BOOK REVIEW

SIMON FOLEY: INTELLECTUAL DISABILITY AND THE RIGHT TO A SEXUAL LIFE (2019)

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1 Introduction

The last two decades or so have seen a growth in literature addressing disability from a variety of revisionary perspectives, including human rights law, applied philosophy, sociology, and critical social theory in general. The growth has intensified with the adoption of the Convention on the Rights of Persons with Disabilities (CRPD) by the United Nations in 2006.1 The literature, especially that emanating from Critical Disability Studies (CDS),2 is not just revisionary but is also set on a transformative path. It evinces a sharpened disability consciousness in the manner it questions old assumptions about disability and deconstructs disablism as a deeply entrenched system of oppression analogous to racism, sexism and other status-subordinating ‘isms’.3

2 I am using ‘Critical Disability Studies’ as a generic description of discourses and academic programmes that seek to inflect how we think about disability with critical social theory to argue that disability is discursively created and not something comprehensible only through the intrinsic body.
3 ‘Disablism’ or its variants such as ‘ableism’ or ‘ablism’ are terms that find favour amongst commentators who treat disability as the outcome of structural power. See, for example: IM Young Justice and the politics of difference (1990) 124, 145, 164; M Oliver The politics of disablement (1990) 77; C Ngwena ‘Developing juridical method for overcoming status subordination in disablism: The place of transformative epistemologies’ (2014) 30 South African Journal on Human Rights 275.
Across cultures, there is an acute awareness of the historical legacy of systemic exclusion of persons with disabilities and the imperative to restore human dignity and equality. The adoption of a regional treaty on disability under the African human rights system - the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities in Africa by the African Union in 2018 (the Protocol) – is part of rising inter-cultural disability consciousness.\textsuperscript{4} The Protocol, which emulates the CRPD,\textsuperscript{5} underlines that, apart from combatting negative stereotyping and prejudice, what is also required is changing radically, that is, transforming how we normatively treat persons with disabilities as social, political, economic and juridical subjects.

At the very least, a transformative approach to disability means reconceptualising disability to depart from hegemonic cultural systems that stigmatise and colonise certain forms of bodily variations as corporeal deficit in order to legitimise unequal distribution of ontological status, resources and power.\textsuperscript{6} Such cultural systems have produced and reproduced relations of inequality and status subordination.\textsuperscript{7} Transformation enjoins us to accept human diversities substantively. To achieve parity in participation, it is necessary to dismantle systemic barriers erected on the assumption of able-bodiedness. This is an essential step in building an inclusive social, political, economic and legal environment in which the equality and human dignity of persons with disabilities, including autonomous will and preferences, are protected on an equal basis with others. Simon Foley’s book, \textit{Intellectual disability and the right to a sexual life: A continuation of the autonomy/paternalism debate}, which is the subject of this review, belongs to Critical Disability Studies. It reinforces the argument for a transformative approach to disability in ways that are synergic with the goals of the CRPD and, by implication, the Protocol.

\textit{Intellectual disability and the right to a sexual life} is a book written by a sociologist based in Ireland. Foley develops his arguments from a synchretic sociological archive, drawing mainly on Michel Foucault’s


\textsuperscript{5} Though inspired by the CRPD, the Protocol is not a replica of the former. The Protocol does not detract from the protection guaranteed by the CRPD. However, in some instances it amplifies the rights guaranteed by the CRPD and in others extends the rights: L Mute & E Kalekye ‘An appraisal of the Draft Protocol the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities in Africa’ (2016) \textit{East African Law Journal} 68, 84-89.


theory of power\textsuperscript{8} and Julia Kristeva’s psychoanalytic concept of abjection\textsuperscript{9} and its application to disability by Margrit Shildrick.\textsuperscript{10} In addition, he draws on applied philosophy in general and, to a limited extent, Anglo-American jurisprudence. His arguments are also informed by empirical research findings.

Foley’s main proposition is that persons with intellectual disabilities and, more specifically adults with Down syndrome, have sexual needs and that ‘where necessary facilitated sex with prostitutes should be included as part of a new regime of care to ensure that their sexual needs are met’.\textsuperscript{11} He makes a concerted case for reforming societal arrangements for care, especially parental care for adults with Down syndrome. The ultimate goal is to ensure that the arrangements do not continue to serve as overly paternalistic modes of care but, instead, become porous to specifically recognising and accommodating the sexual will and preferences of persons with Down syndrome and the possibility of facilitating sexual intercourse.

2 Overview of the book

The book has six chapters which are preceded by an introduction. In the introduction, Foley considers two main questions. First, he considers what constitutes an intellectual disability. Second, he addresses why the book focuses on Down syndrome. The two questions intertwine. Addressing them is a necessary underbrush-clearing exercise partly because many commentaries use ‘intellectual disability’ interchangeably with ‘learning disability’.\textsuperscript{12} Moreover, some commentaries use ‘mental disabilities’ as an all-inclusive descriptive category for mental conditions that intersect with disability. Given the heterogeneity of disabilities in the mental sphere alone, such conflation is apt to render any analysis of general application only or even questionable use.

The author highlights that his book is not just about disability but ‘intellectual disability’ and, more particularly, persons with Down syndrome. The cogency of his arguments, which seek to promote the sexual autonomy of persons with Down syndrome through a third-party intervention of facilitated sex, crucially depends on the reader first

\textsuperscript{8}M Foucault: Discipline and punish (1977); History of sexuality: Volume 1 (1978); Power/Knowledge (1980); Afterword: The subject and power (1983) in H Dreyfus & P Rabinow (eds) Michel Foucault: Beyond structuralism and hermeneutics.

\textsuperscript{9}J Kristeva: The powers of horror: An essay on abjection (1982).


\textsuperscript{11}p i. Foley uses the word ‘prostitutes’ but without intending to stigmatise. In this review, unless quoting, ‘sex-workers’ is used as the more acceptable lexicon in contemporary discourses on transactional sex.

\textsuperscript{12}p 1.
sufficiently appreciating differences in cognitive impairments and how they are located in differently positioned subjects.13

Foley subscribes to the definition of ‘intellectual disability’ offered by the American Association of Intellectual and Developmental Disabilities (AAIDD) and the World Health Organisation (WHO). The essence of the AAIDD’s definition is that intellectual disability is a cognitive impairment (or impaired intelligence) which is biological in origin and begins before the age of 18.14 It has a lasting effect on development, resulting in significant limitation in intellectual functioning and adaptive behaviour, including the acquisition of age-appropriate social and practical skills.15 The definition of WHO is complementary.16 It formulates intellectual disability primarily in terms of cognitive impairment with a biological source manifesting before adulthood. Both definitions take into account society’s role in creating an enabling or disabling environment for persons with intellectual disabilities.

Foley wants to capture the ‘biological’ nature of intellectual disability in a manner unobscured by the social model of disability.17 His point is not that the environment does not compound intellectual disability through failure to accommodate. Rather, it is that intellectual disability is primarily a congenital condition. It is a condition organically rooted in brain anatomy or physiology and is intrinsically limiting such that the environment can only add to the limitations.18 To underscore his argument, he says:

[A] key premise underpinning the substantive claims made and conclusions drawn [in this book] is an acknowledgement that biology does mean that intellectually disabled people will never transcend a cognitive threshold. Consequently, it is the fact that intellectual disabilities such as Down syndrome are real pre-discursive impairments with real consequences in the real world that informs the subject matter of this book.19

13 p 2.
15 As above.
17 The social model is an approach to disability that prizes the environment rather than the body as the cause of disability. Though it has its variants, the more popularised version of the social model was pioneered by sociologists in Britain: V Finkelstein Attitudes and disabled people: Issues for discussion (1980); M Oliver Understanding disability: From theory to practice (1996); C Barnes Disabled people in Britain and discrimination: A case for anti-discrimination legislation (1991).
18 p 3.
19 p 3 (references omitted and emphasis added).
Thus, Foley argues that intellectual disability would still prevail as an impairment regardless of how society is organised. In this way, Foley is a critic of an exclusive social model. He finds the social model to be politically important but, nonetheless, an incomplete explanation for intellectual disability. He joins other critics not so much in jettisoning the social model but decentering it in order to bring greater attention to disability as a dialectic between the body, its intrinsic limitations and the social environment. The main discontent with the social model is that it has become a meta-narrative which glosses over the complexities and diversities of disability, implicating only a disabling environment but effacing the reality of impairments and personal experiences about disability. Foley is careful to point out that even among persons with Down syndrome, cognitive impairment is not homogeneous as some have mild and others severe impairment.

According to Foley, when determining whether an appropriate balance is being struck between the freedom to make one’s own choices and paternalism in context of the social care of adults with Down syndrome, embodiment is a crucial informing element. It can tell us the degree of paternalism that third parties feel they are justified in exercising, including in respect of sexuality choices. Adults with Down syndrome are appropriate subjects for Foley’s sexual autonomy-recognition arguments as they epitomise a sexually disempowered historical community quintessentially at the receiving end of a ‘paternalistic regime of care’. He explains a ‘paternalistic regime of care in the following way:

Namely, if adults with Down syndrome, or any other form of intellectual disability, either must ask permission and, or are prevented by their parents from taking control over their social/sexual lives (that is, if they are not allowed to do what they want, and particularly at night time) they are being subjected to a paternalistic regime of care.

His point is that, even as adults, persons with Down syndrome are socially constructed as perennial children. Consequently, they are prevented by parents from taking control of their social lives, including sexual lives. Moreover, the facial appearance of persons with Down syndrome marks them out. It comes ensconced in socially constructed ‘spoiled identity’

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22 p 6.
23 As above.
and abjection’, thus, reinforcing the book’s argument that for this category of disability embodiment matters.

The focus on intellectual disability and Down syndrome in this book is also tied to the author’s standpoint as someone who has developed a close relationship with persons with Down syndrome. The author grew up with a sister with Down syndrome and watched her grow into an adult with a need for a boyfriend. As a child and teenager, he socialised with persons with Down syndrome to a degree he regards as sufficient to adequately acquaint him with the lifeworlds of persons with disabilities. In the light of this personal connection, he felt well placed to embark on research and writing about the sexual desires of persons with Down syndrome.

In Chapter 1, Foley explains his overall methodology. Over and above engaging with published commentaries, an important methodological dimension to the book is its empirical component. The book’s arguments are partly informed by findings from empirical research in the form of semi-structured interviews and focus group sessions conducted in the Republic of Ireland. The research subjects were two population groups – adults with Down syndrome who were still living at home and mothers of adult children with Down syndrome who were still providing parental care. The choice of semi-structured interviews and focus group sessions as the empirical approach was prompted by the author’s objective to give direct voice to historically silenced social groups.

Chapter 1 is also taken with Foley explaining his main analytic approach, especially its place in Foucault’s discourse of power and Kristeva’s theory of abjection. Foucault’s concept of ‘discourse’ is appropriated to explain that as society and community, including parents and their adult daughters and sons with Down syndrome, we are discursively created. By this, Foucault means that how we think and how we conduct our lives, including in the sphere of sexuality, is not the free exercise it appears to be. Rather, it is an outcome of language. The choices we make are anchored in an ideology that is tied to power and knowledge that produce an ‘effect’. Foley draws parallels between Foucault’s omnipotent, omnipresent and omniscient ‘panopticon’ with the regime of parental care for adults with Down syndrome and how adults with Down syndrome, themselves, conduct their own lives. The point of Foley’s analogy is to argue that the regime of care for adults with Down syndrome mimics incarceration with parents serving as ‘reluctant jailors’ and their children as compliant ‘prisoners’ of a kind under a system of surveillance. Each group tries to do what is socially expected of it by the dominant cultural imaginary.

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25 M Foucault The archaeology of knowledge (1972) 49.
26 Foucault Discipline and punish (n 8 above).
Foley’s uses Kristeva’s psychoanalytic concept of abjection not just as an important but also necessary tool for understanding the primordial rejection of Down syndrome in the dominant cultural imaginary. Down syndrome is perceived, even by loving parents and persons with Down syndrome, themselves, as outside the range of what is ‘normal’; as something impure and abnormal. Down syndrome is constructed by the dominant cultural imaginary as something that ‘disturbs identity, system and order’ and, even more so, the idea of facilitated sex.27

In Chapter 2, the focus is on the autonomy/paternalism debate. Foley highlights that there are no easy answers for helping us determine the right balance between autonomy and paternalism when addressing the sexual needs of a social group that, on account of cognitive impairment, is vulnerable in a real sense to sexual abuse and exploitation by its non-intellectually disabled counterparts. He concedes that paternalism is warranted but highlights that cognitive impairment creates a dilemma between the liberal ideological ethic to respect the will and preference of the subject and the obligation to concomitantly provide safeguards against the abuse and exploitation of the subject.

Foley does not argue for dispensing with paternalism. What he is most critical of is that, even taking into account the legitimate duty of parents and the state to protect a vulnerable group, intellectual disability is at the receiving end of a classificatory system which recognises differentiated citizenship among its populace and ascribes an inferior ontological status to some. Socially and legally, persons with Down syndrome are instantly marked as the Other and accorded a subordinate status, including in the sexual sphere.

To appreciate the extent of the othering of persons with intellectual disabilities, we only need to look at our domestic criminal justice systems, especially the regimes for regulating consent to sexual intercourse, to see that they have one striking feature in common. Nearly all proceed on the presumption of the normative exclusion of persons with intellectual disabilities from sexual citizenship. Many legal systems have historically condoned forced sterilisation and other sexuality and reproductive autonomy-suppressing sanctions in respect of persons with intellectual disabilities.28

27 Kristeva (n 9 above) 4.
28 In Buck v Bell, 274 US 200 (1927) the Supreme Court of the United States upheld a statute of Virginia which authorised the compulsory sterilisation of the people that were diagnosed to be ‘mentally retarded’ for the ‘protection and health of the state’. Writing for the majority, Justice Wendell Holmes famously said that: ‘Three generations of imbeciles are enough’: PA Lombardo ‘Three generations, no imbeciles: New light on Buck v Bell’ (1985) 60 New York University Law Review 30, 32; RL Burgdorf & MP Burgdorf ‘The wicked witch is almost dead: Buck v Bell and the sterilization of handicapped persons’ (1977) 50 Temple Law Quarterly 995.
 Whereas non-intellectually disabled adults are, in a Millian sense,\(^{29}\) presumed to be autonomous agents with a capacity to freely consent to sexual intercourse in pursuit of happiness, the opposite is deemed for their intellectually disabled counterparts. The latter are, on account of intellectual impairment, presumed to be lacking in cognitive competence to muster such capacity. Whereas non-intellectually disabled adults are not subjected to a formal test to assess competence to consent to sexual intercourse, the onus is on persons with intellectual disabilities to rebut the presumption of incompetence. The juridical justification for the presumption of incompetence has been the need to protect intellectually disabled persons from rape, sexual abuse and other forms of sexual violence or exploitation. It is glaringly apparent, however, that the legal impulse to protect a sexually exploitable class has not come with equal concern to give recognition to the sexual needs of persons with intellectual disabilities, including the possibility that they might desire sexual intercourse in the same way as their non-intellectually disabled counterparts.

Parental care has emulated legal paternalism in prioritising protection from harm over the possibility that their child with intellectual disability might wish to have sexual intercourse. Even without the intervention of the law, generally, adult children with intellectual disabilities have been cared for by their parents in ways that exclude or at least do not support the notion of autonomous sexual citizenry. Understandably, the need to protect persons with intellectual disabilities from sexual abuse and exploitation by their non-intellectually disabled counterparts together with the assumption that they cannot muster parenthood, have been the main justification for the prohibitory regimes. However, in exchange of care and protection, the price paid by persons with intellectual disabilities has been the infantilisation of their desire to have sexual intercourse. Thus, their sexual autonomy has been historically misrecognised.\(^{30}\)

In Chapters 3 and 4, Foley puts his main proposition to empirical testing. It will be recalled that the proposition is that persons with intellectual disabilities and, more specifically, adults with Down syndrome have sexual needs and that where necessary facilitated sex with sex-workers should be included as part of a new regime of care to ensure that the needs are met. The chapters highlight that adults with Down syndrome desire to have intimate partners and that their parents recognise the legitimacy of this need. However, the praxis of parenting is contradictory in that it does not accommodate this need. Adults with Down syndrome are supervised by parents in ways that do not leave room of being alone with a partner. Foley describes the relationship between parents and their adult children with Down syndrome as defined by unproductive power

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30 Fraser *Justice interruptus* (n 7 above); Fraser ‘Rethinking recognition’ (n 7 above).
with the former almost serving as sovereign power and latter as ‘docile bodies’. A major explanation for the asymmetrical relationship is that both the parents and the adult children are the products of a normative social discourse that includes law and religion. The discourse constructs adults with Down syndrome as children and condemns the idea of sexuality for persons who are deemed to be asexual.

Facilitated sex was, foremost, viewed by mothers of adult children as morally reprehensible and a major breach of their paternalistic role. The mothers were prepared to accept sex work as legitimate work but not for the provision of services to their adult children. They could not imagine the ‘pimp’ and supervisory roles they would be required to play. The fact that in the dominant cultural imaginary sexual intercourse is a private act accentuated the unacceptability of facilitated sex. However, parents could possibly imagine facilitated sex if it was a ‘last resort’. Drawing on Kristeva and her adherents, Foley argues that the unequivocal rejection of facilitated sex by parents is largely explicable as psychanalytic abjection. It is the rejection of what is ‘unclean’ and would contaminate their identity as parents and moral persons.

Chapter 5 is aptly titled ‘A modest proposal regarding the normalisation of facilitated sex’. In this chapter Foley highlights that he is not arguing for paternalism to be dismantled as it has its assured and necessary place in the care of adults with Down syndrome. However, he wants our social systems, including law, policy and parental care, to accommodate the possibility of facilitated sex where such sex meets the sexual needs of adults with Down syndrome. He wants us to reimagine society in ways that are conscious to sexual desire as something experienced not just by non-intellectually disabled persons but also by their intellectually disabled counterparts. In this new imagination, facilitated sex becomes one of the means of supporting sexual autonomy of persons with intellectual disabilities. He reminds us that we are not pre-social and that we can remake the existing social order.

Chapter 6, the last chapter, recaps Foley’s arguments. It is reminder of what *Intellectual disability and the right to a sexual life* is about.

### 3 Significance

Albeit in a moral rather than a human rights domain, discursively, *Intellectual disability and the right to a sexual life* speaks to the same cause as the CRPD. It makes an unequivocal demand on recognition of unqualified equality for a group whose ontological status has been historically accorded a diminished status by an ableist ideology. Foley’s book is a

31 The question of facilitated sex was only put to mothers during focus group sessions.
narrative on inclusive equality but in the sexuality sphere where it seeks to give concrete recognition to the sexuality rights of persons with intellectual disabilities not just through language but also praxis.

The right of persons with intellectual disabilities to a sexual life on an equal basis with their non-intellectually disabled counterparts has historically been a non-subject at the receiving end of implicit ableist assumptions about what a ‘disabled’ body or mind cannot do. The marginalisation of this right has come with official imprimatur and embedded cultural practices. Foley is right to disturb ‘the order of things’.  His arguments are counter-hegemonic. He is challenging the status quo of an Althusserian interpellated ability/disability system that asexualises persons with Down syndrome. His goal is not to dismantle a paternalistic system but to fundamentally revise the manner in which the system has been normatively tied to a cultural imaginary that classifies humanity into categories with a hierarchical order for apportioning ontological status.

The arguments in Intellectual disability and the right to a sexual life have striking resonance with the CRPD. The book implicitly speaks to article 23 with requires states to eliminate discrimination against persons with discrimination relating to relationships on an equal basis with others. In similar vein, it speaks to article 25 which recognises that persons with disabilities have a right to health including 'sexual health'. Above all, Foley’s book speaks to article 12 of the CRPD. This article reaffirms that persons with disabilities have the right to recognition as persons before the law. It requires states to recognise their legal capacity in all spheres of life. Legal capacity is not only a right to hold rights but also to exercise rights. Cognitive impairment does not deprive one of the right to legal capacity as it is an inherent right that is not dependant on mental capacity. In anticipation of the fact that mental capacity can adversely interfere with the exercise of legal capacity, the CRPD requires states to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. It is incumbent on states to

34 Art 23(1) of the CRPD.
35 Art 25(a) of the CRPD.
36 Art 12(1) of the CRPD.
37 Art 12(2) of the CRPD.
39 Art 12(3) of the CRPD.
ensure that measures relating to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse.\footnote{Art 12(4) of the CRPD.}

Looked at through the lens of the CRPD, it is possible to argue that Foley’s main proposition is not in fact radical but is a means of giving practical effect to what international human rights already envisages. For far too long, the mode of care for persons with intellectual disability has prioritised substitute decision-making over the will and preferences of the subject class. The placement of a duty upon society to accommodate persons with disabilities is the CRPD’s most critical transformative lynchpin, providing us with the jurisprudential raison d’être for reconceptualising disability and instituting fundamental societal reforms.\footnote{The duty to accommodate is a foundational principle under the CRPD, see art 5(4) of the CRPD.} We can, therefore, relate to facilitated sex for persons with intellectual disability as one of the possible accommodation measures for fulfilling autonomy and achieving inclusive equality in the sexuality domain.\footnote{I use ‘inclusive equality’ synonymously with ‘substantive equality’ as a genus of equality that, unlike formal equality, addresses structural inequality and is aimed at achieving parity in participation, taking into account power relations. However, the Committee on the Rights of Persons with Disabilities inexplicably appears to draw a distinction between the two equalities. In General Comment No 6 (2018) on equality and non-discrimination CRPD/C/GC/6, para 10, the Committee seems to imply that inclusive equality is a fuller genus of equality than substantive equality in that it envisages parity in participation but so does substantive equality. See, for example: C Albertyn ‘Substantive equality and transformation in South Africa’ (2007) 23 South African Journal on Human Rights 253; C Sheppard Inclusive equality: The relational dimensions of systemic discrimination In Canada (2010).}

\section*{4 Conclusion}

Foley addresses an area of social life that has been largely overlooked or even shunned from in social discourses not so much because it is so intimate and so personal but because it relates to a social group that has been historically constructed as asexual. Of course, Foley’s proposal of facilitated sex raises problems of its own. Sex work and the role of the state in regulating sex work remain areas of controversy across cultures.\footnote{S Tamale ‘Paradoxes of sex work and sexuality in modern-day Uganda’ in S Tamale (ed) African sexualities: A reader (2011) 145-173; J Scoular ‘What’s law got to do with it? How and why law matters in the regulation of sex work’ (2010) 37(1) Journal of Law and Society 12.}

There is also the issue of privacy and how far third parties can go in supervising what is ultimately an intimate and personal activity. At the same time, if we agree that persons with intellectual disabilities have sexual desires that are not less human than those of their non-intellectually disabled counterparts, Foley is asking us to consider seriously the means of giving not merely rhetorical but more significantly practical recognition to the desires.
Foley’s book is a provocative addition to a rapidly growing canon of disability theory and praxis but for a specific class of disability – intellectual disability. It has appeal across cultures, not least because the asexualisation of persons with disabilities epitomises an area of social, political and legal life with a globally shared discursive history. The asexualisation is present in the Republic of Ireland in the same way as it is present across the African region and for substantially similar reasons.

Whilst constructed around critical social theory, Foley’s book is written in an engaging and accessible style. It has appeal across disciplines, including law and human rights.