## Valuable buildings, disabled people: Tinkering with maintenance and care in situations of socio-material oppression<sup>1</sup>

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Today, I would like to talk about intersections of two modes of maintenance, which, I think, are pictured quite well by this photograph. In the first of these modes, mundane everyday activities of people identified as disabled are taken over by the state authorities in the name of higher, more important good. In the other mode, those activities are re-claimed, so people could care for their living spaces themselves. This building houses the so called "home for seniors", a residential institution for people identified as disabled by health problems related to age, people who are partially or fully dependent on someone else's help. The functioning of the institution — and of the building which houses it — is fully managed by professionals in the framework of state-designed and state-sponsored social services. But there are also other things going on. The flower box on the balcony handrail signals presence of a concrete human being, habitation of somebody who tries to upkeep her or his surroundings in the most simple, immediate fashion.

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In their exploration of breakdown and various object ontologies enacted in maintenance, Jérôme Denis and David Pontille conceptualize two basic regimes of maintenance, one aiming at high degree of professionalization, perfection of results and invisibility of the small everyday tasks, the other essentially open to all, accepting fragility and imperfection and not-striving to cover the traces of constant tinkering (Denise & Pontille 2017). In this presentation, I would like to accept their invitation to further explore different modes of maintenance, refracting some of their thoughts and adding, perhaps, some fragments to the expanding catalogue of documented maintenance practices. It is a first tentative formulation of a developing project, which builds on some five years of an ethnographic research done on various issues of institutional long-term care, and which tries to re-frame these issues in terms of maintenance studies. In short, it is an attempt to conceptualize disability as a *misappropriation of the care of things*.



In the residential institutions for people identified as dependent on other peoples' support due to their cognitive disability or age related health issues, the processes of maintenance and care seem to be inextricably interwoven. The buildings of big residential institutions, some of them dating back to classical period, need constant up keeping and renovation. Confiscated from their owners after the war, some of them had never been returned, due to legal problems or lack of interest on the owners' side. They became state property and their "protection" one of the important responsibilities and worries of the local authorities in the post-communist era. Due to their number, technical condition and strict regulations of historic protection, finding an appropriate usage or new owners for them is almost impossible. Thus, to get necessary resources for ongoing restoration efforts, they need people to live in them, functioning thus as vacuous spaces drawing in hundreds of inhabitants labelled by various kinds and degrees of disability. A contemporary variation on Michel Foucault's "great confinement" of the 17th Century is taking place (Foucault 1988: 38–64). While more and

more people labelled "mentally impaired" are being taken care of at home and so the number of potential clients of the so called "homes for persons with health impairment" declines, the big asylum buildings are being filled up with older persons, mostly those diagnosed with dementia or severe mental illness, as sufficient infrastructure and support for home-care and community care is un-available. Often, the true reason for institutionalisation is poverty – as in many cases when people are being locked in and provided with diagnosis by family members, covering thus their unpayable debts.



While providing shelter to people lacking other accommodation options, the buildings also complicate caring for their inhabitants, as the "cultural" and "economic worth" of the historic sites prevents their transformation into places suitable for dignified and comfortable living. Windows are obstructed by historic bars, big rooms could not be partitioned by walls and so have to house to up to six people, dining takes place in the cloisters and links with villages and towns surrounding the institutions are severed by ramparts, gates and beautiful romantic parks. As one of the directors put it in a foreword to a development plan advocating further renovation works: "An ideal place for a summer stay of a princely pair."



This situation creates tensions not only for the inhabitants of the residential institutions, but for the carers as well, as conceptualisations of caring strongly reminiscent of the relational ethics of care represents an important formal structure by which the staff members shape their activities and their accounts. But notwithstanding unsuitability of the building for their current use, they have to be maintained as they stand, in their perfect shape, as a "truthful and reverential memory". Thus, the people deemed disabled still live today as hostages to relics of classical episteme, the very discourse that according to Foucault established the silence between "them" and the able-bodied and able-minded population.



While former castles and convents are considered "cultural treasure" to be preserved in their authentic state, new buildings are being planned, designed and built, as a measure to counter the so called "silver tsunami" and "pandemic of dementia". As in the case of historic sites, these buildings are enacted, in the words of Denis and Pontille, as "flawless objects that users are supposed to enjoy without thinking about maintenance" (Denis & Pontille 2017: 13), while the inhabitants play little or no part in the care for the place where they live.



For the politicians at the helm of the social services, the new shiny castles, some of them resembling Jeremy Betham's panopticon, represent occasion to prove their political party's social sentiments, as well as an opportunity for economic gain.



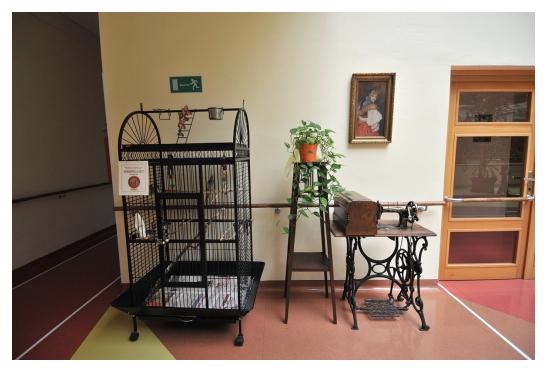
Most of the work done here is carried out by professionals, while participation of the inhabitants in the maintenance tasks is severely obstructed by various economic, hygienic and organizational regulations.



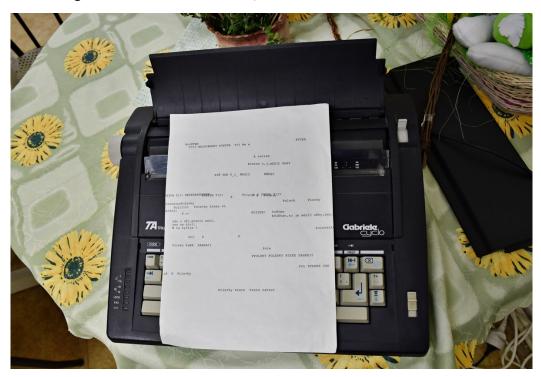
This appropriation of the everyday mundane activities by professionals has not escaped attention of critics. Based on the Goffmanian analysis of the total institutions, where many basic live sustaining tasks are concentrated in the hands of staff members, the proponents of the so called "transformation of social services" propose abandoning the big buildings housing tens or hundreds of inhabitants, and constructing new, much smaller places of habitation for up to twelve clients. In relation to responsibilities for maintenance of the historic or modern edifices, the proposal is a radical one. While the sole change of the housing is expected to cause radical change in relations between disabled identified and the able-bodied and ableminded population and re-introduce the former asylum inmates into "normal life", the buildings themselves are to be left to their fate, the only exception being demolition of the newer houses sponsored mainly from the European Union grants. Human rights — as the right to privacy or to normal life — are given preference before the responsibility for maintenance of things. On a web of an organization offering supported living to former residential institution inmates, the photos of an abandoned baroque convent are presented in the context of happy snapshots from clients' lives.



In contrast to the efforts of the radical innovators, the humanizing projects aiming at creating home in the "home" don't envision radical change of the physical surroundings, but only partial alterations, with the general aim to "activate" clients and to bring about their involvement in everyday activities. But as most everyday needs are provided for by professionals, "activity" is often performed outside the framework of the actual maintenance work. For older people, "reminiscence corners" are constructed, inviting them to remember – but mostly not to do – activities of the past. While the fake entrance into a wine cellar could hardly elicit any caring activities,



as the old sewing machine without a thread,



the historic typing machine had been used, by someone, to write strangely beautiful poetry: "May is the month of tenderness. Soups, soups that warm you up..." Could we see in this a parallel to the unfolding capacity of design, as Fernando Dominguez Rubio calls it, operating rather unintentionally, and not on a political, but on a poetic plane (Dominguez Rubio 2015)?



At the places where the flawlessness of the total institution is being constantly restored by small maintenance tasks, people deemed unable to do important things are sometimes allowed to put their hands on the real work. However, these cases are riddled with

complicated legal and financial issues, as "users of the social services" are not supposed to act as carers or maintainers or to receive salary for their work.



However, in the world created and maintained by activities in which the residents of the institutions do not and could not take part, private spaces occasionally thrive, where people could do many maintenance activities, alone or with an assistance. Do these islands of small, unprofessional upkeeping resemble in any way the participative regime of maintenance described by Denis and Pontille? And what about their relation to the residential institution as a whole, what about their participation in the re-production of the "myth of order" (Graham & Thrift 2007)?



To tentatively answer this question, let's visit the small garlic salsa workshop of Peter and Paul. In a room which they share in a "home for seniors", these two men set out to season the food cooked in the institution's kitchen with their favourite flavour. While institutional regimes of dining are hard to change, Peter and Paul used the private space they have at their disposal to transform them with the most potent additive.



Their project would be impossible without special utensils, working procedures and supply of necessary ingredients. In trying to add to the existing regimes of dining, they have to use available resources to their advantage and negotiate with guardians of the broader modes of ordering. They have to divide the tasks between them and to formulate certain economy of (in)visibility. From an organizational point of view, their project is not qualitatively different than that of a nutrition therapist preparing menu for the full house (Latour 2013: 389–404). But a check against the criteria set by Denis and Pontille could help us to pinpoint certain characteristics, which set Peter and Paul's maintaining act apart, not only from the big maintenance tasks keeping in shape the residential institution as a whole, but from the inclusive, open mode of maintaining as well.



What Peter and Paul do is rather un-professional, even though a strict division of tasks exists between them. It calls for exclusive participation – the garlic sauce will be eaten only by the two members of the private club – but has a potential to include, as when Peter and Paul invite a researcher interested in regimes of dining into their workshop, to exchange their stories for an occasional delivery of their favourite goat milk. It is done with the help of mundane everyday utensils, whose unfolding capacity is, as with the electric typing machine used for writing abstract poetry, quite unintentional, and it is – or rather it was, before the researcher and the photographer walked into the room - invisible to all but the main protagonists and their immediate surrounding. In contrast to inclusive, open and visible maintenance, this mode of preparing food is rather intimate – it does not strive to include others or to widen its sphere of influence, but is satisfied with thriving in the private space circumcised by broader maintenance regimes. In fact, it might live only in a sanctuary – that is in a space created by people setting the rules of the big game, due to certain relaxation consensual or enforced – of other organizing regimes. As for their activity's subversive and emancipatory effects, the judgement is, as with the pilling up of organizational scripts (Latour 2013), only a matter of scaling. While Peter and Paul's garlic salsa could not improve even the food of their most immediate neighbours, let alone the overall functioning of the social services, in their little world, it transforms the taste of everything, allowing them to maintain something they could directly care for. With the help of simple tools and through rather exclusive and invisible activities, it re-appropriates part of the living space usurped by regimes of collective dining.

So, contemplating (in)sensitivities of STS, a discipline interested mostly in ways of creating associations with ever larger impact and deeper effects, I would like to conclude with a plea for exploring, protecting and supporting small, intimate, circumcised sanctuaries for care of things. In them, as in the 'larger' works, priorities are formulated and fought for. Is care for

humans always more important than maintenance of things? How do we weight our rights against community interests, often valued as an unquestionable cultural treasure? In them, too, associations are built not only on consent, but on oppression, imposition and objectification. In them too, borders are marked and guarded, to create limited spaces of influence. Through activities done in sanctuaries, object ontologies are enacted into being.

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