

Introduction

If you are reading this monograph then you are engaging in an activity denied to hundreds of millions of print-disabled people across the globe. For most of human history, reading equality has been an unrealised and impossible dream for people who are unable to read and handle standard books, including people with blindness, quadriplegia or dyslexia. Technological advancements have revolutionised what is possible. While books have been born digital for decades, almost exclusively they have been published in standard paper formats. Books are now born digital and are being distributed as E-Books via E-Libraries, and read on E-Readers. There is now no reason that people with print disabilities cannot enjoy full access. People with print disabilities can use adaptive technologies to read digital content, unless that content is published in ways that block the use of adaptive technologies. Reading equality remains an unrealised dream that is technologically, commercially, economically and legally possible.

This monograph contributes to disability rights scholarship and legal advocacy. It builds on international and domestic notions of digital equality and rights to access information. The core thesis of this monograph is that technology now creates the possibility that everyone in the world, regardless of their abilities or disabilities, should be able to access the written word. Why, then, is there still a book famine, where only 5 to 7 per cent of the world's books are available to people with print disabilities in wealthy, advanced economies, and less than 1 per cent in the majority of countries?

While anti-discrimination and equality laws operate to enable access, these laws have limited impact on the overriding impact of market forces and copyright laws that focus on restricting access to information. For decades, the print-disabled have been denied reading equality and have instead had their access to information limited by legal frameworks and resource allocations that tolerated minor exceptions to the mainstream consumption of books

and information. The recent United Nations *Convention on the Rights of Persons with Disabilities* (CRPD), and other international developments, have swept in a new disability politics that is altering what is expected from laws and institutions.¹ The human rights paradigm has created the possibility of achieving equality. The challenge is to analyse barriers to this dream of reading equality, and to craft laws and institutions that open the E-Book for the world's print-disabled.

TERMINOLOGY: DISABLEMENT OR HUMANITY FIRST

This introductory chapter, and the remainder of the book, adopts the terms 'persons with print disabilities' and 'print-disabled'. Whether the person or disability is placed first has theoretical and practical significance.² Medical professionals describe people by reference to their impairment. Under this approach, a person with an impairment loses their humanity and is described as the 'person with paraplegia' or, even worse, simply as 'the paraplegic'.

To turn the focus away from the medical label and towards the role society plays in disabling people with impairments, social model advocates in the United Kingdom sought to emphasise that it is society that causes the disablement. To emphasise the role society has in causing disablement, the 'disabled person' terminology was adopted.³ This social model approach, discussed further in Chapter 2 of this monograph, emphasises that the person is disabled by barriers in society.

Advocates in Australia, Canada and the United States predominantly use the person-first approach to emphasise the humanity of the individual over the impairment.⁴ The United Nations *Convention on the Rights of Persons with Disabilities* has enshrined a human rights model reflecting a wider civil rights model that places humanity first and uses the term 'persons with disabilities'.⁵

¹ *Convention on the Rights of Persons with Disabilities* (CRPD), opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008).

² Darcy Granello and Todd Gibbs, 'The Power of Language and Labels: "The Mentally Ill" Versus "People with Mental Illnesses"' (2016) 94(1) *Journal of Counseling & Development* 31; Paul Harpur, 'From Disability to Ability: Changing the Phrasing of the Debate' (2012) 27(3) *Disability and Society* 325.

³ Colin Barnes, *Disabling Imagery and the Media: An Exploration of the Principles for Media Representations of Disabled People* (1992) The British Council of Disabled People, 43; Michael Oliver and Colin Barnes, *Disabled People and Social Policy: From Exclusion to Inclusion* (1998) Longman, 18.

⁴ Gerard Goggin and Christopher Newell, *Disability in Australia: Exposing a Social Apartheid* (2003) University of New South Wales Press, 25.

⁵ CRPD; Paul Harpur, 'Embracing the New Disability Rights Paradigm: The Importance of the *Convention on the Rights of Persons with Disabilities*' (2012) 27(1) *Disability and Society* 1, 1.

Despite the debates, Tom Shakespeare argues that ‘the person first is the politically progressive choice in America, Australia and other English speaking countries’.⁶

The author has previously argued for the person-first approach,⁷ and will predominantly adopt the person with disabilities approach in this monograph. The author believes that in most situations it is more important to emphasise the humanity of the individual over focusing on the role society has in creating disability. There will be situations throughout this monograph, however, where the disablement caused by society is so stark that it requires particular emphasis. For example, if a person who has no eyesight can use adaptive technology to read an E-Book, but the only reason they cannot read the book is a decision by an E-Publisher to use coding that does not follow universal design, then that person can be said to be disabled by that ableist decision. But for the ableist E-Publisher, the existence of the impairment would not be disabling. By employing both terminologies in this monograph, the author is fence-sitting, while leaning towards one side of the debate. The author believes this theoretically uncomfortable position is correct for this monograph, especially considering the fact that the *CRPD* recognises the role society has in creating disablement (the social model), while engaging with the health aspects of the individual.⁸

WHO ARE THE PRINT-DISABLED?

The terms ‘print-disabled’ and ‘persons with disabilities’ both describe an impairment category which constitutes a disability. The notion of disablement is analysed in Chapter 2 of this monograph, and the situations where an impairment is regarded as a disability in the *CRPD* and anti-discrimination laws is analysed in detail in Chapter 6. At this stage, it is sufficient merely to define when an inability to consume standard print material amounts to a print disability.

The notion of print disability extends wider than the estimated 39 million clinically blind persons and 246 million vision-impaired persons in the world.⁹ Until recently, no international legal instrument has provided a definition of

⁶ Tom Shakespeare, *Disability Rights and Wrongs Revisited* (2014) Routledge, 19.

⁷ Harpur, ‘From Disability to Ability’.

⁸ For a further discussion of the medical model, social model and human rights paradigm adopted in the *CRPD*, see Chapter 2 of this monograph.

⁹ Kaya Koklu, ‘The Marrakesh Treaty – Time to End the Book Famine for Visually Impaired Persons Worldwide’ (2014) 45(7) *International Review of Intellectual Property and Competition Law* 737, 737; Jingyi Li, ‘Reconciling the Enforcement of Copyright with the Upholding of Human Rights: A Consideration of the Marrakesh Treaty to Facilitate Access to Published

what a print disability is. The *Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print Disabled* (*Marrakesh Treaty*), discussed in Chapter 3 of this monograph, benefits persons with print disabilities and defines ‘beneficiary persons’ to include a person who:

- (a) is blind;
- (b) has a visual impairment or a perceptual or reading disability which cannot be improved to give visual function substantially equivalent to that of a person who has no such impairment or disability and so is unable to read printed works to substantially the same degree as a person without an impairment or disability; or
- (c) is otherwise unable, through physical disability, to hold or manipulate a book or to focus or move the eyes to the extent that would be normally acceptable for reading; regardless of any other disabilities.¹⁰

While the scope of beneficiary disabilities in the *Marrakesh Treaty* extends protection to many well-established disability categories, concerningly, it fails to extend protection to many impairment categories which have historically been recognised as print-disabled.

It is troubling that the scope of beneficiary disabilities in the *Marrakesh Treaty* does not include people who have long been recognised as being people with print disabilities. The scope of print disability in the *Marrakesh Treaty* is limited to sensory and physical impairments. This excludes all persons with print disabilities related to cognitive impairments. Cognitive disabilities include impairments categorised as intellectual and developmental disabilities; acquired and traumatic brain injury, autism, learning and reading disabilities; and attention, perceptual, memory and communication-processing limitations.¹¹ Many of these impairments are associated with reading difficulties. Copyright exemptions, discussed in Chapter 5 of this monograph, extend exemptions for the print-disabled to impairments relating to comprehension. Moreover, it is widely accepted in scholarship and in the disability community that print disabilities include people experiencing disabilities that impact on their capacity to consume standard

Works for the Blind, Visually Impaired and Print Disabled’ (2014) 36(10) *European Intellectual Property Review* 653, 655.

¹⁰ *Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print Disabled* (*Marrakesh Treaty*), opened for signature 28 June 2013, WIPO Doc. VIP/DC/8 (not yet in force), art. 3.

¹¹ Peter Blanck, *E-Quality: The Struggle for Web Accessibility by Persons with Cognitive Disabilities* (2014) Cambridge University Press, 27; Tom Campbell, *Dyslexia: The Government of Reading* (2013) Palgrave Macmillan, 105–40.

books.¹² A person with dyslexia, for example, may use a screen reader which reads the content of the screen to them in the same way as a person who is blind. Arguably, it should not be relevant whether the person has a cognitive or physical disability, but whether their impairment prevents them consuming standard print content. The leading authority on the human rights of persons with disabilities, the *CRPD* discussed in Chapter 2 of this monograph, does not define print disability, and encourages an inclusive approach to protecting the rights of persons with disabilities. Accordingly, this monograph regards all impairments that restrict consumption of print as print disabilities, regardless of whether the impairment is categorised as sensory, physical or cognitive.

HOW DO THE PRINT-DISABLED CONSUME DIGITAL CONTENT?

As a group, persons with print disabilities consume information differently from those without any impairments. In addition, persons with print disabilities may consume content differently from each other, depending on their attributes. Technology can be used to enable persons with various disabilities to communicate and consume content to enable them to exercise their rights.¹³ To enhance social inclusion, hardware and software are increasingly including universal design features so that disability-specific technology is not required.¹⁴ In addition to universally designed products, persons with print disabilities may utilise adaptive technology to consume content. Examples include:

¹² See, for example, Learning Ally, which was founded in 1948 as Recording for the Blind & Dyslexic: <www.learningally.org> (accessed 18 November 2016); for examples discussed in the author's other works: Paul Harpur and Nicolas Suzor, 'The Paradigm Shift in Realising the Right to Read: How E-Book Libraries Are Enabling in the University Sector' (2014) 29(10) *Disability and Society* 1658; Paul Harpur, 'Ensuring Equality in Education: How Australian Laws Are Leaving Students with Print Disabilities Behind' (2010) 15(1) *Media and Arts Law Review* 70; Nicolas Suzor, Paul Harpur and Dylan Thampapillai, 'Digital Copyright and Disability Discrimination: From Braille Books to Bookshare' (2008) 13(1) *Media and Arts Law Review* 1.

¹³ Piers Gooding, Anna Arstein-Kerslake and Eilionoir Flynn, 'Assistive Technology as Support for the Exercise of Legal Capacity' (2015) 29(2/3) *International Review of Law Computers & Technology* 245.

¹⁴ Janet E Lord, 'Accessible ICTs and the Opening of Political Space for Persons with Disabilities' in Michael Stein and Jonathan Lazar (eds), *Frontiers in Human Rights: Disability Rights, Law, and Technology Accessibility* (forthcoming) University of Pennsylvania Press; Emily J Steel and Gunnel Janeslätt, 'Drafting Standards on Cognitive Accessibility: A Global Collaboration' (2016) *Disability and Rehabilitation: Assistive Technology* (published online 13 June).

1. For the vision-impaired and the blind – screen readers that provide an audio description of the text content (but not images or complex graphs) of computer screens, and screen magnification, which enables people with low vision to read content;¹⁵
2. For persons unable to physically handle books, such as people with quadriplegia or tetraplegia, robotic devices which enable movement and use of computers;¹⁶
3. For people with cognitive impairments, the inclusion of images and multimedia that can aid understanding, as well as screen readers that assist users with low vision.¹⁷

While such technologies enable people with print disabilities to consume digital content, disability adaptive technologies can be prohibitively expensive and may not work on certain devices.¹⁸ Even where persons with disabilities can utilise adaptive technologies or universally designed products, not all E-Books or E-Libraries are in accessible formats, and many books remain solely in standard formats printed on paper. This denial of the right to read is why there is said to be a book famine.

THE BOOK FAMINE CONFRONTING THE PRINT-DISABLED

Chapter 1 of this monograph will illustrate how technological advances created the possibility that persons with print disabilities could enjoy reading equality for the first time in human history. Rather than enjoying reading equality, however, the denial of reading equality has been labelled a ‘book famine’.¹⁹ While this language may appear overly emotive, the adoption of such language has wide support and was not challenged to any notable degree

¹⁵ Marion Hersch and Michael A Johnson (eds), *Assistive Technology for Visually Impaired and Blind People* (2010) Springer Science and Business Media.

¹⁶ Michel Busnel et al., ‘The Robotized Workstation “MASTER” for Users with Tetraplegia: Description and Evaluation’ (1999) 36(3) *Journal of Rehabilitation Research and Development* 217; R Platts and M Fraser, ‘Assistive Technology in the Rehabilitation of Patients with High Spinal Cord Lesions’ (1993) 31(5) *Spinal Cord* 280.

¹⁷ Blanck, *E-Quality*, 173.

¹⁸ Delia Ferri, G Anthony Giannoumis and Charles Edward O’Sullivan, ‘Fostering Accessible Technology and Sculpting an Inclusive Market through Regulation’ (2015) 29(2/3) *International Review of Law Computers & Technology* 81; Greg Vanderheiden, Jutta Treviranus and Amrisha Chourasia, ‘The Global Public Inclusive Infrastructure (GPII)’ (Proceedings of the 15th International ACM SIGACCESS Conference on Computers and Accessibility, ACM, 2013).

¹⁹ Brian Watermeyer, ‘Freedom to Read: A Personal Account of the “Book Famine”’ (2014) 3(1) *African Journal of Disability* 144.

by the copyright lobby in the recent debates in the World Intellectual Property Organization which resulted in the adoption of the *Marrakesh Treaty*.²⁰

There are over 129 million book titles in the world,²¹ but persons with print disabilities in wealthy developed countries can obtain less than 5 to 7 per cent of these titles in formats that they can consume.²² The situation in emerging and majority world countries is even grimmer. For example, in India, one of the world's strongest emerging economies, only 0.5 per cent of published books are converted into formats that persons with print disabilities can access.²³ Even if books in accessible formats are available, people who are socio-economically disadvantaged encounter additional barriers in accessing the written word.²⁴

²⁰ Lior Zemer and Aviv Gaon, 'Copyright, Disability and Social Inclusion: The Marrakesh Treaty and the Role of Non-Signatories' (2015) 10(11) *Journal of Intellectual Property Law & Practice* 836.

²¹ This figure was reported by a Google engineer as part of the Google Books project. See Leonid Taycher, 'Books of the World, Stand Up and Be Counted! All 129,864,880 of You' on *Booksearch Blogspot* (5 August 2010) <booksearch.blogspot.com.au/2010/08/books-of-world-stand-up-and-be-counted.html> (accessed 18 November 2016).

²² Brook Baker, 'Challenges Facing a Proposed WIPO Treaty for Persons Who Are Blind or Print Disabled' (Research Paper No. 142, Northeastern University School of Law, 21 May 2013); Paul Harpur and Nicolas Suzor, 'Copyright Protections and Disability Rights: Turning the Page to a New International Paradigm' (2013) 36(3) *University of New South Wales Law Journal* 745; World Blind Union, 'June 17 Press Release for WIPO Book Treaty' (17 June 2013) <www.worldblindunion.org/English/news/Pages/JUNE-17-Press-Release-for-WIPO-Book-Treaty.aspx> (accessed 18 November 2016).

²³ Patrick Hely, 'A Model Copyright Exemption to Serve the Visually Impaired: An Alternative to the Treaty Proposals before WIPO' (2010) 43 *Vanderbilt Journal of Transnational Law* 1369, 1375.

²⁴ Lea Shaver, 'Copyright and Inequality' (2014) 92 *Washington University Law Review* 117, 127–8.