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This essay has been inspired by a couple of recent events. Firstly, whilst on a panel discussion at a student study weekend, the question was asked why academics had to use such difficult language. In my response I conceded that academics often confuse people and could make more of an attempt to be accessible, but also suggested that academic terms were just another form of a ‘practice language’, where one can learn the meanings and partake in such language if one has access to people utilising such words on a regular basis. I pointed out that such terminology was a form of shorthand which academics could ‘un-pack’ for better communication with others. Recently, I posted a comment on twitter with the academic conceptual word ‘iatrogenic’ contained in it. I received one response, which was what I was hoping for with the original post. This response said they had looked the word up on the internet and agreed with the point I was making. In the spirit of explaining the use of such terms as an autistic sociologist, what better to apply them to than the social structures of Assessment and Treatment Units (ATUs) at the heart of the #7Daysof action campaign? So, I have chosen 7 sociological concepts to explain and show the potential relevance for such an analysis.

1. The (degradations of) bureaucracy – Max Weber

To begin this sociological journey, where better to start than with one of the ‘founding fathers of sociology’ (yeah I know – what about the mothers? Yet, there is a reason for this being historical...): Max Weber. This German academic worked over 100 years ago and who, amongst exploring many other topics, was drawn to the notion that social institutions were becoming increasingly rationalised. Weber suggested that the establishment of bureaucracies were one of the defining aspects of the then ‘modern era’. Only through such large-scale planning could the modern world, as he saw it, be taking the shape that it was. Weber also thought that modern bureaucracies were technically superior to previous forms of administration. Yet, bureaucracy in Weber’s analysis was not without its downsides. With the ever increasing rationalisation and ability to ‘calculate results’, such large-scale organisations became overly constraining when dealing with individual cases (“The computer says no” could be seen as a recent cultural example of this frustration being expressed). The more idiosyncratic and unique the case, the more a bureaucracy would struggle to cope with how to process it. In other words, bureaucracy leads to depersonalisation. The increasing rationalisation of society, Weber thought of as an inescapable trajectory and forecast that the 20th century would be characterised by an ‘iron cage of bureaucracy’.

Despite such reservations about the rationalisation of society, Weber proposed an ‘ideal type’ bureaucracy, regarding how they could be ideally run efficiently. The first aspect of such an organisation Weber saw as formal hierarchy. Whilst I have my own issues with such hierarchical ways of organising people, he envisaged such a structure as the basis of central planning and accountability, with communication up and down the structure also being of importance (the Mazars review I hear you cry – well yes...moving on...). Weber suggested that one needed consistent
management of rules, that are then executed across all levels of the organisation (cough!), that work is done by ‘specialists’ (oops!), that work is organised based on type of work and skills that practitioners have, that organisations can be either ‘up-focused’ serving those at the top of the organisation, or ‘in-focused’ serving the organisation itself and those within it (or I guess if not ideal – umm... unfocused perhaps?), are purposefully impersonal – in that employees and customers are treated equally and dispassionately and not influenced by individual differences (okay – yes I know, this is getting a bit ridiculous now), and employment is based on technical qualifications (not awards then?).

2. The Sick Role – Talcott Parsons

Parsons?? Yes, one cannot really look at the sociological concepts in this area and escape this guy...but I have my reasons for including him...

Talcott Parsons was an American sociologist working in the early-mid 20th century who argued that being ‘sick’ was not just a biological condition, but a social one involving the ‘sufferer’ entering a social role of legitimised deviance (yep – you did read that correctly!). For Parsons, a sick person was not a fully functional and productive cog within a wider functioning social machine, but a form of deviance that needed management (by medical professionals). For Parsons, being sick brought with it certain ‘obligations’ to uphold in order to be afforded to benefits or ‘rights’ of the ‘sick role’. The ‘rights’ the sick person were entitled to consisted of being exempt from ‘normal social roles’ and not being held responsible for their medical condition. In order to meet these rights however, the sick person was obliged to ‘try and get well’ and to ‘cooperate with the medical professional’. Parsons then went on to categorise the sick into three categories: the conditionally sick (i.e. requiring a sick note to be excused from work), the unconditionally legitimate (seen as permanently incapable of being functional productive individuals), and illegitimate (or people seen as ‘malingering’).

Why do I introduce such an ableist theory you might ask? Perhaps to show the historical theoretical roots of the rationalisation of those classed as sick and disabled. Of course, there are many criticisms made of this theory, patients may not be erm... ‘patient’, those under such management may resist dependency on medical expertise, doctors may not be as perfect in their prescriptions as Parsons may have hoped for. Also, how does one assess and treat someone, who is umm... not ‘ill’ in the first place? Despite the obvious flaws in this theory, it has certainly been part of a legacy of justifications for the power of medical expertise over that of the (sometimes not so) ‘patient’.

3. The mortification of self – Erving Goffman

A list of sociological concepts would not ever feel right to me without this guy being included...

Erving Goffman was a sociologist who began publishing his work in the 1950s. His work covered many fascinating areas of study, from impression management to stigma. I often wondered how someone in an elevated position deals with their impression management when they have been found to hold a discrediting stigma, such as presiding over numerous failed inspections, but I digress...
It is Goffman’s seminal work on Asylums and what he called ‘total institutions’ that I want to draw attention, and its adjoining concept of the ‘mortification of self’. A total institution is one that has been rationally developed to house the socially taboo and stigmatised, where the ‘inmates’ live their entire lives under institutional rules, and where they attempt to close themselves off from the attention of the outside world, such as prisons, concentration camps, and mental asylums. It is quite clear that ATUs fit this category only too well.

For Goffman, total institutions were ‘experiments in what could be done to the self’, where the ‘inmates’ went through a process of ‘mortification of self’. This concept refers to how the individual identities of those living within total institutions are stripped away. The more degraded and institutionalised they become, the more they are subjected to conditions which remove identity markers, from being called by one’s surname at a boarding school, to having to wear a designated uniform, the tactics are many. Such treatment creates a separation between the ‘inmates’ previous sense of self and their new institutionalised sense of self, where an individual is not allowed private space, or even a self which one can manage the impression of.

When one looks at the inhuman treatment that often occurs in ATUs, one needs to look beyond individual psychological explanations of conduct and analyse the way that such ‘treatment’ is socially organised.

4. Fatalistic suicide – Emile Durkheim

Why do I bring up something like suicide in relation to the theme of ATUs? This is because of a framework proposed by Emile Durkheim in the late 19th century (another of those ‘founding fathers’ of sociology). Durkheim contended that incidences of suicide were dependent on social circumstances. He suggested that within the fragmenting societies of the then ‘modern era’, that suicide rates would rise due to increasing social isolation and a lack of moral regulation of its members (something those wishing to understand why in a recent study in Sweden it was found that autistic people without additional learning difficulties were nine times as likely to commit suicide than the average may wish to look into perhaps?). Durkheim also hypothesised that there would be an increase in what he called ‘fatalistic suicide’ within social conditions where a person encounters extreme oppression and excessive regulation of their lives, having their interests and passions suffocated. Durkheim hypothesised that for some, for example prisoners or slaves, they may find themselves in such a fatalistic situation, that the only perceived route of escape is that of suicide.

Durkheim did not have much in the way of evidence to support this claim, yet the idea of what could happen to a human being when their autonomy was stripped away (such as in the process of the ‘mortification of self’) was to again, be theorised in the 1960s, this time by a psychologist by the name of Martin Seligman in the theory of ‘learned helplessness’ (yes, I know I am cheating here by introducing a psychological concept, but it is relevant to the idea of fatalism within a social situation...). Yes, as my friend and colleague Andy McDonnell likes to point out, Seligman – the champion of positive psychology, started out experimenting with electric shocks through floor plates to subject an animal (dogs) to inescapable aversive stimuli to see how they would react! What Seligman found in these experiments was that the dogs would eventually stop trying to avoid the
stimulus and behave as if utterly helpless, to change the situation. Even when opportunities to escape were presented anew, the dogs had learned to feel helpless and did not act.

Whilst humans may react quite differently to dogs, it is not difficult to imagine a hopeless situation where one has no control over the outcome, and how this might affect how one acts (or not). Such a feeling of helplessness has been linked to depression and anxiety.

Autistic people have often commented that when under extreme stress, they can exhaust themselves, ‘burnout’, and ‘shut down’. In rare cases, it has been known for people to enter a catatonic state, although this has can also be linked as a potential reaction to antipsychotic medication. When one looks at the stories emerging from #7Daysofaction, it would suggest that extreme measures of prone restraint, overmedication, and barriers to family contact are commonplace. Of course, autistic people can be stubborn, resistant, and persistent, and may not understand fully what is happening to them, and thus may well rebel (often leading to ever more constraining practices). Yet, even the strongest of wills can be damaged, sometimes beyond repair. Such rationalising of extreme measures can only originate from seeing the people in one’s ‘care’ being treated as ‘other’, as not fully human.

5. The other – Simone de Beauvoir

One of the primary influences on what is often referred to as the ‘second wave’ of feminism was the seminal work ‘The Second Sex’ written by Simone de Beauvoir and published in 1949. In this book, she argued that men had traditionally seen themselves as complete or in reference to other men, with women being seen as a deviation from this central power, the ‘other’. Whilst one could argue to what extent this centrality has shifted or not, little could perhaps compare to the extreme ‘othering’ that occurs within total institutions. The abuses documented in #7Daysofaction could not be possible without the mortification of self process and a level of ‘othering’ to a level of being dehumanised.

Relating this concept again to psychology, an important contribution to this area was made by Henri Tajfel and colleagues in their work regarding ‘Social Identity Theory’. In this theory, a social identity is the sense of who a person is when related to group memberships, which can be self-identifications or imposed upon people (sometimes with very negative consequences – see Goffman again – this time on his notions of stigma). For Tajfel, the groups people perceive that they belonged to, were at the same time a source of pride and belonging, but also gave rise to discriminating against those seen as part of an ‘out-group’, especially if such a group is set up in opposition to one’s own in terms of its defining features. This can produce difficulties in all walks of life – just think of the negative spiral that can ensue when a teacher moans negatively about their students and vice-versa. If one sees others purely by their role and build an oppositional culture, battles will be the end product. Often it is the ‘inmates’ (and their loved ones) who are classified as ‘oppositional’ by the (ir)rationalised view of those running total institutions, and in the case of the battles that rage within and outside ATUs, they can become further reasoning for incarceration.

An essential part of Tajfel’s theory is categorisation, thus when someone is categorised as essentially ‘other’ and not like oneself, this becomes an excuse for all kinds of abuses. Tajfel also suggested that
such actions can be legitimised by reference to group norms — or the attempt at them anyway (need I reference the line “we are not an outlier”?).

6. Iatrogenesis — Ivan Illich

And so I get to the concept that gave me the idea for this essay. Iatrogenesis is a term that originates in the Greek term for ‘brought forth by the healer’ and is used to refer to when a person is adversely affected by the actions of medical practitioners. The mid-20th century theorist Ivan Illich utilised this term and broadened it to a framework of three kinds. Firstly — clinical iatrogenesis, where direct injury is patients due to ineffective, unsafe, and erroneous treatments and practices, you know — like when people are regularly subjected to prone restraint, overmedicated, or die whilst unsupervised and taking a bath. The second aspect Illich talked about was that of ‘social iatrogenesis’, which referred to the ever-increasing medicalisation of life, so more of our lives become under the rationalised direction of medical professionals and companies. Lastly, Illich talked of ‘cultural iatrogenesis’, where traditional ways of coping with life were removed from people to be replaced by rationalised medical prescriptions. For Illich, through this process, people can lose their own autonomous coping skills and strategies. Under the processes of the mortification of self within ATUs, such autonomous skills may fall away, whilst ‘coping strategies’ such as self-harming increase.

7. Interactional expertise — Harry Collins and Rob Evans

The last concept I want to explore is that of ‘interactional expertise’ developed by contemporary theorists Harry Collins and Rob Evans. Collins and Evans produced a classification of how people come to acquire expertise and tacit knowledge. Whilst the ‘contributory experts’ regarding what it is like to be autistic or have learning disabilities, or be a family member of someone placed in an ATU, are the people themselves, ‘interactional expertise’ is when one is able to communicate the practice language of contributory experts. So, by reading this essay, you may have gained a small amount of expertise in being able to talk the talk of a sociologist, although (unless you are one) you would probably not be able to ‘pass’ as a sociologist from such limited information alone. As I have argued in academic papers myself — the interactional expertise that even so-called experts in the field of autism can have with autistic people can leave something to be desired. Given what I have previously called the ‘double empathy problem’ (simplistically — that both autistic and non-autistic people can struggle to empathise with one another) between people of differing dispositions however, this is perhaps to be expected. Yet if one were to be looking to better the welfare and wellbeing of autistic people, people with learning disabilities, and family members, perhaps learning from these ‘contributory experts’ would be a good starting point (you’d think!). Instead, we have a situation where people are subjected to life in a total institution, rationally designed to mortify their self-identities and replace them with institutionally prescribed roles — leading to ‘othering’ and depersonalisation (of staff too), an ‘us and them’ mentality, and people becoming worse off than they were to begin with (thus triggering more tools of surveillance and control — yes — oh and I got this far without mentioning Foucault...).

What if things were different?
When looking at social relations, however ‘reified’ (oh – there I go again – okay – made to seem natural and real when something is socially created by people – or ‘clumped’) they become, one can change social structures and relations (or ‘unblock the clump’).

What if the support and care of autistic people and those with learning disabilities were not organised by large-scale bureaucracies?

What if those commissioning services were autistic people, people with learning disabilities, and their families (the contributory experts)?

How can one hold degraded and dysfunctional bureaucracies to account if they are allowed to continue failing?

If autistic people and people with learning disabilities are not ‘ill’ and normativity is a moving target and not an ideal, than autistic people and those with learning disabilities are not ‘deviant’ either (although no doubt would be to Parsons) – so what is being controlled? A social taboo?

What if one reversed the mortification of self – what would that look like? Empowerment of self-identity? What structures could help in this regard?

An empowered life would not be a fatalistic one without a future to be imagined. An empowered life means not being seen as ‘other’. As the autistic activists Jim Sinclair once said:

“Grant me the dignity of meeting me on my own terms.”

It also doesn’t mean doing the opposite and providing no support at all. If such ‘care in the community’ is to work, it means commitment and a transfer of funds away from ATUs.

What would social supports look like if not premised on a medicalised account of disability?

This essay may seem like I am simply ‘bashing’ medical professionals – this is not my intent. My intent is for people to analyse what is happening and to think of alternatives. Having said that, most of these concepts are getting quite old now, perhaps it is time those rationalising services ‘learnt lessons’?

In the spirit of action though, we better finish with the words of Karl Marx (the last of those ‘founding fathers’ of sociology):

“Philosophers have merely interpreted the world in various ways, the point is to change it.”