People with learning disabilities and Covid-19

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There is an argument that the pandemic has revealed the fragility and inhumanity of the neoliberal system that characterises British society. For some people, including disabled people, this has been self-evident for a considerable time. For learning disabled people, in particular, life in the UK has had a fragility and inhumane coating for decades. Just one example, from a 1981 documentary called Silent Minority. Nigel Evans, the filmmaker spent some time in two long stay institutions. In Borocourt Hospital, Reading, he filmed a patient called Terry Green sitting in a wheelchair. A nurse noticed Green seemed to be trying to reach for the wheel. A different chair was found and he tentatively moved forward. Evans commentary:

'After 40 years in bed, 10 years on a bean bag, Terry Green takes his first inching steps towards independence. For decades, the full panoply of the medical profession has trooped through this ward and no one had the wit, initiative or imagination to give Terry this opportunity. This kind of neglect invites a whole new definition of the phrase 'mental handicap'.

Nearly 40 years later, learning disabled people are still treated as disposable people with inferior bodies and mind. People die on average 20-30 years before their peers from drowning, scabies, constipation, ignorance and neglect.

We are all implicated in this. All of us, including academics. In 2016 I did a content analysis of the publications in the journal *Disability and Society* between 1994-2013. This was my son Connor Sparrowhawk's life time. A small number of articles involved learning disabled participants and the subject matter of these were about learning disability. Learning disabled people were excluded from wider, disability related research, a grotesque exclusion within what you would assume is barrier free. There is a wider history here. Francis Galton presented his eugenic aims at the first meeting of the Royal Sociological Society in London 1904 and there is clear evidence of derogatory perceptions of disability in early US sociological meetings. It is clear that sociologists have long failed to see the epistemological and methodological value disabled people bring to the discipline.

So, what light has the current pandemic shone on the treatment of and responses to disabled people?

A series of measures have been taken that directly impact on and underline the disposability of certain people; people marked as different and of less, or no, value. The Coronavirus Act 2020 has introduced an easing of duties that have too often been enacted poorly (see also Dr Brian Sloan's paper). The weight of this easing is causing undue pressure and stress on people and their families. This is happening in education where there are temporary changes to the law relating to education, health and care (EHC) assessments and plans. For example, the absolute obligation to deliver the provision in EHC plans under the Children and Families Act 2014 has been temporarily 'eased'. Instead local authorities must now use 'reasonable endeavour' to ensure it is made.

Care Act easements have been enacted by at least eight local authorities in the UK allowing these councils to suspend social care duties to disabled adults. This means they no longer have a duty to carry out assessments of individuals' and carers' needs, the provision of detailed care plans, or the duty to meet the needs of someone assessed as eligible for care and support. Again, a deeply concerning move.

There has been considerable coverage about the prioritisation of particular patients over others based on judgements of value and the placing of Do Not Resuscitate orders on people without their knowledge or permission. Poorly worded guidance was rescinded in March after disability rights organisation and campaigners wrote an open letter raising their concerns. However, research by Learning Disability England published in May showed that DNR orders are still being placed on people in some social care provision. Turning Point raised concerns that it has received 13 “unlawful” DNRs from hospital specialists and GPs since the beginning of April.

Alongside the DNRS, there was initial resistance by NHS England and the Department of Health and Social Care to publish the numbers of learning disabled and/or autistic people who have died across all care settings including hospitals. This is in part because robust data is not collected. As such those with learning disabilities and autism, were not being recorded and accurately included in the overall numbers of deaths reported At the same time, the Care Quality Commission has revealed a stark increase in the numbers of deaths in care settings compared to this time last year which is around twice the increase in deaths of the wider population. The patchy and poor quality data are concerning given the pre-pandemic mortality rates for learning disabled and/or autistic people. We need to understand who is dying in order to act to reduce further deaths.

In addition to systemic assaults there have been micro assaults. Fears about an overburdened and struggling NHS has generated a space in which people are allowed to say the unsayable. In response to a piece in the Health Services Journal, for example, an anonymous medic commented that concessions for learning disabled and/or autistic people to go out more than once a day allowed them ‘to go out and kill’. It took nearly two days to get this comment removed. These unpalatable truths have long been promoted by the likes of Toby Young who published a recent attack on ‘valueless’ members of society. We cannot allow a normalisation of views that would, outside of a pandemic, be denounced and challenged. There is a growing creep of what is dressed up and passed off as unpalatable truths.

I want to finish with a nod to Amartya Sen. Sen argued state action is required to remove impediments that hinder the realisation of human capabilities. The government’s response to COVID-19 is working (whether deliberately or otherwise) to generate additional impediments to the freedom of disabled people to lead flourishing lives, reinforcing this notion of disposability. We come back full circle to Terry Green and his wheelchair; a wilful disregard to engage with certain people as fully human.

Recommendations:

1. **The impact of COVID-19 on all marginalised groups needs urgent examination and review.**
2. **We need to end the longstanding disregard and dehumanisation of learning disabled people**. To achieve this, the government must enshrine the human rights model of disability in law. This model focuses on the inherent dignity and inestimable value of each human being and places the individual centre stage ‘in all decisions affecting him/her and, most importantly, locates the main “problem” outside the person and in society’.
3. **The government must reverse the so-called ‘relaxation’ of duties under the Children and Families Act 2014 on local authorities to provide Educational Health Care Action Plans to young people with Special Educational Needs and Disabilities.**