (Shildrick 2012: 31). And that “[t]o be aligned with normative forms of embodiment automatically and naturally entitles one to range of external goods, benefits and advantages, while to be named as disabled signals a marginalization that can only be countered by the strength of unified resistance and a claim to access what is denied” (Shildrick 2012: 36). If the general category of mental disability really has this effect, it certainly could not be neutralized by crossing it out in (any) texts. However, writing mental disability under erasure is also one of my feeble ways of trying to “avoid colluding with and adding to the power and dominance of an order of the normal” (Moser 2005: 668).

ordering. It also opens, or so I hope, a way to question claims of some of those modes of ordering to hegemony, which, if left unchallenged, sometimes transform precarious pools of ordering into almost ubiquitous oceans of order.⁸

In this text, however, I do not attempt a comprehensive survey of the modes of ordering mental disability in the care home. They only spring up from time to time, as I wrestle with my central problem of consulting people with mental disability and with related issues of communication. The central question, which I want to explore in this text, is this: *How could I do interpretative ethnography – and ethnography based on trying to understand meaning of words and actions of actors and on diplomatically aligning my understanding with their understanding – in a setting where many of the important actors could not voice their matters of concern? What sense could I ascribe to and discuss with people whose life projects (Ricoeur 1971: 536), according to many others around them, make no sense at all?* I will approach this question by telling little narratives from the care home, and then trying to deduce some tentative answers. In doing so, I will not try to disentangle myself from the networks of research and care, of which I feel to be an integral part. That means that the questions of how I could consult people with mental disabilities will be dealt with together with the questions of how my consultants – both the clients and the carers of the care home – consult one another.⁹ I find this to be the only (reasonable) way, because, as John Law has put it, we too, as researchers, are products (Law 1995: 16). And that means – if I have understood it right – that my ways of hearing, interpreting and consulting clients of the care home are interwoven with the ways they are (or are not) being heard, interpreted and consulted by other people living around them, even if I sometimes try to alter these ways.

A perfect etiquette

As an answer to the question “what sense could I ascribe to and discuss with people whose life projects, according to many others around them, make no sense at all”, I would like to tell a story about my lunch with Pete, one of the clients of the care home. He might be around twenty. He is strongly build, you might say corpulent, and has a dark hair and round face with a sweet smile. He talks slowly and thoughtfully; his dining manners are excellent. The mention of the etiquette is relevant in the framework of the dining improvement programme (Zgola, Bordillon 2001), which brought us together, and which explicitly *is not* about manners, but is often understood by carers as a way to improve clients’ challenging behaviour at a table.

Pete’s story first came to me in a form of a diagnosis. I have received by e-mail his *Dining individualisation plan*, an observation record form which I use as a starting point to discuss dining needs and preferences of people with mental disabilities, plus a link to the webpage of *For Prader-Willi* NGO. According to one of the medical texts I have googled on Prader-Willi, “[o]f all the characteristics of individuals with PWS [Prader-Willi syndrome], hyperphagia [abnormally increased appetite for consumption of food] and obesity appear to have the most debilitating effects. Due to hyperphagia, individuals with PWS are thought to have a delayed satiation response to food” (Singh et al. 2011: 91). In the column “General information about the client”, the *Dining individualisation plan* said: “As a result of his illness, the user [of social services] exhibits strong voracity, he takes food from others, eats scraps from the floor, eats away from the cat’s bowl.” Information about Pete having Prader-Willi syndrome – a medical diagnosis – could not be included in the *Dining individualisation plan*, as it is understood to be confidential, and thus reserved only for the attending physician and the medical staff

⁸ Shildrick thinks “that all of us – regardless of our own individual morphology – are participants in the socio-cultural imaginary that pervasively shapes the disposition of everyday attitudes and values – and we all therefore have a responsibility to interrogate it” (Shildrick 2012: 36).

⁹ This needs little clarification. The research for this article took place in the framework of care improvement programme concerned with dining, in which I also play the role of a consultant. Thus seemingly confused use of the term “consultant” in this text is fitting to the nature of my encounters with other relevant actors. We meet to discuss the issues of dining and to experiment with various ways of care improvement, while continually consulting each other on our interpretations of things we say and do together.

of the care home.¹⁰ Pete's mental disability, wrote the department head, is "in the mild zone".

I have done some research on the internet, looking for texts about social aspects of the problem, and did not find much – a brief mention in a behaviourally oriented challenging behaviour management textbook (Emerson, Einfeld 2011) and a text about mindfulness-based health program for Individuals with Prader-Willi syndrome (Singh et al. 2011). Thus feeling sufficiently armed to confront Pete's situation, I set out to discuss the case with his carers. It soon becomes evident that my feeble research sufficed to find out more about Prader-Willi than the carers did during their long acquaintance with Pete (except for the head of the care home department, who sent me the e-mail). Pete, repeated one of the carers, suffers from "voracity" and "steals food from others". He also "steals" cat food. From the ensuing debate, I come to the conclusion that far from being explained away on medical grounds, Pete's behaviour is judged ethically, giving the client strong, if somewhat twisted, autonomous moral agency. When I try to question the interpretation of irresistible eating urge as stealing, the offended carer answers that the word does not matter, because its substitution with another word "does not return the stolen food to its owner". Inspired by Emerson and Einfeld, I stress the "constructional approach" and "functional analysis", quoting my authors "that people with genetic disorders causing intellectual disability may also have behaviour disturbance attributable to environmental circumstances or learned experience" (Emerson, Einfeld 2011: 91). But the carers (including the head of the department) find Pete's behaviour not susceptible to environmental changes and do not try to find more about suggested management strategies (mindfulness training or menu adjustment). As for aggressive behaviour mentioned in connection with the syndrome in the work of Emerson and Einfeld, there was only one such accident in the care home, apparently caused by feeling of unfairness, when Pete was refused food which had been previously promised to him. Notwithstanding his motives, the carers think that their firm stand on refusal was the main reason why Pete did not repeat his attack.

Our lunch together (I was only drinking water, as I did not order food into the ward dining hall) took place the day after the discussion, in the framework of training in observation methods aimed at identifying possibilities for dining improvement. Here is an excerpt from my notes:

While training's participants stand behind the glass wall [separating dining hall from the doorway], so they do not disturb serving of lunch, [I ask Pete if I could make him a company and when he nods with a smile,] I sit at his table (he eats alone for some time, because he took food from his mates) and wait for him to start gulping down food or stealing water from me; but nothing like that happens; Pete eats very decently, slowly and spends the bigger part of his lunch talking to me (mostly about food); when I interrupt his dining with a question (do I do it on purpose, to test his – what? – self-control?), his hand bringing a mouthful to his lips stops in the midair and Pete slowly and thoughtfully answers my question, finishing the bite later; but his interest in food is reflected in his stories, and then in the moment when serving tables are being brought into the room and he says: "The scoops are ready in the *kantles* [food containers]!" and rubs his hands together; client knows well he has problems with food and diabetes – he says he had good results lately, so he could eat some sweets from time to time; beside, he sometimes eats piece of a cake "when nobody watches him"; he is looking forward spending weekend with his mother, with whom he plans a trip to IKEA store in Brno – in one of restaurants in the mall (he knows exactly where they are situated) he will have fried cheese and French fries; during the lunch I have a feeling that the client is losing his good humour – is he disturbed by my presence?; he eats with great restraint – he fills his cup with some tea (according to carers he always spills), he eats very slowly his sirloin steak with French fries (a small portion for such a big man); when he spills a drop of the sauce on the table cloth, his eyes look around for a napkin, but there isn't any in the dining hall, so he wipes it with his finger and licks it off; /if I am to judge Pete's behaviour fairly, I would have to say that the client suffers no voracity and at any rate does not steal food or drinks

¹⁰ Legal rules for safeguarding confidentiality of medical information might in fact differ from their interpretation by the workers of the care home. As I do not have a space here to analyse these differences in detail, the reader has to be content with the description of the rules as they are understood in the setting in question.

from his table companions; but the diagnoses and statistically substantiated (??) statements of the carers must gain the upper hand and I must evaluate his conduct at best as a change of behaviour brought about by presence of unknown neighbour at a table and at worst as incomprehensible excess, which has no relevance at all for everyday life/.¹¹

(fieldnotes from the care home)

When we sit down with the carers to discuss our observations, they are stunned – “they did not recognise Pete”, “he was not himself”. They never had similar experience – he always gulps food, steals it and soils himself, and when somebody sits at his table – which the carers themselves never do – it does not change anything. Even radical modification of setting could not help – he behaves the same way even during trips outside of the care home. When I visit the care home three weeks after the encounter, the head of the department still ponders Pete’s “inexplicable” perfect etiquette. For the carers, she says, it will be difficult to incorporate this experience into their routine interpretation of his conduct, because they “do not like him”.

As a researcher trying to “*deploy actors as networks of mediations*” (Latour 2005: 136)¹² and a consultant needing interpretative key useful for improvement, I conceptualize carers’ *not liking* Pete as an interplay of two parallel, but somehow paradoxical modes of ordering ~~mental disabilities~~, enacted in the socio-material networks of the care home.

The first one, which I will call the *wicked man-child* mode (here, I paraphrase Carlson 2010: 28–33),¹³ performs the client as an semi-autonomous person with own psychological motives, combined with limited or no ability to weigh consequences of his own actions. His semi-autonomous agency is tainted with two distinctive personal traits, inscribed deeply in his natural disposition: wickedness and childishness. In the wicked mode, the client’s challenging behaviour is being done on purpose; its aggressive nature and its basic orientation on harming others are stressed, and in the tense regimes of the care home, the carers are often the victims. The childish face of the wicked man-child could be seen in the apparent triviality of some of the client’s wicked deeds and in the infantile joy expressed at their negative effects. But while the childish drives are surely hard to suppress for somebody with restricted powers of self-examination and will, the person could master them, if he has higher, less trivial wicked aim in mind. So, clients with challenging behaviour sometimes behave decently when somebody who could criticise the conduct of the carers is present. The interpretation of mental disability as natural childish wickedness – applied mostly to the “problematic clients”, but sometimes generalized to all disabled-identified – has direct ramifications on the regimes of care. The ill behaving clients should be closely watched and the constant monitoring and documenting of behaviour, which is one of the most time-demanding activities in the care home, finds its missing rationale in the maliciousness of the wicked man-child. But the wicked man-child mode has the strongest impact on tuning the regimes of care up to clients’ individual needs and preferences. The wishes of the wicked men-children should always be viewed with suspicion, as their motives are most probably morally questionable, and towards their ever changing needs, the carers must take a firm stand. “If you give an inch, *they* will take a mile. They really *are* like that. If you do not want *them* to push you too far, you can’t budge” (interview with a carer). If too many adjustments are made in response to the needs and wishes of the clients, the highly structured and tense regimes of the care home might – or so fear the carers – collapse. Thus, the wicked man-child mode serves as a rationale for and an ordering principle of certain ways of “caring” – cautious monitoring and documenting clients’ behaviour,

¹¹ I use slash “/” to indicate my own comments to the observations. This one was added a couple of days later, when I was transcribing the hand-written notes on a comp.

¹² Emphasis by Latour.

¹³ By using and paraphrasing terms belonging in Carlson’s “conceptual pairs”, I do not want to suggest that I talk about the same orderings of mental disability as she does when subjecting to the foucauldian historical analyses the world of America’s 19th C asylums for “feeble-minded”. The specific historical socio-materiality of my own modes of ordering is yet to be analysed. “What we see,” writes Carlson, “is that the history and nature of this classification cannot be abstracted from the complex matrix of power relations out of which it merged” (Carlson 2010: 82).

suspicious attitude towards registering and documenting preferences and needs and unwillingness to make compromises.

The second ordering, the *medical/personal trait* mode (Carlson 2010: 6, 4–9), enacts Pete’s behaviour as manifestation of his medical condition, in this particular case materialised in the form of missing genes and characterised by mild mental disability and uncontrollable urge to eat. But this clear and unequivocally sounding explanation remains esoteric to the carers. As the medical care is performed and supervised by the medical nurses and a visiting general practitioner, people directly taking care of the client hardly ever come into the contact with Pete’s behaviour understood as a symptom of illness. Because the medical documentation, constructing him as a patient with Prader-Willi syndrome and mental disability, is confidential, information about the diagnoses comes to the lower strata of the organisation hierarchy blurred and distorted. (“I could look into the documentation,” says the head of the department, “but I usually do not do it” /an interview with the head of the department/.) Meanwhile, the *medical/personal trait* mode is losing its power due to recently implemented structural and organizational changes in the system of social services. Based on the Goffmanian critique of “total institutions” (Goffman 1961), invoked in the discourse of the social services “transformation” (Ministry of Labour and Social Affairs 2013: 11), and on the critique of medicalization of social services, medical institutions, approaches and personnel are being scaled down or pushed outside of the care homes, to make room for the “normal life” of the clients, characterised (in the Goffmanian sense) by distribution of various life activities between different institutions and sites. While strategic and financial matters (e.g. low salaries of workers in social services in comparison to medical nurses) play an important part in medical model’s retreat from the field of care for disabled-identified, the controversies surrounding this process are often being played out around the contesting notions of health considerations versus social aspects of care. However, given the persisting power of medical mode of ordering disability in the networks of institutional care and the esoteric nature of medical information, medical explanations of clients’ behaviour still play the role of indisputable and *at the same time* inaccessible *facts about the client*. When life of the person with mental disability is radically medicalised, it is situated firmly outside the sphere of intervention.¹⁴

Because of distant and mysterious nature of client’s ailments, the medical diagnosis of mental disability could serve as a complement to his wicked childish nature, as far as it is understood as the main reason for arrested or slowed mental *and* moral development. The man is ill, and because he is ill, he is voracious, unclean, not obliging and wicked. But he could master many of the symptoms, if this mastery is achieved in harmony with central nature of his illness, which is the wickedness itself. The medical mode offers strongly naturalised explanation of client’s behaviour and in relations to other modes of care strives for indisputable dominance, endorsed by expert authority, special institutional arrangements and esoteric organisation of knowledge. Behaviour and needs of the person with mental disability are located far away and out of reach of people most directly influencing his well being. The wicked man-child mode, on the other hand, while it does not strip the man with mental disability of all his agency, nevertheless grants him only limited range of behavioural patterns and motives, giving his relationships with the carers decidedly negative value. The combined *medical/personal trait/wicked man-child* mode thus leaves the professional carer in the situation when she has to deal with largely unchangeable problematic behaviour, which is located firmly in the body and mind of the client, but which is nevertheless purposely aimed against her.

While in majority of everyday situations the wicked man-child and the *medical/personal trait* modes work smoothly together, they crash and start to contest each other as soon as the question of moral status of the disabled-identified person is brought up. The reason for this is their contrary way of performing agency and responsibility. In this specific example, while the carers explain client’s “usual” behaviour as childish, almost animal-like “voracity” tainted with malice, the head of the department, struggling for more positive interpretation, attempts radical medicalization of his conduct. The question is: Who, or what, is responsible for

¹⁴ The critique of medicalization of mental disability is a well rehearsed theme of disability studies. For an overview, see e.g. Shakespeare 2014: 56–66. For the major conceptual issues concerning medicalization and social control, with and emphasis on studies published since 1980, see Conrad 1992.

the client's behaviour? While in the medical/personal trait mode the full responsibility lies with the disease, and so any modification of behaviour could be attempted only on medical grounds (by prescribing medicines, dietary regimes, physical rehabilitation etc.), agency as played out in the wicked man-child mode is more complicated. While the client is largely responsible for his wicked deeds (actions despised by carers), acting them out on purpose, his good deeds (actions liked by the carers) are usually interpreted as result of carers' educative and rehabilitative efforts (carers often say that they "have made" clients into something). Another paradox afflicts interpretation of the "problematic behaviour". While the client does the bad things at will, he is not fully responsible for his actions or, to be more precise, "he does not bear the fruits of his deeds" (interview with a carer) – that is, while he surely suffers and enjoys results of his actions physically, he does not do so mentally, because he is not – due to his mental disability – able to understand the causative relations between the actions themselves and their outcomes. As a consequence of this, the moral responsibility lays fully on the shoulders of the carers, who are not only accountable for them before the law and before the authorities, but also pay for them emotionally, experiencing resulting joy or suffering. Such a mode of ordering disability not only puts heavy load on the carers, making them the sole victims of the wicked man-child's wicked designs, but also complicates and puts under question any possible intervention. If the person ~~with mental disability~~ is not able to connect his deeds with their results, then any attempt to influence his behaviour must seem meaningless.

As the discussion with the head department and the carers about my lunch with Pete clearly shows, for practical purpose of debating and implementing interventions aimed at improvement of client's problems with food consumption and enhancing his joy of dining, both orderings of care for people ~~with mental disability~~ – the medical/personal trait mode and the wicked man-child mode – have only limited (if any) value. None of the two conceptualisations – by now disentangled and competing one with the other in the controversy concerning clients' agency – offers any hope for positive intervention, less for viable explanation of what we have all experienced during our observation lesson. Could I, as a researcher and a consultant, as somebody coming into the care home from outside, offer any alternative, meaningful and useful interpretation of this experience?

Bringing in the social model

In their foreword to the anthology *Care in Practice. On Tinkering in Clinics, Homes and Farms* Annemarie Mol, Ingunn Moser and Jeannette Pols define good care as "persistent tinkering in a world full of complex ambivalences and shifting tensions" (Mol, Moser, Pols 2010: 14). "Care is attentive to such suffering and pain, but it does not dream up a world without lack. Not that it calls for cynicism either: care seeks to lighten what is heavy, and even if it fails it keeps on trying. Such, then, is what failure calls for in an ethics, or should we say an ethos, of care: try again, try something a bit different, be attentive" (Mol, Moser, Pols 2010: 14). It is precisely this ethos of careful attentiveness and persistent experimenting, which, in my view, is compromised by the wicked man-child and the medical/personal trait modes of ordering mental disability and which I would like to restore by re-interpretation of my lunch with Pete. But when I strive to ward off the emotionally charged ghosts of medical/personal trait and wicked man-child modes, I feel – almost physically – how the conditions of possibility for my discourse (Moser 2005: 669–671) are limited by the existing orderings of mental disability in the care home. The thing is, I do not want to offer *just meaningful* interpretation (that is meaningful to me), but also interpretation which is useful, that is, in the first instance, an interpretation which could be taken seriously (as meaningful) by my consultants. And I want to include both the carers *and* the client into this group. And so, while I would like to delete the naturalising, universalising and homogenizing effects of general category of mental disability by explaining it to my consultants (Pete's carers) as "powerful normalizing discourse" (Moser 2005: 668), I find myself instead clinging to the social model of mental disability, which, as Tom Shakespeare puts it, shifts "attention away from individuals and their physical or mental deficits to the ways in which society includes or excludes them", while it "roots the problem firmly in material social forces

and physical environments” (Shakespeare 2014: 12).¹⁵ The social model’s dual concept of impairment/handicap, differentiating physical and/or psychological otherness situated firmly in the person’s body and mind from environmental conditions of disability,¹⁶ seems to me, in this particular situation, an ideal tool for discussing impact of various regimes of care, without attacking directly the deeply rooted ideas about naturalness of the category in question. In my report from the visit to the care home, addressed to the head of the department and to the carers, I write:

During an experiment it became evident that Pete is under certain circumstances perfectly able to master his “uncontrollable” urge to eat. It is worth to consider how this experience could be used in everyday practice of care. Apart from that, we talked about certain methods which have been successfully used in management of challenging behaviour connected with Prader-Willi, specifically suitable diet adjustment (the client has diabetes meal plan, but it is possible that he should avoid some diabetetic foods as well) and various methods of “mindful eating”.

(report from a visit to the care home)

But while I think that my social model of Pete’s mental disability is more useful for envisioning change than medical and wicked man-child modes, and in this specific circumstance it is more understandable and thus more viable than radical post-structuralist model, I am aware that in reality of this part of the care home, it remains only a model, and not a mode of ordering of mental disability, as for the moment there are almost no actors – apart from me – and no materials – apart of my flipchart – to enact it.¹⁷ It is certainly not the case that the social model is not present at all in the care home – its emphasis on the environmental aspects of mental disability and impairment/handicap duality play certain role, if only implicitly, in the discourse of transformation of social services and in the social services quality standards.¹⁸ It is also not so that the carers do not manipulate the physical environments to influence client’s behaviour. But in doing so, they only go so far as to restrict his access to the direct stimuli causing the trouble (i.e. food) and do not attempt to change the environment with the aim to arise more positive ways of behaviour. So, I might conclude, the social model *in this particular situation* is not present, and if it is present, it is somehow switched off, and thus it is not fully functional. In the site in question this mode of ordering does not order anything, or, to put it another way round, there are no actor-networks enacting it (e.g. no case management conferences, putting together humans and non-humans working on the medical *and* on the social aspects of care and thus linking an interest in client’s medical condition with the recognition of environment’s effects).

The limitations of the wicked-man child and the medical/trait modes of ordering disability as a interpretative key for explaining agency and moral personality of disabled-identified and as a tool for care improvement have been, unfortunately, confirmed and highlighted by the next episodes of Pete’s residence in the care home. Together with the shortcomings and paradoxes of these two modes of ordering, it has also highlighted my

¹⁵ For an historical overview of the social model and concise survey of its feminist and post-structuralist oriented critique, see Shakespeare 2014: 11–45. See also Goodley 2011.

¹⁶ This duality, of course, is one of the main topics in the feminist critique of the social model, modelled closely on Judith Butler’ challenge to the duality of sex and gender (Butler 1990).

¹⁷ There are different sites in the care home, where conditions of possibility for introducing the social model might be more favourable. I will try to say more about them in the second and the third part of the text.

¹⁸ An archaeology of knowledge/power structures of the Czech social services’ discourse would certainly be an important and interesting project. At the current level of learning, I could only say that explicit mentions of the social model in Czech political writing on mental disability are extremely rare. The *Manual of institutions’ transformation* (Ministry of Labour and Social Affairs 2013), the key document of the currently ongoing process of transformation of social services, defines categories of mental disability and of disability in ambiguous terms. While the more general category of disability explicitly mentions “organization of society” as one of the main reasons for low life quality of the disabled-identified people, evoking thus the spirit of the social model, the definition of mental disability is perfectly in line with radical medical model. However, a need for stressing the environmental aspects of care is often mentioned in the accounts of professionals criticizing the present-state of affairs and arguing for de-medicalization of social care. As an example of practical ramifications of such ideas I could mention recent efforts to replace medical nurses on the posts of department heads in the care home with expert in special needs education.

failure to bring in a more flexible model of mental disability and to introduce it as a mode of ordering. As Pete's mother was unable to find a place for her son in a supported living and his provisional stay in the care home thus continued, his situation was gradually worsening, with "fluctuations" of his physical and mental state, attributed mainly to the changes of season. Couple of months after my first lunch with Pete, the carers' struggles to reign in his challenging behaviour resulted in an open conflict. Once, when returning from bowling with six other clients and a couple of carers, Pete refused to get off the bus, with the explanation that the station has been moved and his medical condition does not allow him to walk the few hundred metres to the care home (a somewhat radical self-medicalization, to be sure). As carers' usual ways of persuasion had been already exhausted, because he already had his snack in his pocket, they attempted to make him oblige with other means. They carried Pete out of the public bus and dragged him, kicking, biting and screaming, to the gates of the care home. When we discussed the event a couple of weeks later during our consultation session, the carers still blushed with strong emotions. The high emotional charge of the event, however, did not bring us any further to envisioning positive change. In their account, they insist on two basic points: 1. any other action could endanger the clients more than what they did, which in the case of Pete could mean his hospitalization in the mental asylum; and 2. when "dealing with people with mental disability", a "firm mantinels" are necessary, because "if you just budge once, it is all over". They refuse all attempts to design alternative ways of dealing with the situation and when I express my worry that the violence of the event could threaten good relations between them and their client, they say that their relationship could by no means be threatened, as their professionalism does not allow them to harbour any negative feelings against clients and Pete has no reason to feel hurt. But their strongest reaction is provoked by my use of the word "violence". If there was anything violent in the encounter, it was his behaviour, a result of his wicked man-child nature *and* his diagnosis, while their own reaction was "the least evil" option. Violence is certainly not a word they want to hear in connection with the way they are doing care. Professionals or not, *now* they are really feeling hurt. And when I am eventually discussing the case with the department head, I have a strong feeling I have gone too far. "I am not judging you," I try to excuse myself, "I am only offering alternatives." "Not true," answers the department head, my gatekeeper in the care home and an enthusiastic proponent of any possibility for care improvement, "you *are* judging us."

Mental disability de-naturalised – a bad case of arguing with members?

Now back to the *question* what sense could I ascribe to encounters with people whose actions, according to many others around them, make no sense at all, and the *hypothesis* that stories about people ~~with mental disabilities~~ make more sense and have more positive impact on the lives of the protagonists, if mental disability is put under erasure and deployed instead as a multiple modes of ordering. When I read my fieldnotes quoted above, it is apparent to me how I struggled with the contradiction between the client as he is constructed by the carers through the use of the medical/personal trait and the wicked man-child modes and my own experience with him. By using the social model of mental disability, I have tried to reconcile this contradiction, without angering my consultants and driving even sharper wedge between Pete and his carers. I have tried to offer a model – perhaps potential mode of ordering – allowing both for naturalisation of client's disability *and* for social interpretation of our encounter as an exceptional, but meaningful experience, which could have beneficial effect on Pete's living. I have failed, because the concurrence of the existing modes of ordering mental disability did not enable enactment of the situation as a meaningful exception brought about by specific configuration of social actors involved, and performed it instead as an incomprehensible folly, caused by irrational mental disability and/or implicit wickedness. But from this failure, a tentative answer to my central question might be deduced.

By judging the medical/personal trait and the wicked man-child modes of ordering disability inadequate for analysing and improving Pete's situation and offering a *replacement* in the form of the social model, I have no doubt committed an offense against the rule of "ethnomethodological indifference", which, according to

Garfinkel and Sacks (1970) means that researchers must seek “to describe member’s accounts of formal structures wherever and by whomever they are done, while abstaining from all judgments of their adequacy, value, importance, necessity, practicality, success, or consequentiality” (1970: 345). I had, as Melvine Pollner put it, “argued with members” (Gubrium, Holstein 2011), and by doing that I betrayed my intention to “to speak well to people about matters of their grave concern”. Instead of debating with the carers about rationality and usefulness of their view on mental disability and about superiority of my own alternative, I could have done – I should have done – two alternative analytical moves. First, I could have put more emphasis topicalizing the accounts of my consultants, turning their apparent inadequacies “analytically into functional, even correct claims of a sort under the prevailing circumstances” (Gubrium, Holstein 2011: 92). I had, to be sure, done this to a certain extent by surveying the socio-materiality of the modes of ordering under examination. But I could have paid more attention to the question what sense these modes of ordering make under given circumstances. The highly emotional reaction of the carers to the use of the word “violence” and to my (perceived) questioning of their best intentions should have alerted me to the fact that they perform the medical/personal trait and the wicked man-child modes of ordering disability as the best and perhaps the only reasonable – given the circumstances – way to do good care. And second, instead of *replacing* the functional modes of ordering with a model somewhat exterior to the care home I could *displace* them into a different context and ask what function they serve there (Gubrium, Holstein 2011: 93). “[R]esearchers,” say Gubrium and Holstein, “would not be arguing with members if they tracked the displacement of members’ actions— whether in talk, activity, or both—to alternate contexts, that might construct talk, behavior, and meanings in contrasting terms, rendering them substantively different” (Gubrium, Holstein 2011: 95). In the world of the care home, one of such possible context into which actions of the carers might be – and perhaps should be – displaced, is the context of the world of the disabled-identified people, who, while sharing with the carers many of the everyday situations, might not share with them their accounts, meanings and results. But here, I hope, I have not strayed too far from the way indicated by Gubrium and Holstein, when I took seriously Pete’s way of seeing and doing things, which emerged over our common meals, and try to measure the prevailing modes of ordering against them.

But if my move to replace or supplement the medical/personal trait and the wicked man-child modes with the social model seems not very productive in the light of my heated argument with the carers, how successful and skilful have I been in bracketing out the naturalness, universality, homogeneity and matter-of-factness of the general category of mental disability? Wasn't this, after all, what angered my consultants most, more than the violence word and my reckless experiments with the social model? Aren't these features exactly those which every mode of ordering must achieve – which every actor enacting a mode of ordering must perform – for it to be productive, that is, to order socio-material networks of the social? And doesn't writing ~~mental disability~~ under erasure thus constitute the most explicit case of arguing with members? Perhaps – but in this case, or so I hope, my displacement of the general category of mental disability into the world of the clients of the care home was more successful than my crude attempt to replace existing modes of ordering with an ordering mode in making. By writing mental disability *sous rature* I have tried to and hopefully achieved constructing a hermeneutic cycle. I have weakened – in my writing and in my discussion with the carers – the unquestionable power of mental disability as central interpretative key, but at the same time, I let it peep out from time to time from in between words, meanings and actions. I have concentrated on the various functional modes of ordering disability, describing how they are being enacted into fairly stable orders, claiming hegemony and dominance. When left undisturbed, the combined modes of the medical/personal trait and the wicked man-child modes help to create a world, which, as I have shown by its displacement into the context of disabled lives, does not seem to be adequate or pleasant to live in. And this, I believe, is the reason why at the end of our journey, when precarious and contingent modes of ordering disability finally appear in a role of indisputable oceans of order, we must go back to the beginning of the circle and erase them out again. In a

participative mode of research, this circle fortunately doesn't have only one loop, leading from my consultants into the text and back to consultants as potential readers. Instead, it is a continuing journey in circles, in which all participants exchange and gradually re-model their views.

If Latour's maxim that to do good ethnography means to "speak well to someone about something that really matters to that person" (Latour 2013: 46, 58) is to be taken seriously, then "making more sense" and "having more positive impact" of my central question must necessarily mean more sense and more positive impact *to all those persons* with whom I am doing research, or, in the framework of a participative action research, *together with all of them*. And this "together with all of them" must embrace all members of the situations described, including the carers, the clients, and the researchers, disabled-identified or not. And so while I strive to respect meanings that the workers of the care home construct in their every day encounters with people ~~with mental disability~~, in this text, intended for the academy, where conditions of possibility for meaningful discourse might be more favourable to polemical statements than the discourses of the care home, I want to conclude with re-stating my personal point of view on Pete. He is a very genteel man, with perfect table manners. He has some medical problems he is aware of. He has – and sometimes struggles with – hearty appetite, which sometimes he is not able to control as much as he would like to. But there is absolutely no reason to believe that supporting him in this effort is useless, because he is mentally disabled, because he has Prader-Willi, or because he is a wicked man-child. As for him being an unpleasant companion at a table, I could only look forward to a next chance to lunch with him.

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