



Healthy Minds and Intellectual Disability

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INTRODUCTION

This chapter concerns itself with the concept of a healthy mind as applied to people with intellectual or learning disabilities. It traces its roots back to the early part of the twentieth century, particularly the pervasive belief in eugenics, and uses historical practice and experience as a prism to consider the situation in the present. The principal argument is that people with intellectual or learning disabilities, by definition, do not have minds that can be regarded as ‘healthy’. This is an important, if not controversial, starting point. If people with learning disabilities in the twenty-first century are to gain equal status as fellow citizens, as was promised in the Valuing People White Paper (England and Wales 2001), Same as You (Scotland 2000), and the United Nations Convention on the Rights of People with Disabilities to which the UK was a signatory in 2007 there needs to be a change that goes beyond stirring policy statements, a pious belief that things will get better, or even ‘more resources’.¹ This chapter addresses two major questions; firstly, how far were people with intellectual disabilities regarded as having healthy minds during the twentieth century? And, secondly, what relevance does this have to people with learning or intellectual disabilities in the present?

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This chapter will focus on a number of issues, including Western philosophy, eugenic theory, changing labels, psychotherapy and control of reproduction, in order to find answers to these questions.

LABELS—LANGUAGE AND ITS SIGNIFICANCE

A brief discussion of language, especially the changing nature of labels applied to people currently known as having ‘learning’ or ‘intellectual’ disabilities, is essential to frame the analysis of the chapter. Alfred Tredgold, a highly influential doctor and member of the 1908 Radnor Commission, used the term ‘amentia’ (absence of mind) in early editions of his book *Mental Deficiency* which was the key textbook in medicine and nursing until the late twentieth century.² If the mind is associated with reason, perception, judgement, intellect and understanding, what does it mean not to have a mind, or to have a mind that is impaired? The early twentieth-century term ‘feeble-minded’ was officially adopted in legislation passed in 1913 in England and Wales and was widely used in the USA, Canada and the rest of the English-speaking world³ although Steven Taylor observes in Chapter 4 of this volume that definitions could fluctuate according to space and place. The very use of the word ‘feeble’ means that these could not be considered healthy minds. ‘Feeble-minded’ was used as a social and medical category until the second half of the twentieth century, as the legislation which perpetuated it, the Mental Deficiency Act, 1913, was not repealed until 1959. Indeed, ‘feeble-minded’ lingered on in common speech beyond that time. A parent in an interview used it with the author in 1991 to describe another parent who had two children with learning disabilities.⁴ The word ‘ineducable’ was introduced into official language in 1944, to label those deemed incapable of benefitting from an education also suggests that medically and legally a mind was considered less than healthy if it was incapable of education. These children were only admitted to the education system in 1970.

The Mental Deficiency Act, 1913 subdivided the term ‘defectives’, into the following classifications: ‘idiots’, ‘imbeciles’, ‘feeble minded’ and ‘moral defectives’. These were replaced in the Mental Health Act, 1959, by the terminology ‘sub-normal’, which was then itself replaced by ‘mental handicap’, ‘learning disabilities’, and now the term ‘intellectual disabilities’ appears to be gaining favour. Alongside these legal and medical classifications, have been less formal designations like ‘backward’, applied to children until well into the late twentieth century,

and also terms which started life as having a medical significance, like ‘mongol’ and ‘cretin’ but which quickly degenerated into terms of abuse. In the final quarter of the twentieth century, there was a shift towards the language of disability/disabled. This realignment, from association with madness and mental affliction to association with people who are physically impaired has been significant—for example, it opened the way for the influence of the social model of disability to learning disability.⁵ The shift has, in some respects, left people marooned between the two and neglected by both.⁶ Paradoxically, the medical specialty most closely associated with learning/intellectual disability remains psychiatry, despite the official dropping of the ‘mental’ label. The connection with ‘learning’ remains in ‘learning disabled’ and its user preferred variant ‘learning difficulties’. In the internationally used variant ‘intellectual disabilities’, the problem remains in the mind, specifically with the intellect.

Valerie Sinason, leading psychotherapist, is of the view that the ever-changing labels, and the bitter conversations accompanying debates about the proper language to use, are no coincidence. They are a means to hide deep discomfort about ‘learning disability’ as a toxic identity, the ultimate outgroup.⁷ In a world where intellect, reason and judgement are paramount marks of esteem, to be labelled as lacking these, is indeed stigmatising. Despite the shift to apparently less stigmatising language—intellectual disability is preferable to ‘feeble-minded’ or ‘idiot’ to the modern ear—the abbreviation ID for ‘intellectual disability’ is widely used in academic papers. It seems somewhat disrespectful, distancing and dehumanising to abbreviate what is supposed to be a respectful modern term, but it is a common practice.

THE EUGENIC INFLUENCE AND LEGACY

The spectre of eugenics cannot be separated from terms such as defective, idiot, imbecile and feeble-minded. It would have come as a surprise to campaigners and legislators of the early twentieth century to find the idea of healthy minds applied to what were then generically called ‘mental defectives’. The minds of these people were, according to the official Radnor Report (1908), so diseased as to be ‘a terrible danger to the race’ (a phrase attributed to Winston Churchill).⁸ At the turn of the nineteenth and twentieth centuries, Binet’s IQ tests were deployed to show that most convicts and prostitutes were illiterate and therefore feeble-minded.⁹ These tests provided quasi-scientific truths that these

people were the cause of many of the ills with which society grappled—illegitimacy, drunkenness, promiscuity and fecklessness to name but a few. So hideous was this often hidden danger—the feeble-minded could often pass as normal—that they needed to be sought out, ascertained and detained in segregated institutions.¹⁰ There was a belief that feeble-mindedness was hereditary and unless the breeding of the feeble-minded was curtailed, the ‘healthy’ stock would, it was believed, be overwhelmed by larger numbers of defectives. US Scientist H. H. Goddard affirmed that feeble-minded people were ‘multiplying at twice the rate of the general population’,¹¹ thus producing ‘more feeble-minded children with which to clog the wheels of human progress’.¹² He too cited quasi-scientific research to back up these claims. Goddard met a young woman whom he called Deborah Kallikak in an institution and later looked into her family tree. Her great-grandfather had been Martin Kallikak. According to Goddard, the Kallikak family was divided into two strains—one ‘good’ and one ‘bad’—both of which originated from Martin Kallikak, Sr. The ‘Normal N’ and ‘Feeble Minded F’ were deduced by what these ancestors achieved in their lives. When Martin Kallikak, Sr. was a young soldier, he had a liaison with an ‘unnamed, feeble-minded tavern girl’. This relationship resulted in the birth of an illegitimate son, Martin Kallikak, Jr. It was argued that the ‘bad’ strain of the Kallikak family descended from this line. Later Martin Kallikak, Sr., married a Quaker woman from a ‘good’ family. The ‘good’ line descended from this marriage. Goddard’s genealogical research purported to show that the union with the feeble-minded tavern girl resulted in generations of ‘mental defectives’ who were plagued by illegitimacy, prostitution, alcoholism, epilepsy and lechery. His investigation into the other Kallikak branch revealed the opposite: Goddard believed that the striking schism separating the two branches of the family was due entirely to the different genetic input from the women.¹³

In the UK, the Mental Deficiency Act 1913 was introduced in direct response to the moral panic associated with these eugenic beliefs. This legislation made it possible to segregate ‘defectives’ in institutions, with men and women kept strictly apart to prevent ‘breeding’.¹⁴ Other measures to restrict childbearing, associated with negative eugenics, included prohibition of marriage, which was widely canvassed in England during the 1920s, legalised sterilisation, and other forms of birth control.¹⁵ None of these were formally adopted in any of the British Isles, but sterilisation was widely practised.¹⁶

The heyday of segregation as the preferred way to manage mental defectives, and to prevent their breeding, was the first three-quarters of the twentieth century. In the Western world at least, following scandals and journalistic exposes, buildings based on the idea of segregation in large remote ‘colonies’ fell out of fashion.¹⁷ However, these buildings and institutions continue to be the dominant form of provision, other than family-based care, in much of the rest of the world.

In the countries of the west, which had been amongst the earliest to adopt a ‘colony’ solution, a combination of factors came together to bring that era to an end. Segregation was an expensive way to prevent the ‘unfit’ from having children once the employment of ‘high grade’ patients became unacceptable during the 1950s. At a time of high employment and rising wages, it became ever more difficult to recruit staff to work in remote institutions often run on quasi-military lines.¹⁸ Academic critiques, such as that of Goffman¹⁹ and parent-run organisations like the National Association of Parents of Backward Children (England), and the National Association for Retarded Children (USA) also exerted pressure on politicians to move cautiously away from institutional solutions.²⁰ The last large state-run institutions to open in the UK were in the early 1970s at Princess Marina Hospital in Northampton, and Lea Castle Hospital in Kidderminster: the last one to officially close was Orchard Hill, on the outskirts of London in 2010. However, the demise of the institutional solution did not signal a true reappraisal of people with learning disabilities, rather it proved that technology opened the way for new forms of reproductive control, negating the need for physical segregation.

STERILISATION AND CONTRACEPTION

Control of reproduction was the driving force behind segregationist policies. The arrival of more effective contraception meant that physical segregation became less necessary. Sterilisation also offered an alternative to achieving the pre-eminent eugenic aim of preventing procreation and child-rearing by people with feeble-minds. In numerous countries, including many states of the USA, Canada, Sweden and Iceland, involuntary sterilisation was practised lawfully during much of the twentieth century.²¹ In Sweden, Iceland and the USA, it was a condition of release from the institution.²² Oral history accounts provide a greater degree of insight, such as this recollection from Ragnheiður, a former inmate of an Icelandic institution:

It is so strange. When I moved to the group home I had to undergo sterilization. I didn't agree but I had to agree because otherwise I would not be allowed to move from the institution.²³

Sociologist Robert Edgerton, writing in the 1960s, noted that 44 of the 48 ex-patients he interviewed about life outside had been subject to 'eugenic sterilisation' before their release from the Pacific State Colony, California.²⁴ The letter sent from the Colony seeking parental permission emphasised that it would enable parole and visits outside, and unless there were strong objections, the patient was sterilised. Edgerton records that a few respondents, all single men, approved of the operation, giving them greater freedom. However, most regretted it, and several saw it as a 'permanent source of doubt about their mental state'.²⁵ One woman speculated a connection with an unhealthy mind in her musing to the researcher on the subject:

I still don't know why they did that surgery to me. The sterilization wasn't for punishment, was it? Was it because there was something wrong with my mind?²⁶

Edgerton noted that the most significant cause of concern was the difficulty it posed for hiding a discredited past, to tell or not to tell potential partners—or in the terms of this volume, to conceal the diagnosis of not having an acceptably healthy mind. The resulting scar was regularly explained as the result of an appendectomy. Edgerton notes the irony that this was how the hospital explained the operation, saying to patients that it was to remove an appendix, a subterfuge that was also recorded in England, Canada and Iceland.²⁷

Famously, in the four countries of the UK involuntary sterilisation was never legalised after the failure of the Brock Committee to persuade Parliament to legislate in the 1930s.²⁸ Nevertheless, this did not mean it did not occur as shown by Tilley et al. via oral histories, and by Stansfield et al. who scrutinised court records of the later twentieth century.²⁹ Sterilisation was widely canvassed in the mid- and later twentieth century. A survey undertaken in England in the 1990s found that over half of 274 responding family members would or had considered sterilisation for their child.³⁰ Roy et al.'s study found that family members considering sterilisation had not explored alternative contraception.³¹ In 2011, the author interviewed two elderly parents of a woman born in 1950

who recounted how they had obtained sterilisation for their daughter in 1970 by requesting it from the GP.³² Their fear was, not that she would have sex, which she apparently much enjoyed, but that it would result in a child that she would be unable to adequately care for. Ladd-Taylor argues that it was child-rearing that was the focus, not childbearing:

Sterilization policy was as much about preventing child rearing by the so-called feeble minded as it was about preventing child bearing.³³

The most recent study on the subject of sterilisation in England and Wales was a detailed review of 73 applications which went before the Official Solicitor between 1988 and 1999.³⁴ Seventy of these cases were women, three were men, and 37% were minors. The average age of the women was 21.4 years. The court approved thirty-one sterilisations; six procedures went ahead without the need for court approval because it was deemed ‘therapeutic’. Thus, roughly half the cases that were considered were deemed suitable for sterilisation.

There is little evidence about sterilisation practices after this period, despite the implementation of the Mental Capacity Act 2005, in England and Wales, which arguably provided a new framework for decision-making in relation to reproductive rights. However, evidence about recent practice from other countries shows that sterilisation remains widespread. A Belgian study of 397 women aged 18–46 found that 22% had been sterilised.³⁵ A Dutch study involving 397 women aged 15–59 of whom 112 were using contraception, found that 25 had been sterilised, 20 of these prior to 2000.³⁶ Intellectually disabled people may be sterilised, without their consent, under New Zealand law, and court authorisation is not always necessary.³⁷ Concern about people with intellectual or learning disabilities reproducing continues in twenty-first-century thinking and practice. It is estimated that between 40 and 60% of children born to parents with intellectual disabilities in Western countries are removed from their care.³⁸

The drive to prevent people with ‘unhealthy’ minds from having children has not ended, but it is much less visible and in the UK sterilisation appears to no longer be widely practised. The literature indicates that in the early twenty-first century, women’s capacity to conceive and bear children is, in the main, controlled through social and contraceptive care interventions rather than surgical sterilisation.³⁹ While the law in England and Wales has changed to make sterilisation without

legal sanction virtually impossible, ‘newgenic’ social practices continue to restrict the sexual and reproductive freedoms of learning disabled women. Tilley et al. comment:

Whilst medical technologies may have changed, essential questions about intellectually disabled women’s rights to participate in decisions about their own reproductive futures remain.⁴⁰

McCarthy and Ledger et al. argue that continuing use of long-acting patches to prevent pregnancy is a form of reproductive control which does not require legal sanction.⁴¹ Two small-scale studies indicated that many women with intellectual disabilities are prescribed long-acting contraception without requesting it, frequently when they are not in relationships.⁴²

This discussion of reproductive control concludes with an exploration of policy changes. Policy statements of the twenty-first century are bold, optimistic and unambiguous, for instance England’s *Valuing People Now* explicitly stated, ‘people with learning disabilities have the choice to have relationships, become parents and continue to be parents and are supported to do so’.⁴³ Yet the gap between rhetoric and reality is yawning. Prevention of childbearing and child-rearing continues to inform practice, under a cloak of changing policy. The drive to privilege reproduction of ‘healthy minds’, untainted by intellectual disability, has not gone away.

NORMALISATION AND SOCIAL ROLE VALORISATION

Normalisation and social role valorisation are perhaps the most explicit acknowledgement in theory that it matters to hide the unhealthy mind. The question of how to address what appeared to be the low valuation of people with intellectual disabilities became a preoccupation of the late twentieth century. Drawing on sociologist Goffman’s argument that to overcome stigma, it was essential to ‘pass’ as normal, to conceal the discrediting attributes, normalisation and social role valorisation, came to dominate learning disability policy and practice from the 1970s onwards.⁴⁴ Normalisation was defined by Dane Bank Mikkelsen as letting the mentally handicapped (sic) obtain an existence as close to normal as possible.⁴⁵ These ideas from the Nordic countries were recast by the American theorist, Wolf Wolfensberger as social role valorisation:

The utilization of means which are as culturally normative as possible in order to establish and / or maintain personal behaviours which are as culturally normative as possible.⁴⁶

To achieve this, a positive image of people with learning disabilities was vital as it would assist in people being accepted in mainstream society. Social role valorisation emphasised the importance of people with learning disabilities taking on ‘valued social roles’—if people with learning disabilities occupied valued roles such as worker—or researcher—then fuller integration into society would become possible. Wolfensberger also advocated association with ‘valued’, i.e. non-disabled people. It was, I would suggest, a way of concealing their stigma of an ‘unhealthy’ mind, as the route to wider acceptance.

ERADICATION

The final example of the ‘low’ value which has historically been attributed to people with learning disabilities is their potential for eradication. This practice was associated with the Nazis in the mid-twentieth century when they murdered people that they labelled *Unnütze Esser* or, in English, ‘useless eaters’.⁴⁷ It was, until quite recently, believed that this had discredited eugenics, and that the eradication of people with learning disabilities is no longer countenanced.⁴⁸ Wolf Wolfensberger, mentioned above as the architect of social role valorisation, disagreed. His view was that ‘deathmaking’ is one of the functions of learning disability services. He cited case studies which demonstrated how medical services fail disabled people, primarily because to some their lives are still perceived to have low quality and value.⁴⁹ He wrote:

handicapped people are given massive doses of psychoactive drugs so that they die from drug effects – even though the death certificate will list only the complications such as cardiac arrest, pneumonia.⁵⁰

Within his work, he also targeted abortion. He drew parallels between Nazi Germany’s extermination practices and contemporary practice of aborting disabled fetuses.⁵¹

I think that the liberalisation of abortion is one of the expressions of the lowering of human life and I do believe we will soon see legalised euthanasia. We will see it applied to the aged and the retarded first We will

have to see that you can't have this part way; that once you break through a qualitative barrier of defining human life and its value, then there's no stopping.⁵²

Some recent events suggest that Wolfensberger's views cannot be lightly dismissed. The poor health care offered to people with learning disabilities revealed in Mencap's *Death by Indifference* campaign and the findings of the University of Bristol's Confidential Enquiry into Premature Death (CIPOD) can both be considered to be evidence of this.⁵³ Moreover, the failure to investigate unexpected and premature deaths to which the Mazars Report drew attention, reinforced by the Care Quality Commission's findings in 2016, is further evidence to point to the low value which, in some contexts, continues to be accorded to the lives of people with learning disabilities.⁵⁴

Wolfensberger's starting point for arguing that we are on a slippery slope to discarding lives perceived by others to be of 'low value' was the widespread practice of aborting foetuses identified as disabled through prenatal testing.⁵⁵ Recent medical 'advances' open up the real possibility that Down's Syndrome will be eradicated entirely by early detection in utero, followed by abortion, discussed in Sally Phillips's TV Programme *A World Without Down Syndrome* first broadcast in 2016.⁵⁶ Genetics offers the potential to identify more traits than Down's Syndrome in utero which as long ago as 1977 Reilly cited as having the potential for negative eugenics.⁵⁷ If the gene for autism can be located, for example, it opens the way for this also to be detected and eradicated before birth. Barnbaum uses absence of theory of mind to argue that parents have a moral obligation not to bring autistic individuals into the world, although she argues that once born, a different approach needs to prevail.⁵⁸ It is difficult to escape the view that the emphasis on 'healthy minds' in modern discourse continues to influence policy and practice in relation to the abortion of disabled foetuses.

Despite this discussion, the question remains why, despite modern policies and stirring words, do people with learning disabilities continue, in certain contexts, to have such low social value and how might this be rectified? This returns us right back to the idea of 'healthy minds' as a concept. In 2008, before things got as bad as they were at the time of writing (see, for example, the UN's condemnation of UK's failure to uphold the CPRD 2016),⁵⁹ Kelley Johnson and I pondered the question—why, after 3 decades of social inclusion policies, a good life

for people with learning disabilities seemed so elusive.⁶⁰ We looked at Western philosophy for answers. We found that ‘reason’ was pre-eminent in the qualities philosophers valued for a rounded life. Overwhelmingly, male philosophers have outlawed emotions and passion as disturbing to the equilibrium sought through the exercise of reason. Of particular significance was the view associated with the eighteenth-century Enlightenment which equated human history with progress related to man’s reason, increasing knowledge and understanding of the natural world, and the means to control it. Certainly, the implications of not being seen to possess reason run deep. John Rawls argued that as rational human beings we develop a social contract resting on two principles. The first is the freedom to pursue the life we want to lead providing it does not harm others. The second is that economic and social inequality is unavoidable, but the institutions of society should protect the less well off.⁶¹ Like many preceding philosophers—John Locke amongst them—Rawls assumed that a social contract existed between individuals who are equal to one another in their freedom to suggest how society should be organised, based on their reasoning and ability to participate. People with learning disabilities are those whose interests must be protected in a Rawlsian sense, rather than being active citizens who participate in formulating a just and fair society. There is a fundamental inequality here, built into the social contract.

Notoriously, twentieth-century thinker Peter Singer placed reason at the core of what makes us human and used this to exclude many people with learning disabilities from the status of human being.⁶² This extolling of reason, we argued then, is at the core of the exclusion of people with learning disabilities. Subsequently, another advocate for people with learning disabilities, Chris Goodey argued that since the eighteenth-century Enlightenment, if not before, people now called learning disabled have been the ultimate outgroup.⁶³ He traces this to the pre-eminence of intellectual ability in modern claims to species membership; he stated that ‘intellectual ability or intelligence is in modern societies the foremost claim to status’.⁶⁴ This, he argued, is used to justify classifying people with learning disabilities as an outgroup, suggesting that ‘classifying a human group by intellectual criteria is today’s prevailing symptom of inclusion phobia’.⁶⁵ He further develops the argument to say that ‘intellectual disability is vital to the dominant in-group because of its relationship to that quality which that group attributes to itself’.⁶⁶ In other words, we need people with learning

disabilities to prove our intellectual ability—there is no point in having it—if everyone has it. Unless this idea changes, he argues, no amount of bold pronouncements will produce change. Taken together, these two attempts at understanding the persistent othering of people with intellectual disabilities alluded to in this chapter are depressing. However, unless these conclusions are faced up to and challenged for what they are, change will only be superficial, and only for the few who can—as numerous self-advocates assert—do things other people can do.

CONCLUSIONS

This chapter has argued that some of the impulses that drove the movement to privilege and protect ‘healthy minds’, by segregating people with intellectual disabilities to prevent their ‘breeding’, have not vanished, as some would argue. Rather the desire to prevent childbearing and child-rearing remains, but thanks to technology, the means of prevention are far less obvious; they are well hidden under rhetorical flourishes proclaiming rights. Efforts to change this state of affairs, such as normalisation/social role valorisation, rely, not on challenging the fundamental undervaluing of people with intellectual disabilities, but on persuading people to ‘pass’ as normal, and persuading others to support such passing by offering and talking up ‘valued social roles’. My challenge to readers is to recognise that until the overinflated value attributed to intellect and reason changes, until we re-evaluate what constitutes a ‘healthy mind’, such undervaluing will continue.

NOTES

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