
MEASURING OURSELVES

The interwar years made the previously invisible limits of the body visible and measurable. In the eighteenth century, there had been interest in and attempts at measuring the boundaries of human capabilities. In the nineteenth century, these attempts took on eugenic imperatives as disability was increasingly defined as abnormality. However, the First World War changed the way we thought about disability through greater recognition and awareness that disability could be acquired and could affect anyone. Furthermore, the war marked the start of strong connections between both the Post Office and the MRC with the state, which allowed them to interact as and with the wider British government. Ameliorating the impact of disability on society thus became a concern of national importance as the post-war years were marked by growing state intervention into welfare and increased recognition of government's duty to moderate societal health. Further state explorations of disability were motivated by the incentive to generate national anthropometric standards to measure and halt the progress of perceived interwar degeneration. The idea of degeneration inspired stricter definitions of disability that could be utilised in the military/industrial complex to test potential employees and moderate subsequent compensation.

How relevant are these classification systems today? Deaf activist Chrissy provoked a conversation on this topic when she asked why people with only 50 db loss were identifying as deaf. She believed 90 db was the threshold point that counted as deafness and queried 'all these "deaf" people who can easily talk on the phone and have all this privilege.'¹ In response to her inquiry, people hotly debated this issue and explained why they identified as deaf or hard of hearing in different contexts and situations and discussed the extent to which this decision related to the associated number on their audiogram. The ensuing discussion showed that

the kinds of single-number measurements discussed in this book are not only important to medical classification systems and compensation frameworks; they are significant markers of identity and meaning for us. How we are classified matters to us. Numbers are elevated on an individual level, as well as a bureaucratic level.

As a result, in this conclusion, I move from focusing on clinical measurement to ask what it means to turn these tools onto ourselves in the form of self-tracking. Self-tracking typically involves regular recording of personal data, such as information about bodily function, diet or activity. But such devices are not always used positively: users sometimes fixate on their data to the point that they develop conditions like anxiety, anorexia, orthorexia, obsession with perfect sleep (orthosomnia), or even use their wearables to enable dangerous drug use. We have almost no understanding of how usage of such devices impacts on individual interoception, embodiment, anxiety or cognition of sensation. Related concerns are growing about how the data these devices generate will be stored and used in the future, especially by the state. The kind of data embedded in spirometric standards and in the artificial ear was recoverable and available in archives, but this is unlikely to be the case in the context of private commercial companies used in nationalised contexts. Indeed, an influential think tank has proposed that fitness trackers should be prescribed on the NHS to help tackle health inequality and ensure the poor and the disabled are not left out of this 'technological revolution in medicine'.² However, it is unclear what cost or benefit this move would bring to healthcare outcomes. Moreover, it is an assumption that these devices – which are calibrated to healthy bodies – will work effectively on disabled bodies. Furthermore, it is becoming apparent that the increased potential for measurement associated with these tools may shift our understanding of normalcy, for example in the consistent and systematic measurements of glucose enabled by self-trackers, which has changed the standard for 'normal' blood-sugar ranges.³

The control and management of our health data is emerging as a key site for future conflict between citizens, corporations and healthcare authorities. This conclusion will therefore pose a series of questions about big data and health to ask: how does self-tracking relate to the longer history of measurement as a normative force outlined in this volume? Can we use our knowledge of the past to look to the future and use self-tracking to mitigate against the kinds of mechanical epistemic injustice explored in Chapter 2? In other words, can this kind of technology be a good thing?

As Crawford et al. point out, 'The already tired binary of big data – is it good or bad? – neglects a far more complex reality that is developing.'⁴ In particular,

we need to consider how self-tracking might enable clearer expression of embodied knowledge and how this might help individuals to assert their lived experience. Self-tracking may offer a way out of these binary dichotomies by offering a way for people to more clearly correlate their sensations to 'objective' evidence and thus demonstrate the validity of their experiences. However, this possibility is likely to depend on what exactly is being measured. How we measure the more ineffable sensations of health and illness is a key focus here. Whether there is a conflict between self-tracking and embodiment may depend on what is being measured and whether the experience of it holds the essence of the sensation. As Chow-White and Green argue, data are treated as synonymous with facts without consideration of how they have been represented and *made to mean*: 'data are representations, cultural objects that stand in for stimuli and mediate relations'.⁵ As I have shown in this book, data which is made to 'stand in' as a proxy measurement for that which is usually individual, inaccessible and subjective, like hearing and breathing, is particularly vulnerable to error or abuse, and we need more awareness and consideration of this in the context of disability and big data.

As I outlined in Chapter 1, health measurements are prioritised if they are easily calculable and capable of producing single-number proxies. The decision to use certain group categories (reference classes) and the process of selecting people to represent the ideal standards of health within these classes have impacted on our understanding of disability. As Chapter 2 elucidated, decisions about which groups are important have historically interrelated with the prioritisation of certain groups as valuable. Against this selective valorisation of certain bodies as normal, other bodies were defined as abnormal. Exploring these processes of disablement has been necessarily intersectional, as gender, class and race variously intersected with this decision-making process through the choice of suitable reference classes. Considering the changing historical usage of reference classes not only indicates the ways in which they can interact with and modify disability levels, but also highlights the difficulty of attributing disease to either biological or environmental/social factors. This focus thus draws attention to the biopower associated with systems, which has emerged as a central area of concern for modern healthcare in the second decade of the twenty-first century.

Professor Philip Alston (UN Special Rapporteur on extreme poverty and human rights) recently visited the UK and reported on the impact that the austerity measures recently implemented since 2010 had had on the disabled. One of the aspects of these measures that he repeatedly emphasised was the extent to which the system for claiming employment and support benefits (ESA)

had been designed *to be difficult*. This was facilitated by the system's 'digital by default' design, which he argued had been purposefully intended to work as a 'digital barrier' to put off applicants and to help ensure application failure.⁶ He argued:

There is nothing inherent in Artificial Intelligence and other technologies that enable automation that threatens human rights and the rule of law. The reality is that governments simply seek to operationalize their political preferences through technology; the outcomes may be good or bad.⁷

As I have made clear in this book, technologies can and do feature innate political preferences. For example, biases are embedded through the choices of inclusion in data set compilation. We are becoming more aware of the potential ramifications of this in machine-learning software, which actively amplifies the stereotypes and biases embedded in data sets.⁸ As Chapter 2 detailed, the reference classes utilised in categorisation systems can also work to obscure the social determinants of health inequalities. Reference classes may serve to essentialise inappropriate social classes, and through this process conceal causes of health inequality. Alston further emphasised that one of the reasons why it was difficult to assess poverty in the UK is the way it measures poverty – utilising four separate measures which 'allows it to pick and choose which numbers to use'.⁹ Alston's insights are reflected in the findings of this book, which has shown how bureaucracies and measurement systems can be powerfully utilised to control access to compensation. As I discussed particularly in Chapter 5 of this book, using proxy or 'surrogate' measurements in this way has historically been used to promote such systemic manipulation.¹⁰

Moreover, while it is important to look at these measures and how they may be manipulated, this book has also shown that we need to look at the numbers that are missing. As I demonstrated in Chapter 3, such measures may include a disability data gap. We saw this in the case of the artificial ear, which allowed the Post Office to manage the variability of hearing and standardise the norms of human hearing while simultaneously distorting it to reflect an idealised average. As Amundson emphasises, these decisions are practical ones that have epistemological consequences: 'If medical textbooks emphasize average or typical cases, there may well be pragmatic reasons to do so. It would be a mistake to infer from this that diversity constitutes abnormality.'¹¹ Such diversity has been a key concern of this book, as individuals' inherent variance has repeatedly been at odds with the movement for standardisation driving institutions like the Post Office and the MRC. The main project of this book has been to outline the complex historical circumstances

and contingencies which have led to the prioritisation of measurements of particular kinds. Through this analysis, we can see that the statistical promotion of the average has often worked in opposition to individual variance and that this has been especially problematic in attempts to quantify breathing and hearing. Tools like the audiometer and the spirometer defined disability as measurable pathology within a naturalistic paradigm, which linked trusted instruments with objectivity and accuracy. This determination to consider body processes as quantifiable was driven by the need to compensate for hearing loss and respiratory disability occasioned by warfare or industry. Audiometry and spirometry were therefore embraced as objective ways of testing, which could confound malingerers and allow for testing of large groups of people. The resulting disconnect between objective and subjective measures has emerged as a crucial theme in this book.

Biomedicine demands quantitative data, and yet there is growing realisation that testing procedures fail to measure breathlessness or capture the rich realm of feeling associated with it. Despite the multidimensional aspects of hearing and breathing, hearing loss and breathlessness that were not obviously biological were misinterpreted in the absence of clinical evidence as 'hysterical', as I demonstrated in Chapter 3 and Chapter 5. In Chapter 2 I introduced the concept of 'mechanical epistemic injustice' to better elucidate this specific kind of instrument-based discrimination. This, as might be anticipated, is paralleled in illnesses that do not clearly map onto signs of physiological function, a phenomenon associated with conditions like chronic fatigue or MUS (medically unexplained symptoms). As the discussion about what decibel threshold level 'counts' as deafness demonstrated, diagnostic tools can be very meaningful and helpful, not only in identity formation. They are critical in enabling access to adequate and appropriate healthcare. However, lack of concordance between subjective symptom reports and physiological change has been found in a long list of conditions more commonly assumed to be somatic, including diabetes, gastro-oesophageal reflux disease, heart disease and a wide variety of respiratory conditions.¹²

Highlighting these issues is not intended to undermine or call into question the necessary procedures of biomedicine without offering any kind of solution – an oft-repeated criticism of medical humanities researches. Nonetheless, the prevalent assumption in the clinic is that patients' sensory experience of a symptom is directly related to measurable physiological disease. Indeed, the paradigm of symptom assessment following through consequent diagnosis depends on our faith that the relationship between symptom experience and measurement is accurate.¹³ While I am not advocating for an enduring state of pessimistic meta-induction in which we are unable to trust in scientific

progress because of awareness of past error, it is clear that historically our faith in this accurate relationship has been misguided. As I have demonstrated, this is especially true in cases where disease causation was linked to the biological traits of a group rather than associated with specific ways of living as a member of that group. The choice of certain subjects to create a standard of normalcy worked as a powerful way to categorise disability as well as obscuring its true causes. Whose bodies mattered for these measurements mattered.

The instrumental measurement of disability is not only an epistemologically significant issue, it has been embraced by the military/industrial nexus to control and moderate compensation claims and to avoid corporate responsibility for health. Responsibility has been a recurring theme within this book, with repeated discussion over who was responsible for the design of prosthetics and their distribution – whether prosthetics were products for engineering or for medicine to design was debated while they were variously rejected or appropriated by users creating devices for themselves. My discussion of the Post Office also highlights the extent to which nationalisation worked as a positive force to ensure extensive state support for those with hearing loss – a positive consequence of nationalisation that has remained largely invisible to posterity. On the other hand, while this book has highlighted innovation within the state, it has equally demonstrated the innovation of disabled users. Moreover, the embodied knowledge gained through disability has been consistently undervalued and obscured. We saw in Chapter 4 that individuals' lived experience of hearing conflicted with the Post Office's desire for standardisation. And as the example of the Bragg–Paul pulsator in Chapter 6 made especially clear, technologies designed by individuals for individuals were not trusted or easily standardised, and patients were increasingly encouraged to adapt themselves to machines rather than the other way around.

Diversity of user experiences of these hearing and breathing machines recurred not only between 'kinds' of disability but between individuals classified in the same way. The apparent dichotomy between visible and invisible is thus problematised through consideration of the lived experience of individuals. Bringing together connections between hearing and breathing, and sound and breath reveals some of the conceptual difficulties in using disability as a catch-all term. Indeed, I argue that the heterogeneity and uniqueness of individual bodies has often been at odds with the standardisation of biomedicine. In Chapter 2 I raised the question of whether disability could be a reference class of its own. Steven Epstein has argued that the likelihood of groups being considered as medically relevant distinct classes is reduced when 'the group is not so well mobilized; when it articulates demands in relation to a form of social difference that is not already institutionalized in state policies;

and when its frames do not resonate with the public of policymakers, perhaps because of the difficulty of advancing a biological difference argument'.¹⁴ If we consider disability, as Elizabeth Barnes does, as primarily a social phenomenon, then we could indeed argue that there are good health-related reasons to consider disability to be a reference class. Against this, we should perhaps be cautious of essentialising disease as natural to that class. Some have used this worry to argue against using class instead of race (in opposition to those who decry that race is being used as a proxy for class) in lung function measurements. And yet using class as a relevant categorisation may well allow us to make the social and political causes of ill health clearer and so drive political campaigns to improve societal health. What is clear is that these are difficult questions that require an intersectional approach. As I pointed out in Chapter 2, approaches that only consider one category (such as gender) miss the powerful complexities of these categorisation processes. Insisting on considering disadvantaged groups as different has, as this book has demonstrated, been historically used to their disadvantage. Despite these caveats, I argue that we need to prioritise further research to answer these questions. In particular, more work is needed to answer how equating the average with the normal has impacted on our understanding of disability.

In making this argument I offer a new contribution to disability history, using a multidisciplinary approach to understand multisensorial phenomena. My approach here is especially salient to the social model of disability as it shows how the naturalist approach to disability is undermined through consideration of relevant data sets and instrumental measurements. The classification of disability has been dependent on, and variable according to, certain measurements. Technology perceived as 'objective' has been utilised to control the messy variability of human bodies.

Measurement has shaped disability. Measurements, and their manipulation, have been underestimated as crucial historical forces motivating and guiding the way we think about disability. The standards embedded in instrumentation created strict, but ultimately arbitrary thresholds of normalcy and abnormalcy. Considering these standards from a long historical perspective reveals how these dividing lines shifted when pushed. The necessary pressure was brought to bear by diverse and varied impacts: different data sets, newly created categorisation systems, updated technologies, and through the conscious and unconscious manipulation of political actors working to negotiate compensation frameworks. This history leads us to a heightened awareness of the importance of prioritising disabled actors' voices as we work to facilitate ongoing resolution between lived experience and the clinical view.

Notes

- 1 Chrissy @life_laughter_, 'I Identified as HoH for a Long Time with 80 db Loss ...': Twitter thread, 18 July 2019. https://twitter.com/life_laughter_/status/1151976942108889099. Accessed July 2019.
- 2 Savage, M., 'Call for Poor and Disabled to Be Given NHS Fitness Trackers', *The Observer*, 5 May 2019. www.theguardian.com/inequality/2019/may/04/fitbits-nhs-reduce-inequality-health-disability-poverty. Accessed July 2019.
- 3 Fiore-Gartland, B., and Neff, G., 'Communication, Mediation, and the Expectations of Data: Data Valances across Health and Wellness Communities', *International Journal of Communication*, 9 (2015), 1466–1484, p. 1469.
- 4 Crawford, K., Miltner, K., and Gray, M. L., 'Critiquing Big Data: Politics, Ethics, Epistemology', *International Journal of Communication*, 8 (2014), 1663–1672.
- 5 Chow-White and Green, 'Data Mining Differences', p. 562.
- 6 Alston, P., 'Statement on Visit to the United Kingdom, London, 16 November 2018', p. 9. www.ohchr.org/Documents/Issues/Poverty/EOM_GB_16Nov2018.pdf. Accessed July 2019.
- 7 *Ibid.*, p. 11.
- 8 Bolukbasi, T., Chang, K.-W., Zou, J., Seligrama, V., and Kalai, A., 'Man Is to Computer Programmer as Woman Is to Homemaker? Debiasing Word Embeddings'. Boston University and Microsoft Research Paper, submitted 21 July 2018. <https://arxiv.org/abs/1607.06520>. Accessed July 2019.
- 9 *Ibid.*, pp. 15–16.
- 10 We might ask where whether the growing self-tracking movement is a naïve attempt to 'manipulate back' but this is a question for future research.
- 11 Amundson, 'Against Normal Function', p. 45.
- 12 Van den Bergh, O., Witthoft, M., Petersen, S., and Brown, R. J., 'Symptoms and the Body: Taking the Inferential Leap', *Neuroscience and Behavioral Reviews*, 74 (2017), 1–79, pp. 15–16.
- 13 Malpass et al., 'The Body Says It'
- 14 Epstein, *Inclusion*, pp. 142–143.