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# **Addressing Health Inequalities for People with Learning Disabilities in NHS England through Legal Reform**

Selen Rana Shah, LL.B. (Hons)

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## Abstract

This thesis examines the health inequalities experienced by people with learning disabilities in NHS England and considers legal reforms to address these disparities. It builds on a body of reports in England demonstrating that people with learning disabilities have shorter life expectancies and are more likely to die from avoidable causes, with these outcomes linked to poor quality health and social care provision. The thesis argues that the current equality framework under the Equality Act 2010 is inadequate to address these inequalities. In particular, it contends that the framework remains grounded in a predominantly medicalised conception of disability and fails to reflect a substantive equality model.

In examining this issue, the thesis adopts a doctrinal and theoretical approach to analyse the current equality framework in England, drawing on theoretical frameworks of disability and equality. It draws upon interdisciplinary sources, including medical research, public health data, qualitative research, reports by disability organisations, and public inquiries documenting the experiences of people with learning disabilities and their families when accessing healthcare.

The thesis proposes three key reforms. First, it recommends replacing the current definition of disability in the Equality Act 2010 with the definitions of ‘disability’ and ‘persons with disabilities’ under the United Nations Convention on the Rights of Persons with Disabilities. This proposal is grounded in the Convention’s human rights-based approach, which recognises persons with disabilities as rights-holders entitled to the full and equal enjoyment of fundamental human rights. Second, the thesis advocates for embedding the rights and obligations guaranteed by the Convention into healthcare law and policy, thereby ensuring that the fundamental human rights of patients with learning disabilities are effectively realised in practice. Third, it calls for improved implementation of the reasonable adjustments duty under the Equality Act 2010 across health and care services within NHS England.

These reforms aim to reduce the health inequalities experienced by people with learning disabilities, particularly premature and avoidable deaths, while also improving access to and experiences of care. The recommendations, therefore, focus on developing a healthcare system that recognises and respects the inherent dignity and human rights of people with learning disabilities.

# Table of Contents

|                                                                          |      |
|--------------------------------------------------------------------------|------|
| ABSTRACT .....                                                           | II   |
| TABLE OF ABBREVIATIONS .....                                             | V    |
| TABLE OF CASES .....                                                     | VI   |
| TABLE OF LEGISLATION AND INTERNATIONAL INSTRUMENTS .....                 | VIII |
| ACKNOWLEDGEMENTS .....                                                   | X    |
| AUTHOR'S DECLARATION .....                                               | XI   |
| CHAPTER ONE: INTRODUCTION .....                                          | 1    |
| 1.1. OVERVIEW OF RESEARCH TOPIC.....                                     | 1    |
| 1.2. METHODOLOGY .....                                                   | 3    |
| 1.3. A NOTE ON LANGUAGE .....                                            | 4    |
| 1.4. ARGUMENT AND STRUCTURE .....                                        | 5    |
| CHAPTER TWO: HEALTHCARE IN ENGLAND .....                                 | 8    |
| 2.1. INTRODUCTION .....                                                  | 8    |
| 2.2. THE HISTORY OF THE NATIONAL HEALTH SERVICE .....                    | 9    |
| 2.2.1. <i>Healthcare Before the NHS</i> .....                            | 9    |
| 2.2.2. <i>The NHS Constitution</i> .....                                 | 11   |
| 2.2.3. <i>Issues of Scarcity</i> .....                                   | 12   |
| 2.3. HEALTH INEQUALITIES FOR PEOPLE WITH LEARNING DISABILITIES.....      | 14   |
| 2.3.1. <i>Treat Me Right!</i> .....                                      | 14   |
| 2.3.2. <i>Death by Indifference</i> .....                                | 14   |
| 2.3.3. <i>The Progress Report</i> .....                                  | 15   |
| 2.4. CONNOR SPARROWHAWK .....                                            | 16   |
| 2.4.1. <i>Connor's Death</i> .....                                       | 16   |
| 2.4.2. <i>Post-Death Investigation</i> .....                             | 17   |
| 2.4.3. <i>The Justice for Laughing Boy Campaign</i> .....                | 18   |
| 2.4.4. <i>Following on from Connor's Death</i> .....                     | 19   |
| 2.5. CURRENT HEALTH INEQUALITIES .....                                   | 21   |
| 2.6. CONCLUSION .....                                                    | 22   |
| CHAPTER THREE: THE LEGAL FRAMEWORK.....                                  | 24   |
| 3.1. INTRODUCTION .....                                                  | 24   |
| 3.2. THE EQUALITY ACT 2010: INTRODUCTION AND BACKGROUND .....            | 25   |
| 3.2.1. <i>Recognition of Disability Discrimination</i> .....             | 25   |
| 3.2.2. <i>The Development of the Equality Act 2010</i> .....             | 26   |
| 3.2.3. <i>The Impact of Harmonisation</i> .....                          | 28   |
| 3.2.4. <i>Structure of the Equality Act 2010</i> .....                   | 29   |
| 3.3. PROTECTED CHARACTERISTIC OF DISABILITY.....                         | 30   |
| 3.3.1. <i>Asymmetric Protection of Disability</i> .....                  | 30   |
| 3.3.2. <i>Definition of Disability Under the Equality Act 2010</i> ..... | 31   |
| 3.4. PROHIBITED CONDUCT.....                                             | 33   |
| 3.4.1. <i>Section 13 Direct Discrimination</i> .....                     | 33   |
| 3.4.2. <i>Section 19 Indirect Discrimination</i> .....                   | 35   |

|                                                                                                                |           |
|----------------------------------------------------------------------------------------------------------------|-----------|
| 3.4.3. Section 15 Discrimination Arising from Disability.....                                                  | 37        |
| 3.5. MODELS OF EQUALITY LAW .....                                                                              | 41        |
| 3.5.1. Formal Equality.....                                                                                    | 41        |
| 3.5.2. Substantive Equality .....                                                                              | 42        |
| 3.6. CONCLUSION .....                                                                                          | 46        |
| <b>CHAPTER FOUR: A HUMAN RIGHTS APPROACH TO DISABILITY .....</b>                                               | <b>48</b> |
| 4.1. INTRODUCTION.....                                                                                         | 48        |
| 4.2. SOCIAL AND MEDICAL MODEL OF DISABILITY .....                                                              | 49        |
| 4.2.1. The Medical Model .....                                                                                 | 49        |
| 4.2.2. The Social Model.....                                                                                   | 51        |
| 4.2.3. Criticisms of the Social Model .....                                                                    | 52        |
| 4.2.4. Significance of the Medical and Social Model .....                                                      | 54        |
| 4.2.5. An Emerging Human Rights Model of Disability .....                                                      | 55        |
| 4.3. THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES .....                            | 56        |
| 4.3.1. The Human Rights Model Under the CRPD .....                                                             | 56        |
| 4.3.2. The (Non-)Definition of Disability.....                                                                 | 58        |
| 4.3.3. Recommendation One: Adopt the CRPD Definition of Disability.....                                        | 61        |
| 4.4. RIGHTS AND OBLIGATIONS UNDER THE CRPD .....                                                               | 62        |
| 4.4.1. CRPD Rights and Obligations in Healthcare .....                                                         | 63        |
| 4.4.2. Recommendation Two: Implementation of the CRPD Rights and Obligations into the UK Legal Framework ..... | 68        |
| 4.5. CONCLUSION .....                                                                                          | 69        |
| <b>CHAPTER FIVE: THE DUTY TO MAKE REASONABLE ADJUSTMENTS.....</b>                                              | <b>71</b> |
| 5.1. INTRODUCTION.....                                                                                         | 71        |
| 5.2. THE DUTY TO MAKE REASONABLE ADJUSTMENTS .....                                                             | 71        |
| 5.3. REASONABLE ACCOMMODATION UNDER THE CRPD .....                                                             | 75        |
| 5.4. UNDERUSE OF REASONABLE ADJUSTMENTS IN HEALTHCARE .....                                                    | 76        |
| 5.5. RECOMMENDATION THREE: IMPROVE ACCESS TO REASONABLE ADJUSTMENTS .....                                      | 78        |
| 5.5.1. Individual-Level Changes .....                                                                          | 78        |
| 5.5.2. System-level Implementation.....                                                                        | 81        |
| 5.6. SCARCITY AND REASONABLE ADJUSTMENTS .....                                                                 | 83        |
| 5.7. CONCLUSION .....                                                                                          | 84        |
| <b>CHAPTER SIX: CONCLUSION.....</b>                                                                            | <b>86</b> |
| 6.1. CONTRIBUTION.....                                                                                         | 86        |
| 6.2. THE FUTURE.....                                                                                           | 89        |
| <b>BIBLIOGRAPHY .....</b>                                                                                      | <b>91</b> |

## Table of Abbreviations

|                     |                                                                                 |
|---------------------|---------------------------------------------------------------------------------|
| CIPOLD              | Confidential Inquiry into Premature Deaths of People with Learning Disabilities |
| CLJ                 | Cambridge Law Journal                                                           |
| CRPD                | Convention on the Rights of Persons with Disabilities                           |
| DDA 1995            | Disability Discrimination Act 1995                                              |
| DRC                 | Disability Rights Commission                                                    |
| EAT                 | Employment Appeal Tribunal                                                      |
| EqA 2010 or the Act | Equality Act 2010                                                               |
| ICON                | International Journal of Constitutional Law                                     |
| IJDL                | International Journal of Discrimination and the Law                             |
| IJHR                | International Journal of Human Rights                                           |
| ILJ                 | Industrial Law Journal                                                          |
| JAN                 | Journal of Advanced Nursing                                                     |
| LeDeR               | Learning Disabilities Mortality Review                                          |
| MCA                 | Mental Capacity Act 2005                                                        |
| MLR                 | Modern Law Review                                                               |
| NHS                 | National Health Service                                                         |
| PCP                 | Provision, Criterion, or Practice                                               |
| UK                  | United Kingdom                                                                  |
| UN                  | United Nations                                                                  |

## Table of Cases

### United Kingdom Cases

A Ltd v Z UKEAT/0273/18/BA; [2020] ICR 199

Banaszczyk v Booker Ltd UKEAT/0132/15/RN; [2016] IRLR 273

City of York Council v Grosset [2018] EWCA Civ 1105; [2018] 4 All ER 77

Fareham College Corporation v Walters [2009] IRLR 991

Hewage v Grampian Health Board [2012] UKSC 37; [2012] 4 All ER 447

Homer v Chief Constable of West Yorkshire [2012] UKSC 15; [2012] 3 All ER 1287

James v Eastleigh Borough Council [1990] 2 AC 751 (HL)

London Borough of Lewisham v Malcolm [2008] UKHL 45; [2008] 1 AC 1399.

McNicol v Balfour Beatty Rail Maintenance Ltd [2002] EWCA Civ 1074; [2002] ICR 1498

Nagarajan v London Regional Transport [2000] 1 AC 501 (HL)

Paterson v Commissioner of Police of the Metropolis UKEAT/0635/06; [2007] IRLR 763

R (on the application of E) v Governing Body of JFS and the Admissions Appeal Panel of JFS and others [2009] UKSC 15; [2010] 2 AC 728

R (on the application of Elias) v Secretary of State for Defence [2006] EWCA Civ 1293; [2006] 1 WLR 3213

R v Birmingham City Council ex p Equal Opportunities Commission [1989] AC 1155 (HL)

R v Secretary of State for Employment ex parte Equal Opportunities Commission [1994] UKHL 2; [1995] 1 AC 1

Shamoon v Chief Constable of the Royal Ulster Constabulary [2003] UKHL 11; [2003] 2 All ER 26

Sheikholeslami v University of Edinburgh [2018] UKEAT/0014/17/0510, [2018] IRLR 1090

Sheikholeslami v University of Edinburgh UKEATS/0014/17/JW; [2018] IRLR 1090

Williams v Trustees of Swansea University Pension and Assurance Scheme [2018] UKSC 65; [2019] 2 All ER 1031

### **European Union**

Coleman v Attridge Law (C-303/06) [2008] ECR I-5603

## **Table of Legislation and International Instruments**

### **Statutes**

Disability Discrimination Act 1995

Disability Discrimination Act 2005

Disabled Persons (Employment) Act 1944

Equality Act 2010

Mental Capacity Act 2005

Mental Health Act 1983

Special Educational Needs and Disability Act 2001

### **Statutory Instruments**

Equality Act 2010 (Disability) Regulations 2010

### **European Union**

Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation [2000] OJ L 303/16

### **Table of International Instruments**

Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) UNGA Res 61/106, Annex I

Optional Protocol to the Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) UNGA Res 61/106, Annex II

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Finally, I would like to express my gratitude to my friends and parents for their endless support throughout this journey.

## **Author's Declaration**

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Printed Name: Selen Shah

Signature:

## Chapter One: Introduction

### 1.1. Overview of Research Topic

People with learning disabilities in England have been reported to die, on average, up to 20 years earlier than those without learning disabilities, with a significant proportion of these deaths attributed to avoidable causes.<sup>1</sup> Studies have shown that many of these deaths arise not from a lack of preventative measures but as a result of poor healthcare.<sup>2</sup> Contributing factors include difficulties and delays in diagnosis, a lack of reasonable adjustments, and failures by healthcare professionals to identify patients with learning disabilities.<sup>3</sup> Diagnostic overshadowing is a key cause of premature and avoidable deaths in people with learning disabilities. This occurs when healthcare professionals attribute someone's symptoms of poor health to their learning disability, without exploring other physical or mental health causes.<sup>4</sup> Although there have been some improvements in recent years in reducing premature and avoidable deaths among people with learning disabilities, a significant disparity in health outcomes compared with the general population in England persists.<sup>5</sup>

Notwithstanding this, the health inequalities experienced by people with learning disabilities within NHS England are a largely under-researched area in the legal scholarship. The thesis seeks to address this gap by bringing together theoretical frameworks of disability and equality with doctrinal analysis of equality law in England, alongside interdisciplinary sources that reflect the lived experiences of people with learning disabilities. These include existing empirical research, such as qualitative studies, reports published by disability charities, public inquiries, mortality review reports, and investigations into avoidable deaths. In particular, it draws on medical research conducted

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<sup>1</sup> Adam White and others, 'Learning from Lives and Deaths: People with a Learning Disability and Autistic People (LeDeR) Report for 2023' (King's College London 2023, updated January 2026) <<https://www.kcl.ac.uk/ioppn/assets/pdfs/leder/2023-final-updated.pdf>> accessed 09 April 2026, 7.

<sup>2</sup> Pauline Heslop and others, 'Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD): Final Report' (Norah Fry Research Centre, 2013) <<https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>> accessed 15 February 2025.

<sup>3</sup> See Women and Equalities Committee, *Inequalities in Healthcare and Employment for People with a Learning Disability and Autistic People* (HC 2023–24, 134) para 8.

<sup>4</sup> Eric Emerson and others, 'Health Inequalities and People with Learning Disabilities in the UK' (Learning Disabilities Observatory 2011) <[https://pureportal.strath.ac.uk/files-asset/7402206/vid\\_7479\\_IHaL2010\\_3HealthInequality2010.pdf](https://pureportal.strath.ac.uk/files-asset/7402206/vid_7479_IHaL2010_3HealthInequality2010.pdf)> accessed 13 February 2025, 9.

<sup>5</sup> White and others (n 1) 7.

in hospitals and care settings within NHS England to inform the legal analysis and the recommendations advanced. It is hoped that the discussions in the thesis will contribute to and stimulate further legal scholarship in this area.

For the purposes of this thesis, a distinction is drawn between health and healthcare. Health refers to the overall physical and mental wellbeing and health outcomes experienced by people with learning disabilities. This includes inequalities such as premature mortality, avoidable deaths, and unmet health needs. Although health inequalities arise from a wide range of social, economic, and environmental factors, this thesis focuses on those created by inadequate healthcare provision. As such, healthcare refers to the organisation and delivery of health services within NHS England. This includes access to diagnosis, treatment, reasonable adjustments, and the overall quality of care provided. Accordingly, references to improving health within this thesis should be understood as improving health through legal reform of healthcare services.

The primary objective of this thesis is twofold: (i) to examine the challenges experienced by people with learning disabilities in accessing health and social care services within NHS England; and (ii) to use these findings to develop recommendations for reforming the equality framework to address and reduce these inequalities.

The jurisdictional focus of the thesis is England and its public healthcare system, the National Health Service England (hereafter, NHS England). This focus is justified on two grounds. First, health and social care provision within the UK is devolved, with each administration operating independently of Westminster. Second, the most comprehensive data and reporting on avoidable deaths and substandard healthcare affecting people with learning disabilities are derived from NHS England.<sup>6</sup> While similar issues are likely to arise across the devolved administrations, the relative lack of comparable data limits the ability to conduct a sufficiently comprehensive analysis beyond England. Nevertheless, as equality law remains largely reserved to the UK Parliament, many of the legal recommendations advanced in this thesis will have broader applicability across Great Britain.<sup>7</sup> It should, however, be noted that the Equality Act 2010 (hereafter, 'EqA 2010' or

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<sup>6</sup> E.g., University of Bristol, 'The Learning Disabilities Mortality Review (LeDeR) programme at the University of Bristol 2015-2021' <<https://www.bristol.ac.uk/sps/leder/uob-2015-21/>> accessed 16 February 2025.

<sup>7</sup> Doug Pyper and Allwell Uwazuruike, 'A Short Introduction to Equality Law and Policy' (House of Commons Library 2024) <<https://researchbriefings.files.parliament.uk/documents/CBP-9448/CBP-9448.pdf>> accessed 20 April 2026.

‘the Act’) does not extend to Northern Ireland, which operates under a distinct equality law framework.

## **1.2. Methodology**

The thesis combines a doctrinal analysis of the law with theoretical frameworks of disability and equality. It relies on primary legal sources, including the Equality Act 2010 and the Convention on the Rights of Persons with Disabilities, to evaluate the current legal framework governing disability equality in the UK. This legal analysis is informed by the medical, social, and human rights models of disability, together with the concepts of formal and substantive equality. These theoretical perspectives provide the analytical framework through which the adequacy of the current legal framework and the proposed legal reforms are assessed.

This analysis is supported by secondary sources that evidence experiences of inequality and discrimination in the UK when accessing healthcare in primary and secondary care settings. These sources include reports published by civil society organisations such as Mencap, together with public inquiries, mortality review reports, and qualitative research documenting the experiences of people with learning disabilities and their families. In addition, the thesis draws upon medical research and reports published by civil society organisations that examine the experiences of people with learning disabilities when accessing healthcare through NHS England.

By integrating legal analysis with interdisciplinary evidence, the thesis provides an original contribution to this developing area of legal scholarship. These interdisciplinary sources provide the practical context for assessing the effectiveness of the current legal framework and demonstrate the challenges faced by people with learning disabilities when accessing medical care through NHS England. Integrating legal analysis with interdisciplinary evidence enables the thesis to develop recommendations for legal reform that respond to the realities of healthcare provision and the health inequalities experienced by people with learning disabilities when accessing medical care.

### 1.3. A Note on Language

The definition of learning disability most commonly used in the UK is taken from the Department of Health's government white paper on health and social care for people with learning disabilities, *Valuing People*.<sup>8</sup> It defines learning disability as including the presence of:

*A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;*

*A reduced ability to cope independently (impaired social functioning);*

*which started before adulthood, with a lasting effect on development.*<sup>9</sup>

The definition encompasses people with a broad range of disabilities, taking into account assessments of social functioning and communication skills when determining need.<sup>10</sup>

There has also been a longstanding debate regarding the use of person-first versus identity-first language in the study of disability. In other words, whether it is more acceptable to describe somebody as a 'disabled person' or a 'person with a disability'. It has been argued that person-first language is a better approach, recognising that persons with disabilities are foremost people.<sup>11</sup> Conversely, identity-first language is preferred by some on the basis that it recognises disability as an integral aspect of identity and challenges the implication that disability is inherently negative.<sup>12</sup> As there is no consensus on this area, the thesis will use the approach recommended by Dunn and Andrews, using both forms interchangeably.<sup>13</sup> This is in view of the fact that language is context-dependent

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<sup>8</sup> Secretary of State for Health, *A New Strategy for Learning Disability for the 21<sup>st</sup> Century* (Cm 2086, 2001).

<sup>9</sup> *ibid* para 1.5.

<sup>10</sup> *ibid* para 1.6.

<sup>11</sup> See Dana Dunn and Erin Andrews, 'Person-First and Identity-First Language: Developing Psychologists' Cultural Competence Using Disability Language' (2015) 70 *American Psychologist* 255.

<sup>12</sup> *ibid*.

<sup>13</sup> *ibid*.

and shaped by individual and community preferences. Using both approaches recognises the diversity and complexity of how disability is experienced and understood.<sup>14</sup>

#### 1.4. Argument and Structure

Chapter Two will focus on two key themes. It begins by examining the historical development of the NHS and the contemporary challenges it faces. The NHS was established with the aim of providing equal healthcare to all, and this remains a central objective.<sup>15</sup> However, resource constraints, driven by increased life expectancy and population growth in England, have shaped healthcare provision. Namely, the NHS must now balance healthcare provision with increasing financial pressure. These challenges will be important considerations for the recommendations that follow, which must be responsive to the financial realities shaping NHS England.

Second, notwithstanding the NHS's aim to provide equal services, there has been, and continues to be, inequality in the provision of healthcare services for people with learning disabilities. This chapter draws on national reports, qualitative research, mortality review reports, disability organisation reports, and public inquiries documenting the experiences of people with learning disabilities to demonstrate that significant health inequalities persist within NHS England, particularly in the form of premature mortality and avoidable deaths. Furthermore, it will use the case of Connor Sparrowhawk, a person with learning disabilities who died in NHS care, and the subsequent investigations that followed his death, to illustrate systemic failures in care for people with learning disabilities. Together, this evidence establishes the need for legal and structural reform in health and care services to improve health outcomes for people with learning disabilities.

Chapter Three sets out the legal framework governing equality law in England. This chapter has three aims. First, it situates the EqA 2010 within the broader historical development of anti-discrimination law in the UK, demonstrating a shift from a welfare approach to a rights-based framework. It also considers the critique that the harmonisation

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<sup>14</sup> *ibid.*

<sup>15</sup> Charles Webster, *The National Health Service: A Political History* (2<sup>nd</sup> edn, OUP 2002); Department of Health and Social Care, 'The NHS Constitution for England' (8 March 2012, updated 17 August 2023) <<https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>> accessed 20 February 2025.

of equality law into a single statute has led to a loss of focus on disability and the ways in which disability discrimination is different to the other forms of discrimination. This critique informs a central objective of the recommendations advanced in Chapters Four and Five: to ensure that the distinct experiences of disability are adequately reflected in the provision of healthcare services in NHS England.

Second, Chapter Three will provide an overview of the legal framework, with a focus on disability. It examines the statutory definition of disability under Section 6 of the EqA 2010, highlighting its emphasis on impairment and functional limitation. It then analyses key forms of prohibited conduct under the Act, including direct discrimination, indirect discrimination, and discrimination arising from disability. It argues that Section 15 represents a significant development by removing the requirement for a comparator, thereby recognising that disabled people may require different treatment to achieve equal outcomes.

Finally, Chapter Three explores the theoretical foundations of equality law, focusing on the distinction between formal and substantive equality. It argues that a formal equality approach, treating people alike, is insufficient to address the disadvantage experienced by disabled people, who oftentimes require different treatment to experience equal outcomes. As such, a substantive equality approach is better suited to addressing the multidimensional disadvantage experienced by people with disabilities.

Having contextualised the health inequalities experienced by people with learning disabilities within NHS England and the current equality law framework, Chapter Four advances recommendations to address these inequalities. It begins by examining the medical and social models of disability. It argues that the statutory definition of disability under Section 6 of the EqA 2010 reflects an overly medicalised understanding of disability, focusing on individual impairment rather than social and environmental barriers to full and effective participation in society.

The chapter then considers the social model, which conceptualises disability as arising from societal and attitudinal barriers. However, it acknowledges criticisms that this model may overlook the lived experience of impairment. To address this limitation, the chapter introduces the human rights model of disability, which emphasises autonomy, dignity, and the status of disabled people as rights-holders.

Building on this discussion of the different models of equality, the thesis argues that the British equality framework should adopt a human rights-based definition of disability. Accordingly, the first recommendation is to adopt the definition of disability contained in the United Nations Convention on the Rights of Persons with Disabilities (hereafter, ‘CRPD’ or ‘the Convention’). The Convention takes a human rights approach to disability by recognising that disabled people enjoy ‘full and equal enjoyment of all human rights and fundamental freedoms’.<sup>16</sup> Furthermore, the definition of disability under the Convention acknowledges that ‘disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder full and effective participation in society’.<sup>17</sup>

Building on this argument, the second recommendation calls for the effective implementation of the fundamental rights and obligations set out in the Convention within healthcare policy and practice. In particular, the right to life, liberty and security of the person, protecting the integrity of the person, equal recognition before the law, and health should be reflected in NHS England.<sup>18</sup>

Finally, Chapter Five focuses on the duty to make reasonable adjustments. It argues that, while this duty has significant potential to improve healthcare provision for people with learning disabilities, it is not consistently or effectively implemented in practice within NHS England. Accordingly, the third and final recommendation is to ensure effective implementation of the reasonable adjustments duty in health and social care services across NHS England. Drawing on medical research, the chapter proposes a series of reasonable adjustments to strengthen the application and effectiveness of this duty.

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<sup>16</sup> CRPD, art 1.

<sup>17</sup> CRPD, recital (e).

<sup>18</sup> CRPD, art 10, art 14, art 17, art 12, art 25.

## Chapter Two: Healthcare in England

### 2.1. Introduction

Before considering recommendations to reduce health inequalities for people with learning disabilities, this chapter aims to contextualise the nature and extent of health inequalities experienced by people with learning disabilities in England, situating these within the broader challenges facing the NHS. The chapter is structured around two key themes. First, a central rationale for establishing the NHS was to ensure equal provision of healthcare services for all, and this remains to be a core aim of the NHS. Second, notwithstanding this aim, there has been, and continues to be, inequality in the provision of healthcare services for patients with learning disabilities.

To understand the contemporary challenges facing the NHS, it is necessary first to consider its historical foundations. Prior to its establishment, healthcare provision in the UK was marked by significant inequalities, with varying quality of care across the country. The creation of the NHS sought to address these disparities by ensuring equal provision of healthcare services for all. This aim continues to be reflected in the NHS Constitution today. However, the NHS now operates within a context of resource scarcity driven by rising life expectancies and population growth. These challenges provide essential context for understanding the barriers to improving healthcare services for people with learning disabilities in England.

This chapter then draws on reports and research highlighting institutional discrimination and health inequalities experienced by people with learning disabilities in the NHS. Against this backdrop, the Justice for Laughing Boy campaign offers a particularly significant example of these health inequalities. Emerging from the death of an 18-year-old boy with epilepsy and learning disabilities in an NHS care unit, the campaign drew widespread attention to the inequalities experienced by people with learning disabilities in health and care services. Importantly, it led to the establishment of the Learning Disabilities Mortality Review (hereafter, LeDeR) programme, the first systematic initiative in England to review the deaths of people with learning disabilities. However, despite increased awareness following Connor Sparrowhawk's death, substantial inequalities persist, most notably in the form of premature mortality relative to the general population. The persistence of these inequalities demonstrates the need for legal reform in this area.

## 2.2. The history of the National Health Service

### 2.2.1. Healthcare Before the NHS

The creation of the NHS occurred over about half a century of campaign work and developments in universal state healthcare.<sup>19</sup> Before the inception of the NHS, medical services in the UK during the interwar years were made up of municipal, voluntary, and patient initiatives.<sup>20</sup>

Under the National Insurance Act 1911, millions of people in the UK gained access to General Practitioner (GP) services through a ‘panel’ system. Under the system, if a worker earned less than £250 a year, their visit to the GP was free, paid for by a national fund based on contributions from individuals and the State.<sup>21</sup> However, the panel system was heavily criticised. Reliance on panel doctors often carried stigma, with some GP surgeries providing separate waiting rooms for panel patients. Many working-class patients complained that the care they received was inferior to that of private patients.<sup>22</sup> Moreover, national health insurance often did not apply to women, who were less likely to be economically active, and excluded all children.<sup>23</sup> Therefore, healthcare in Britain relied on a ‘breadwinner’ model of welfare grounded in patriarchal gender roles, leaving many women and children without access to healthcare.<sup>24</sup>

Access to secondary care during the interwar period was provided in municipal and voluntary hospitals. Municipal hospitals were funded and managed by local governments, while voluntary hospitals were independent and funded through charitable fundraising.<sup>25</sup> This resulted in inconsistent standards of healthcare across the UK, as municipal and voluntary hospitals operated without coordinated management.<sup>26</sup>

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<sup>19</sup> Andrew Seaton, *Our NHS: A History of Britain's Best loved Institution* (Yale University Press 2023) 23.

<sup>20</sup> *ibid* 25.

<sup>21</sup> *ibid*.

<sup>22</sup> *ibid* 26.

<sup>23</sup> Geoffrey Rivett, *From Cradle to Grave: Fifty years of the NHS* (King's Fund 1998) 1.

<sup>24</sup> Jane Lewis, ‘The Decline of the Male Breadwinner Model: Implications for Work and Care’ (2001) 8 *Social Politics* 152, 154–155.

<sup>25</sup> Rivett (n 23) 7–9.

<sup>26</sup> *ibid*.

Throughout the early twentieth century, calls grew for a government-administered, centrally coordinated healthcare system. In 1930, the Socialist Medical Association was established to campaign within the Labour Party for a state-run, free-at-the-point-of-access medical service.<sup>27</sup> By 1934, the Labour Party had formally committed to the creation of a unified ‘State Medical Service’.<sup>28</sup>

The publication of the *Social Insurance and Allied Services Report* by economist William Beveridge intensified debate in favour of a unified healthcare system.<sup>29</sup> The report recommended the creation of a national health service as part of a broader programme of social reform.<sup>30</sup> It was positively received by the British public and helped to accelerate discussions on establishing a comprehensive health service in the UK.<sup>31</sup>

Following the election of the Labour government in the immediate postwar period, Aneurin Bevan was appointed Minister for Health. The question of whether to nationalise municipal and voluntary hospitals proved highly contentious, with many members of the public and the Labour Party defending their independence.<sup>32</sup> Despite these initial disputes, Prime Minister Clement Attlee ultimately supported Bevan’s position in favour of nationalisation. As a result, in 1946, Labour passed the National Health Service Act.<sup>33</sup>

To summarise, before the establishment of the NHS, healthcare in the UK was fragmented, with significant inequalities in access and quality. The creation of a nationalised health service sought to address these shortcomings by unifying healthcare services and promoting equitable access. Accordingly, one of the central aims of the NHS was to create a cohesive system that ensured fair access to care. This is particularly significant for people with learning disabilities, who often depend on multiple services across community and hospital settings. Achieving equitable access for this group requires effective coordination between different services. This thesis returns to the issue of

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<sup>27</sup> John Stewart, *The Battle for Health: A Political History of the Socialist Medical Association, 1930–51* (Ashgate 1951) 4–5.

<sup>28</sup> Seaton (n 19) 34.

<sup>29</sup> William Beveridge, *Social Insurance and Allied Services* (Cmd 6404, 1942).

<sup>30</sup> Derek Fraser, *The Beveridge Report: Blueprint for the Welfare State* (Routledge 2023) 2.

<sup>31</sup> Pauline Gregg, *The Welfare State: An Economic and Social History of Great Britain from 1945 to the Present Day* (Harrap 1967) 19.

<sup>32</sup> Webster (n 15) 12–15.

<sup>33</sup> *ibid.*

integrated care systems in Chapter Five, examining how failures in integration can contribute to health inequalities.

### 2.2.2. The NHS Constitution

The NHS Constitution is a document that outlines the principles and values of the NHS in England. The Health Act 2009 requires the Secretary of State to review the NHS Constitution every 10 years, with the involvement of the public, patients, and staff.<sup>34</sup> The most recent version was published on 17 August 2023.<sup>35</sup>

The current NHS Constitution for England aims to balance service delivery with cost-effectiveness. The NHS aims to provide services to all based on clinical need, not a person's ability to pay. However, it is also committed to providing the best value for taxpayers' money.<sup>36</sup> In 1946, it was argued that healthcare costs would fall as the nation's health improved.<sup>37</sup> Today, with a larger population than in 1946, increased life expectancy, and a wider range of available treatments, there is a greater emphasis on managing limited resources effectively.<sup>38</sup>

Another important principle in the NHS Constitution is the provision of a comprehensive service available to all, irrespective of protected characteristics.<sup>39</sup> In particular, the Constitution elaborates that both physical and mental health problems should be treated with equal regard, that the NHS has a duty to respect the human rights of its patients, and that it has a broader social duty to promote equality through service provision.<sup>40</sup> The obligation to promote equality requires the NHS to 'pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population'.<sup>41</sup>

Accordingly, the NHS seeks to ensure that patients are treated equitably, thereby improving health outcomes for all groups in society. However, balancing this commitment to equality with the effective management of limited resources presents an ongoing

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<sup>34</sup> s 3(2)–(3).

<sup>35</sup> Department of Health and Social Care (n 15).

<sup>36</sup> *ibid.*

<sup>37</sup> Aneurin Bevan, *In Place of Fear* (Heinemann 1952).

<sup>38</sup> Jonathan Shapiro, 'The NHS: The Story so Far (1948–2010)' (2010) 10 *Clinical Medicine* 336.

<sup>39</sup> Department of Health and Social Care (n 15).

<sup>40</sup> *ibid.*

<sup>41</sup> *ibid.*

challenge.<sup>42</sup> This tension is especially relevant in the provision of care for people with learning disabilities, who may require additional support to achieve equitable health outcomes.

### 2.2.3. Issues of Scarcity

The modern-day NHS faces significant resource constraints that were not anticipated when the National Health Service Act was passed in 1946. In the early twentieth century, campaigners justified the creation of a national health service as a response to pressing challenges facing British society, namely a declining birth rate and the need to secure economic growth.<sup>43</sup>

It was thought at the time that providing the population with free healthcare would improve national health and, consequently, diminish demand for healthcare services.<sup>44</sup> However, the success of the NHS, alongside childhood immunisations and improvements in hygiene, has instead contributed to a dramatic increase in life expectancy since its inception.<sup>45</sup> In 1948, the average life expectancy in England and Wales was 65.9 years for men and 70.3 years for women.<sup>46</sup> Meanwhile, the projected life expectancy for boys born in 2023 is 86.7 years, and for girls, 90 years.<sup>47</sup> This means that, on average, life expectancies have increased by 20.8 years for men and 19.7 years for women.

Despite our success in extending life expectancies, this has also been accompanied by an increase in the period of time people spend in ‘not good’ health.<sup>48</sup> The Office for National Statistics defines healthy life expectancy as ‘a measure of the average number of years a person would expect to live in good health based on contemporary mortality rates

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<sup>42</sup> See NHS England, ‘Review of NHS Performance and Delivery’ (2025) <<https://www.england.nhs.uk/long-read/review-of-nhs-performance-and-delivery/>> accessed 7 April 2026, paras 1–12.

<sup>43</sup> Seaton (n 19) 23–24.

<sup>44</sup> Emily Jackson, *Medical Law: Text, Cases and Materials* (6<sup>th</sup> edn, OUP 2022) 39.

<sup>45</sup> *ibid.*

<sup>46</sup> Office for National Statistics, ‘2016 Based England and Wales Period Life Expectancies, 1948 to 2016’ (2018) <<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/adhocs/0085772016basedenglandandwalesperiodlifeexpectancies1948to2016>> accessed 20 January 2025.

<sup>47</sup> Office for National Statistics, ‘Past and projected period and cohort life tables: 2022-based, UK, 1981 to 2072’ (2025) <<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/pastandprojecteddatabfromtheperiodandcohortlifetables/2022baseduk1981to2072>> accessed 22 January 2025.

<sup>48</sup> Jackson (n 44) 39.

and prevalence of self-reported good health’.<sup>49</sup> This number is significantly lower, at 61.5 years for men and 61.9 years for women in England between 2021 and 2023.<sup>50</sup> Therefore, although people are living longer, they are also spending more time in poor health, placing greater financial pressure on NHS resources.<sup>51</sup> In addition, the UK’s total population has increased considerably. In 1946, it was estimated at almost 49 million, rising to over 67 million by 2022.<sup>52</sup> Consequently, more people now require access to NHS services than in 1946.<sup>53</sup>

Taken together, a key rationale for establishing the NHS was to ensure equal provision of healthcare services for all, and this aim continues to be reflected in the NHS Constitution. Notwithstanding this aim, the modern-day NHS is shaped by the challenge of balancing equal access to healthcare with the management of finite resources.<sup>54</sup> These resource constraints are central when analysing current provisions and legislation affecting NHS service users with learning disabilities. The aims of the NHS have evolved since 1948, reflecting the unforeseen reality that demand would increase rather than diminish as national health improved. As a result, the NHS now faces ongoing pressure to meet rising demand while maintaining a comprehensive service. Any recommendations to improve provision for people with learning disabilities must therefore consider the practical limitations of funding and resources.

The remaining sections of this chapter will explore the inequalities experienced by people with learning disabilities when accessing healthcare in NHS England. It will do this

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<sup>49</sup> Office for Health Improvement and Disparities, ‘Understanding the drivers of healthy life expectancy: report’ (2023).

<sup>50</sup> Office for National Statistics, ‘Healthy life Expectancy in England and Wales: Between 2011 to 2013 and 2021 to 2023’ (2024)

<<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthstatelifeexpectanciesuk/between2011to2013and2021to2023>> accessed 24 January 2025.

<sup>51</sup> Ara Darzi, ‘Independent Investigation of the National Health Service in England’ (Department of Health and Social Care 2024) <<https://assets.publishing.service.gov.uk/media/66f42ae630536cb92748271f/Lord-Darzi-Independent-Investigation-of-the-National-Health-Service-in-England-Updated-25-September.pdf>> accessed 26 February 2025, 18.

<sup>52</sup> Office for National Statistics, ‘Population estimates for the UK’ (2024) <<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/mid2024>> accessed 24 January 2025.

<sup>53</sup> Office for National Statistics, ‘Mid-1851 to Mid-2014 Population Estimates for United Kingdom’ (2015) <<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/adhoc/004356ukpopulationestimates1851to2014>> accessed 01 February 2025.

<sup>54</sup> Jackson (n 44) 38.

by bringing together interdisciplinary sources that evidence the lived experience of people with learning disabilities.

### 2.3. Health Inequalities for People with Learning Disabilities

#### 2.3.1. Treat Me Right!

Mencap, a UK-based charity supporting people with learning disabilities, published a series of reports in the early 2000s that examined people with learning disabilities' experiences of healthcare in England and Northern Ireland. The first of these reports, published in 2004, *Treat Me Right!*, drew on a survey of nearly 1,000 people with a learning disability.<sup>55</sup> While overall satisfaction with health services was relatively high, the report identified notable instances of poor experiences.<sup>56</sup> These were attributed to factors including poor quality care and a lack of training and skills among those delivering healthcare services.<sup>57</sup> Furthermore, it identified negative assumptions and attitudes among healthcare staff, which could lead to diagnostic overshadowing.<sup>58</sup> It also highlighted potential discrimination arising from value judgements about the worth of people with learning disabilities.<sup>59</sup> Following this, the Disability Rights Commission (henceforth DRC) investigated health inequalities experienced by people with learning disabilities and/or mental health problems.<sup>60</sup> Its findings closely reflected those of Mencap, particularly in identifying experiences of diagnostic overshadowing.<sup>61</sup>

#### 2.3.2. Death by Indifference

Mencap later published a follow-up report in 2007, *Death by Indifference*.<sup>62</sup> The report examined the tragic cases of six people with a learning disability who were believed to

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<sup>55</sup> Mencap, 'Treat Me Right! Better Healthcare for People with a Learning Disability' (2004) <[https://www.mencap.org.uk/sites/default/files/2016-08/treat\\_me\\_right.pdf](https://www.mencap.org.uk/sites/default/files/2016-08/treat_me_right.pdf)> accessed 15 February 2025, 11.

<sup>56</sup> *ibid.*

<sup>57</sup> *ibid* 11–21

<sup>58</sup> *ibid.*

<sup>59</sup> Mencap, 'Treat Me Right!' (n 55) 11–21.

<sup>60</sup> Disability Rights Commission, 'Equal Treatment: Closing the Gap' (2006) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/DRC-Health-FI-main.pdf>> accessed 13 February 2025.

<sup>61</sup> *ibid* 6.

<sup>62</sup> Mencap, 'Death by Indifference: Following up the Treat me Right! Report' (2007) <<https://www.mencap.org.uk/sites/default/files/2016-07/DBIreport.pdf>> accessed 13 February 2025.

have died ‘unnecessarily’.<sup>63</sup> It demonstrated the presence of underlying institutional discrimination within the NHS against people with learning disabilities.<sup>64</sup> Mencap’s follow-up report identified several contributing factors. These included perceptions among healthcare staff that those with a learning disability are ‘low priority’, diagnostic overshadowing, lack of understanding of the law relating to capacity and consent to treatment, and inappropriate reliance on subjective assessments of a person’s quality of life.<sup>65</sup>

Following Mencap’s reports and the DRC’s formal investigation, an independent inquiry was published in 2008 by Sir Jonathan Michael.<sup>66</sup> This inquiry was commissioned by the then Secretary of State for Health, Patricia Hewitt, to investigate the action needed to ensure that people with learning disabilities receive appropriate medical treatment within the NHS.<sup>67</sup>

The inquiry identified unmet health needs and variations in health outcomes for people with learning disabilities.<sup>68</sup> It confirmed earlier findings from Mencap and the DRC regarding diagnostic overshadowing and a belief that a life with a learning disability is a less valued life, which resulted in certain treatments not being offered to people with learning disabilities.<sup>69</sup> In addition, the report found that people with learning disabilities were less likely to receive pain relief or palliative care.<sup>70</sup> The report concluded that unmet health needs were highly likely to be contributing to avoidable deaths among this group.<sup>71</sup>

### 2.3.3. The Progress Report

In 2012, Mencap published a progress report which found that many of the issues identified in earlier reports persisted within the NHS.<sup>72</sup> There continued to be widespread

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<sup>63</sup> *ibid* 2.

<sup>64</sup> *Ibid* 18.

<sup>65</sup> *ibid* 18–22.

<sup>66</sup> Jonathan Michael, ‘Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities’ (Department of Health 2008)

<<https://www.choiceforum.org/docs/healthcareforall.pdf>> accessed 25 January 2025.

<sup>67</sup> *ibid* 13.

<sup>68</sup> *ibid*.

<sup>69</sup> *ibid* 17–18.

<sup>70</sup> *ibid*.

<sup>71</sup> *ibid* 21.

<sup>72</sup> Mencap, ‘Death by Indifference: 74 Deaths and Counting: A Progress Report 5 Years On’ (2012)

<<https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%202074%20deaths%20and%20counting.pdf>> accessed 13 February 2025.

evidence of discrimination and a failure to place equal value on the lives of people with learning disabilities.<sup>73</sup>

The report found that many families described a lack of basic care in hospital settings.<sup>74</sup> This included duties such as cleaning, feeding, and administering medication. Hospital services were found to have fallen short of their duty of care, with responsibilities often being offloaded to families and carers.<sup>75</sup> The findings suggest that people with learning disabilities are less likely to receive fundamental standards of care compared to the general population.<sup>76</sup> Moreover, previous findings of diagnostic overshadowing, delays in diagnosis and treatment, and a failure to recognise pain, remained pervasive within NHS practice.<sup>77</sup>

Overall, these reports from the early 2000s demonstrate that people with learning disabilities have consistently experienced institutional discrimination within the NHS. This discrimination has contributed to significant failures in the provision of healthcare services. Persistent issues include diagnostic overshadowing, poor-quality care, and the perception that the lives of people with learning disabilities are of lesser value.<sup>78</sup> These systemic failings have been directly linked to poorer health outcomes and higher rates of morbidity among this population.

## 2.4. Connor Sparrowhawk

### 2.4.1. Connor's Death

Connor Sparrowhawk, affectionately known as 'Laughing Boy', was an 18-year-old who died in an NHS care unit on 4 July 2013.<sup>79</sup> From a young age, he had been diagnosed with

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<sup>73</sup> *ibid* 8.

<sup>74</sup> *ibid* 9.

<sup>75</sup> *ibid*.

<sup>76</sup> *ibid*.

<sup>77</sup> *ibid* 10–15.

<sup>78</sup> *ibid*; White and others (n 1); Lindsay Allerton and Eric Emerson, 'British Adults with Chronic Health Conditions or Impairments Face Significant Barriers to Accessing Health Services' (2012) 126 *Public Health* 920, 926.

<sup>79</sup> Sara Ryan, 'My Son Connor Sparrowhawk Died Needlessly: Anger Spurred Me into Action' *The Guardian* (London, 11 October 2017) <<https://www.theguardian.com/society/2017/oct/11/connor-sparrowhawk-justice-laughing-boy-death-campaign>> accessed 12 February 2025.

autism, epilepsy, and learning disabilities. He lived at home with his family, but during a period of acute distress and anxiety, his family sought support from NHS services.<sup>80</sup> On 19 March 2013, Connor was admitted as a voluntary patient to Slade House, a residential unit run by Southern Health NHS Foundation Trust for the assessment and treatment of people with learning disabilities.<sup>81</sup>

Prior to his death, on 20 May 2015, Connor's mother, Sara Ryan, asked staff at the unit to investigate whether Connor was having seizures. She noted that he appeared to have bitten his tongue and that his lip was tired.<sup>82</sup> Despite these concerns, on 4 July 2013, Connor was found submerged in a bath after being left unsupervised. He had suffered an epileptic seizure and drowned.<sup>83</sup>

### 2.4.2. Post-Death Investigation

After Connor's death, his family raised concerns about the way in which Southern Health NHS Trust intended to conduct the investigation.<sup>84</sup> This led the Trust to commission an independent investigation carried out by Verita.<sup>85</sup> Despite the Trust initially claiming that Connor had died of natural causes,<sup>86</sup> the report published in 2014 found that his death was entirely preventable.<sup>87</sup>

The report found two broad areas in which Connor's care and treatment had failed.<sup>88</sup> First, the staff failed to risk assess Connor's epilepsy appropriately. This led to poor decisions regarding his care, particularly the decision to allow him to bathe unsupervised with only 15-minute observations.<sup>89</sup> In addition, staff failed to respond

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<sup>80</sup> Sara Ryan, *Justice for Laughing Boy: Connor Sparrowhawk – A Death by Indifference* (Jessica Kingsley Publishers 2017) 61-66.

<sup>81</sup> Verita, 'Independent Investigation into the Death of CS' (2014) <<https://www.verita.net/reports/independent-investigation-death-connor-sparrowhawk-southern-health-nhs-foundation-trust/>> accessed 12 February 2025 para 5.22.

<sup>82</sup> *ibid* paras 5.48–5.49.

<sup>83</sup> *ibid* paras 5.74–5.75.

<sup>84</sup> Ryan, 'My Son Connor Sparrowhawk Died Needlessly' (n 79).

<sup>85</sup> Verita (n 81).

<sup>86</sup> Care Quality Commission, 'Learning, Candour and Accountability: A Review of the Way NHS Trusts Review and Investigate the Deaths of Patients in England' (2016) <<https://www.cqc.org.uk/sites/default/files/20161213-learning-candour-accountability-full-report.pdf>> accessed 05 February 2025.

<sup>87</sup> Verita (n 81) para 3.21.

<sup>88</sup> *ibid* para 3.22.

<sup>89</sup> *ibid* para 3.23.

appropriately to Sara Ryan's concerns about his seizures.<sup>90</sup> Second, the report found that '[t]eam working in the unit and with the community learning disability team was weak.'<sup>91</sup> As a result, decisions were made in isolation and were neither coordinated nor reviewed by other colleagues.<sup>92</sup>

The findings of this report were particularly alarming given that the Trust had initially claimed that Connor's death was due to natural causes.<sup>93</sup> This raised questions about whether there had been other instances of improper investigations into the deaths of patients with learning disabilities at the Trust.

After more than two years, the inquest into Connor's death concluded on 16 October 2015. The Jury found that his death was 'contributed to by neglect', meaning that a failure to provide basic care caused or was a significant cause of his death.<sup>94</sup> In reaching this conclusion, the Jury identified serious failures in Connor's care. The findings included a lack of clinical leadership within the unit and inadequate training and guidance for nursing staff in the assessment, care, and risk management of epilepsy.<sup>95</sup> Furthermore, there were findings of serious failings in relation to Connor's bathing arrangements and evidence of inadequate communication with Connor's family regarding his epilepsy care needs and risk.<sup>96</sup>

### 2.4.3. The Justice for Laughing Boy Campaign

Following Connor's death, his mother, Sara Ryan, launched a campaign under the slogan #JusticeforLB.<sup>97</sup> As a result of Ryan's campaign work, an independent investigation was commissioned by the then chief executive of NHS England, David Nicholson, into the death of all patients in contact with Southern Health NHS Foundation Trust who had mental ill health or learning disabilities between April 2011 and March 2015.<sup>98</sup>

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<sup>90</sup> *ibid* para F8.

<sup>91</sup> *ibid* para 3.23.

<sup>92</sup> *ibid* para 3.24.

<sup>93</sup> Care Quality Commission, 'Learning, Candour and Accountability' (n 86).

<sup>94</sup> Inquest, 'Jury Found Neglect Contributed to the Death of 18-Year-Old Connor Sparrowhawk' (2015) <<https://www.inquest.org.uk/connor-sparrowhawk-inquest-conclusions>> accessed 12 February 2025.

<sup>95</sup> *ibid*.

<sup>96</sup> *ibid*.

<sup>97</sup> JusticeforLB, 'What is Justice for LB?' <<http://justiceforlb.org/#what-is-j4lb>> accessed 15 February 2025.

<sup>98</sup> Ryan, 'My Son Connor Sparrowhawk Died Needlessly' (n 79).

The Mazars Report, published on 17 December 2015, found that the Trust lacked leadership, focus, and time spent on carefully reporting and investigating unexpected deaths of service users with mental ill health or learning disabilities.<sup>99</sup> Concerningly, the Trust had been made aware of this on multiple occasions but had failed to take action.<sup>100</sup> Additionally, the Trust could not demonstrate that they had a comprehensive systematic approach to learning from deaths through action plans.<sup>101</sup> These findings together demonstrated that the Trust had no reliable way of identifying and reflecting upon failures which may have been contributing to the deaths of patients with learning disabilities.

The findings suggested that the failures which had contributed to Connor's death may have led to the deaths of many other patients with learning disabilities at the Trust.<sup>102</sup> Furthermore, the failings surrounding the investigation of Connor Sparrowhawk's death were likely not a one-off incident but rather a repeated pattern across the Trust because there was no systematic approach to investigating the unexpected deaths of patients with learning disabilities.<sup>103</sup>

#### 2.4.4. Following on from Connor's Death

Before the publication of the Mazars Report, in June 2015, NHS England, the Healthcare Quality Improvement Partnership, and the University of Bristol announced the world's first national programme to review premature deaths of people with learning disabilities.<sup>104</sup> The programme was commissioned following the publication of the *Confidential Inquiry into Premature Deaths of People with Learning Disabilities* (henceforth CIPOLD), which examined 247 deaths across five primary care trusts in the southwest of England.<sup>105</sup>

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<sup>99</sup> Mazars, 'Independent Review of Deaths of People with a Learning Disability or Mental Health Problem in Contact with Southern Health NHS Foundation Trust April 2011 to March 2015' (2015) <<https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf>> accessed 29 January 2025, 14.

<sup>100</sup> *ibid.*

<sup>101</sup> *ibid.* 25.

<sup>102</sup> See NHS Improvement, NHS England, and the Care Quality Commission, 'Mazars Report into Mental Health and Learning Disabilities Deaths in Southern Health NHS Foundation Trust' (2015) <[https://assets.publishing.service.gov.uk/media/5a802fa3ed915d74e622cfa9/181217\\_ALB\\_statement\\_on\\_Mazars\\_v8\\_FINAL.pdf](https://assets.publishing.service.gov.uk/media/5a802fa3ed915d74e622cfa9/181217_ALB_statement_on_Mazars_v8_FINAL.pdf)> accessed 13 February 2025, 2.

<sup>103</sup> Mazars (n 99) 25.

<sup>104</sup> NHS England, 'NHS Launches World's First National Review of Deaths of People with Learning Disabilities' (2015) <<https://www.england.nhs.uk/2015/06/reduce-prem-mortality-ld/>> accessed 13 February 2025.

<sup>105</sup> Heslop and others (n 2) 2.

CIPOLD found that nearly a quarter (22%) of people with learning disabilities were under 50 years old at the time of their death.<sup>106</sup> Of the 238 deaths reviewed by the overview panel, 42% were assessed as being premature, defined as cases where, in the absence of a ‘specific event that formed part of the “pathway” that led to death, it was probable that the person would have continued to live for at least one more year’.<sup>107</sup>

According to CIPOLD, the most common causes of premature deaths were delays or problems with diagnosis or treatment, and failures to identify needs and provide appropriate care.<sup>108</sup> Furthermore, there was a lack of reasonable adjustments to facilitate access to healthcare for people with learning disabilities, making it difficult for them to attend appointments and investigations.<sup>109</sup> This failure contributed to their increased vulnerability and premature deaths.<sup>110</sup> In addition, poor coordination of care between services and across disease pathways further heightened this risk.<sup>111</sup> These findings demonstrate that poor quality healthcare for people with learning disabilities directly contributes to premature deaths.

Following CIPOLD, the National Learning Disabilities Review (LeDeR) programme was established. Prior to its introduction, there was no central point for reporting deaths of people with learning disabilities across NHS England. Nor was there an established methodology for reviewing these deaths, or for analysing annual reporting on them.<sup>112</sup> These reporting and reviewing mechanisms have since helped to inform understandings of the impact of health inequality on people with learning disabilities.

In 2017, the first report of the LeDeR programme was published.<sup>113</sup> By 30 November 2017, 103 reviews of deaths reported to the programme had been completed and approved through its quality assurance process. Of these, 13% found that ‘the person’s

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<sup>106</sup> *ibid.*

<sup>107</sup> *ibid* 3.

<sup>108</sup> *ibid.*

<sup>109</sup> *ibid* 4.

<sup>110</sup> *ibid.*

<sup>111</sup> *ibid.*

<sup>112</sup> University of Bristol, ‘The Learning Disabilities Mortality Review (LeDeR) programme at the University of Bristol 2015-2021’ (n 6).

<sup>113</sup> University of Bristol, ‘Learning Disabilities Mortality Review (LeDeR) Programme Annual Report 2016–2017’ (2018) <[https://www.bristol.ac.uk/media-library/sites/sps/leder/leder\\_annual\\_report\\_2016-2017.pdf](https://www.bristol.ac.uk/media-library/sites/sps/leder/leder_annual_report_2016-2017.pdf)> accessed 20 February 2025.

health had been adversely affected by one or more of the following: delays in care or treatment, gaps in service provision, organisational dysfunction, or neglect or abuse'.<sup>114</sup>

The report also found that of the 958 deaths notified to the LeDeR programme, the median age at death for those with learning disabilities was 58 years.<sup>115</sup> This comprised 59 years for males and 56 years for females.<sup>116</sup> These figures were markedly lower than those for the general population of England and Wales, where the median age at death was 81.8 years for males and 85.3 years for females.<sup>117</sup> Accordingly, the difference in median age at death between people with learning disabilities notified to the LeDeR programme and the general population was 22.8 years for males and 29.3 years for females.<sup>118</sup>

It was already known before the report's publication that people with learning disabilities in England are likely to die younger.<sup>119</sup> However, the LeDeR programme was the first attempt to register all deaths of people with learning disabilities to establish a systematic methodology to review these deaths. This has enabled the collection of more reliable national data on the extent of health inequalities experienced by this group and has revealed the degree to which these inequalities contribute to morbidity.

Overall, this section demonstrates that the death of Connor Sparrowhawk and the findings of subsequent investigations exposed significant systemic failures in the provision and oversight of care for people with learning disabilities. The next section examines current health outcomes for people with learning disabilities using the most recent LeDeR report.

## 2.5. Current Health Inequalities

Following on from the numerous reports published in the early 2000s, the Justice for Laughing Boy Campaign, and the establishment of the LeDeR programme, the picture for those with learning disabilities in the NHS remains concerning. The most recent 2023

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<sup>114</sup> *ibid* 7.

<sup>115</sup> *ibid* 18.

<sup>116</sup> *ibid*.

<sup>117</sup> *ibid*.

<sup>118</sup> *ibid*.

<sup>119</sup> E.g., Michael (n 66).

LeDeR report found that the median age at death for people with a learning disability in 2022 was 62.5 years.<sup>120</sup> While this represents an improvement, it still places it 19.5 years younger than the general population.<sup>121</sup> Furthermore, while the rate of avoidable deaths among people with learning disabilities has declined since 2021, it is still nearly double the rate compared to the general population.<sup>122</sup>

The LeDeR report conducted 626 focused reviews on deaths of those with learning disabilities in 2023.<sup>123</sup> Reviewers found that in 25.6% of cases, the person's care package did not meet their needs.<sup>124</sup> The most commonly identified problems in care included delays in care or treatment, problems with organisational systems, gaps in care, and failure to meet diagnosis and treatment guidelines.<sup>125</sup> Additionally, in 27.3% of deaths, the person was reported to have needed at least one reasonable adjustment that they were not provided with.<sup>126</sup>

These findings demonstrate that, despite some improvements, people with learning disabilities remain significantly more likely to die prematurely, and that poor healthcare provision is a major contributing factor. While awareness of the health inequalities experienced by people with learning disabilities has increased, there remains a need for reform of healthcare provision for this group, given the persistence of these inequalities.

## 2.6. Conclusion

This chapter has provided a brief historical overview of the creation of the NHS. Before the NHS, healthcare was provided across many organisations. There was a perceived need amongst campaigners to coordinate healthcare provision to ensure that health services were accessible to all, improve life expectancy, and reduce infant mortality. It was believed that if everyone had access to healthcare, demand for health services would decline as people became healthier. However, it is now clear that improved access to healthcare has increased life expectancy. This increase in life expectancy has increased demand for health

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<sup>120</sup> White and others (n 1) 7.

<sup>121</sup> *ibid.*

<sup>122</sup> *ibid.*, 40.2% among people with learning disabilities, compared to 21.8% in the general population.

<sup>123</sup> *ibid.* 15.

<sup>124</sup> *ibid.* 26.

<sup>125</sup> *ibid.* 27.

<sup>126</sup> *ibid.* 28.

services as people are more likely to develop long-term health conditions in old age. This increase in demand has arguably led to a shift in NHS England's priorities, as reflected in the Constitution. While equal access to healthcare remains an important priority, this is now balanced against utilising scarce resources efficiently.

The NHS Constitution's principles of providing a comprehensive service to all, irrespective of protected characteristics and the requirement to 'pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population' informed the themes of this research.<sup>127</sup> Notwithstanding the NHS's aims to provide health on an equal basis, people with learning disabilities experience inequality in healthcare provision and, consequently, life expectancy.

The chapter also discussed the death of Connor Sparrowhawk. His family's search for truth and accountability led to significant findings of institutional failures affecting people living in the UK with learning disabilities. However, over a decade has passed since Connor's death and the Justice for LB campaign. Despite the shocking findings of health inequalities faced by people with learning disabilities, health outcomes for intellectually disabled people remain poor, with overall care and outcomes still falling well below acceptable standards.<sup>128</sup>

The remainder of this thesis will examine how equality law in England currently operates and how it can be improved to eliminate the health inequalities experienced by people with learning disabilities. The next chapter will advance this discussion by analysing the legal framework for equality law in Britain. It will discuss the origins of the EqA 2010 and the current provisions prohibiting disability discrimination.

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<sup>127</sup> Department of Health and Social Care (n 15).

<sup>128</sup> White and others (n 1) 8–9.

## Chapter Three: The Legal Framework

### 3.1. Introduction

Having established the challenges experienced by people with learning disabilities in healthcare provision, Chapter Three will examine the legal framework governing equality in England. This doctrinal analysis will inform the focus of the thesis in subsequent chapters, namely, identifying and recommending reforms to the legal framework to improve health outcomes for people with learning disabilities in NHS England.

Accordingly, this chapter begins by outlining the purpose and development of the EqA 2010, situating it within the broader historical development of anti-discrimination law. It examines the recognition of disability discrimination in Britain, tracing the shift from a welfare to a rights-based framework in the twentieth century. The chapter also engages with the debate surrounding the harmonisation of equality legislation under the 2010 Act. In particular, it considers the criticism that including disability among eight other protected characteristics has led to a loss of focus on disability and masks the differences between disability and the other protected characteristics.<sup>129</sup>

Following this, the chapter analyses the legal definition of disability under Section 6 of the EqA 2010, which centres on limitations arising from an individual's impairment. It then examines the forms of conduct prohibited under the 2010 Act, including direct discrimination, indirect discrimination, and discrimination arising from disability. It argues that the direct and indirect discrimination provisions are insufficient on their own to address disability discrimination, as they rely on comparisons with a non-disabled person or group. This comparator requirement renders the direct and indirect discrimination provisions ill-suited to situations in which disabled people require differential treatment to participate equally. However, this situation was rectified by Section 15 EqA 2010 on discrimination arising from disability, which does not require a comparator. Section 15 highlights the departure in British disability discrimination law from a strictly formal approach towards substantive equality.

Finally, the chapter considers the theoretical underpinnings of equality law by examining different models of equality. It argues that a formal equality approach, which

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<sup>129</sup> House of Lords Select Committee on the Equality Act 2010 and Disability, *The Equality Act 2010: The Impact on Disabled People* (HL 2015–16, 117).

treats all people alike, masks the structural disadvantage experienced by people with disabilities. Moreover, it fails to recognise that disadvantaged groups may require different treatment to achieve equal outcomes. Instead, substantive equality provides a four-dimensional framework for evaluating the effectiveness of measures to eliminate discrimination against people with learning disabilities.

### 3.2. The Equality Act 2010: Introduction and Background

#### 3.2.1. Recognition of Disability Discrimination

Until the twentieth century, disability was primarily understood as a welfare issue.<sup>130</sup> People with disabilities were not perceived as rights-bearing individuals; rather, their needs were addressed through social security, welfare provision, and charity.<sup>131</sup> The inception of a rights-based approach to disability is a relatively recent development that took root in the 1980s.<sup>132</sup>

In the UK, before 1995, there was no legal protection against discrimination and harassment on the grounds of disability.<sup>133</sup> Prior to 1995, early attempts at protection were limited to the employment context through the introduction of quotas. These measures, introduced towards the end of the Second World War, were intended to provide employment protection for soldiers returning to civilian life.<sup>134</sup> The Disabled Persons (Employment) Act 1944 required employers with 20 or more employees to allocate a proportion of vacancies to people registered as disabled, with enforcement theoretically supported by criminal sanctions.<sup>135</sup>

However, due to low levels of compliance, the legislation was largely ineffective.<sup>136</sup> It was inadequately enforced, and the conditions to be registered as disabled

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<sup>130</sup> Sandra Fredman, *Discrimination Law* (3<sup>rd</sup> edn, OUP 2022) 150.

<sup>131</sup> Theresia Degener and Gerald Quinn, 'A Survey of International Comparative and Regional Disability Law Reform' in Mary Breslin and Silvia Yee (eds), *Disability Rights Law and Policy: International and National Perspectives* (Transnational Publishers 2000).

<sup>132</sup> Fredman, *Discrimination Law* (n 130) 150.

<sup>133</sup> Bob Hepple, *Equality the Legal Framework* (2<sup>nd</sup> edn, Hart Publishing 2014) 42.

<sup>134</sup> Carol Woodhams and Susan Corby, 'Defining Disability in Theory and Practice: A Critique of the British Disability Discrimination Act 1995' (2003) 32 *Journal of Social Policy* 159, 160.

<sup>135</sup> s 9–11; 13–14; 9(6).

<sup>136</sup> Woodhams and Corby (n 134) 160.

were too narrowly circumscribed, excluding many genuinely disabled people.<sup>137</sup> Moreover, as the years progressed, the demographics of disabled persons drastically changed alongside societal understandings of what constitutes disability.<sup>138</sup> Thus, the population of disabled people shifted from primarily ex-service personnel to include people with congenital impairments and acquired disabilities from workplace injuries and illnesses.<sup>139</sup>

After years of campaigning, the Disability Discrimination Act 1995 was passed, marking a significant shift towards a rights-based framework.<sup>140</sup> The Act made it unlawful for employers and service providers to discriminate on the grounds of disability and introduced a duty to make reasonable adjustments for disabled people.<sup>141</sup> These protections were subsequently extended to the education sector by the Special Educational Needs and Disability Act 2001. Further developments followed with the Disability Discrimination Act 2005, which expanded the scope of protection to include public authorities and introduced a public sector equality duty in relation to disability.

The next section will discuss how these provisions were harmonised under the EqA 2010, alongside a suite of anti-discrimination legislation protecting other groups. This section has demonstrated that there has been a shift towards recognising disability discrimination as a rights-based issue, rather than treating it as a matter of welfare. This rights-based approach will inform the recommendations advanced in subsequent chapters, ensuring that people with disabilities are treated as rights-holders entitled to equality and dignity in healthcare provision, rather than as recipients of welfare.

### 3.2.2. The Development of the Equality Act 2010

Before the passing of the Equality Act 2010, equality legislation in the UK spanned over nine major acts covering gender, race, religion or belief, sexual orientation, age, and disability.<sup>142</sup> In 2000, the *Report of the Cambridge Independent Review of the Enforcement of UK Anti-Discrimination Legislation* recommended that the government adopt a single

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<sup>137</sup> Brian Doyle, 'Disabled Workers' Rights, the Disability Discrimination Act and the UN Standard Rules' (1996) 25 ILJ 1.

<sup>138</sup> Woodhams and Corby (n 134) 160.

<sup>139</sup> *ibid.*

<sup>140</sup> *ibid.*

<sup>141</sup> *ibid.*

<sup>142</sup> Hepple (n 133) 2.

anti-discrimination statute.<sup>143</sup> The Cambridge Review argued that this was necessary due to the existing volume of legislation.<sup>144</sup> According to the Review, the extensive volume of legislation had led to poorer outcomes for people seeking to rely on it. Human resource managers, trade union officials, and representatives of victims of discrimination found it too difficult to navigate the framework.<sup>145</sup>

Additionally, the Cambridge Review observed that the different statutes protecting the various groups were ‘inconsistent and inherently unsatisfactory’.<sup>146</sup> It provided several examples, including the Disability Discrimination Act 1995 (henceforth DDA 1995), which did not include indirect discrimination, unlike the Sex Discrimination Act 1975 and the Race Relations Act 1976.<sup>147</sup>

As a result of these issues, the Cambridge Review presented a series of recommendations on how to harmonise equality legislation in the UK. The most widely promoted of these suggestions was the creation of a single Equality Act.<sup>148</sup> The idea was canvassed in examples across different jurisdictions which had unified equality legislation, such as Australia, Canada, and the United States.<sup>149</sup> The review argued that such an approach would ‘recognise the indivisibility of the concept of equality’ and ‘encourage links among groups facing discrimination’.<sup>150</sup> Furthermore, the Review reasoned that it would promote equality by making it easier for employers to understand their obligations, serving as a ‘one-stop shop for business’.<sup>151</sup>

During the 2005 General Election, Tony Blair’s Labour Party pledged to introduce a single Equality Bill in its manifesto.<sup>152</sup> Although the party was re-elected in May 2005, the Equality Bill was not introduced to the House of Commons until April 2009.<sup>153</sup> The bill

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<sup>143</sup> Bob Hepple, Mary Coussey, Tufyal Choudhury, *Equality: A New Framework: Report of the Independent Review of the Enforcement of UK Anti-Discrimination Legislation* (Hart 2000).

<sup>144</sup> *ibid* para 2.1.

<sup>145</sup> *ibid*.

<sup>146</sup> *ibid* para 2.4.

<sup>147</sup> *ibid*.

<sup>148</sup> *ibid* Recommendation 1 at 25.

<sup>149</sup> *ibid* para 2.8.

<sup>150</sup> *ibid* para 2.9.

<sup>151</sup> *ibid*.

<sup>152</sup> Labour Party, ‘Britain Forward Not Back: The Labour Party Manifesto 2005’ (2005) <<https://manifesto-cymru.cavendishconsulting.com/wp-content/uploads/2021/04/Labour-Manifesto-2005.pdf>> accessed 05 April 2025, 112.

<sup>153</sup> Robin Allen, ‘Introduction and Background’ in Anthony Robinson, David Ruebain, Susie Uppal (eds), *Blackstone’s Guide to the Equality Act 2010* (4<sup>th</sup> edn, OUP 2021) 7–8.

underwent intense scrutiny for nearly a year before receiving Royal Assent on 8 April 2010.<sup>154</sup>

### 3.2.3. The Impact of Harmonisation

While harmonising equality law was initially presented as a measure to improve outcomes for all protected groups, there has since been considerable debate as to whether this has been achieved. In June 2015, the House of Lords confirmed the appointment of an ad hoc committee to examine the impact of the 2010 Act on people with disabilities.<sup>155</sup> The committee's report, published in 2016, found that 'it was a mistake to have attempted to deal with discrimination on grounds of disability, sex, race and other protected characteristics in a single Equality Act'.<sup>156</sup> The report further concluded that 'combining disability with other protected characteristics in one Act did not in practice benefit disabled people'. However, it acknowledged that 'separating the statutory treatment of disability from the other protected characteristics would be impractical'.<sup>157</sup>

The Committee heard evidence from various disabled people and interest groups arguing that combining the protected characteristics of disability with the other protected characteristics in a single act has led to a loss of focus on disability. In particular, it was argued that this approach obscured the differences between disability and other protected characteristics.<sup>158</sup> The EqA 2010 aimed to create harmonisation, clarity, and better protection for all protected characteristics. However, the Committee's findings suggest that these objectives were not attained, as many felt the equality outcomes for disabled people resulting from the 2010 Act were worse.<sup>159</sup>

This thesis will consider the criticism of the EqA 2010, leading to a loss of focus on disability, further in Chapter Four. It will argue in favour of changes that place greater emphasis on the differing needs of people with disabilities, focusing on those with learning disabilities accessing healthcare services.

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<sup>154</sup> Hepple (n 133) 6.

<sup>155</sup> HL Deb 11 June 2015, vol 762, col 892.

<sup>156</sup> House of Lords Select Committee (n 129) 5 at summary.

<sup>157</sup> *ibid* para 50.

<sup>158</sup> *ibid* para 47–48.

<sup>159</sup> *ibid*.

The thesis is focused on the EqA 2010, as it will be argued that the measures necessary to eliminate health inequality for people with learning disabilities should be enforceable as rights. Framing these improvements as welfare measures risks presenting them as discretionary ‘additional services’, thereby undermining the recognition of inadequate healthcare provision as unlawful disability discrimination. The remaining sections of this chapter will discuss the provisions in the EqA 2010 relevant to people with disabilities.

### **3.2.4. Structure of the Equality Act 2010**

The EqA 2010 spans over 200 Sections and 28 Schedules. The Act identifies nine ‘protected characteristics’, on the basis of which discrimination is unlawful. These are: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation.<sup>160</sup>

Part 2 of the Act, ‘Equality: Key Concepts’, sets out the foundational principles of anti-discrimination law. It is divided into two Chapters. Chapter 1, ‘Protected Characteristics’, defines the nine protected characteristics. Chapter 2, ‘Prohibited Conduct’, outlines the various forms of unlawful conduct under the Act. For the purposes of the thesis, these include direct discrimination (Section 13), indirect discrimination (Section 19), and discrimination arising from disability (Section 15). Furthermore, the duty to make reasonable adjustments for disabled persons (Section 20) will be examined further in Chapter Five.

The subsequent five Parts of the Act apply these forms of prohibited conduct across specific sectors. Notably, Part 3 refers to ‘Services and public functions’, which includes access to healthcare services; this will be discussed further in Chapter Five.

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<sup>160</sup> EqA 2010, s 4.

### 3.3. Protected Characteristic of Disability

#### 3.3.1. Asymmetric Protection of Disability

Disability is one of the nine protected characteristics under the EqA 2010. Disability discrimination law departs from the other forms of discrimination in the 2010 Act to recognise that disabled people may need to be treated differently to achieve equality.<sup>161</sup> Section 6 of the EqA 2010 establishes who is considered to have the protected characteristic of disability.

The protection provided to disabled people against discrimination under the Act is asymmetric.<sup>162</sup> Therefore, only those with a disability, or who have had a disability in the past, are protected under the Act.<sup>163</sup> This means that the status of a ‘non-disabled’ person is not a protected characteristic, and ‘non-disabled’ people cannot claim they have been discriminated against based on not having a disability.<sup>164</sup>

However, ‘non-disabled’ persons are protected from harassment and disability discrimination if they are falsely perceived to have a disability or are associated with a disabled person, such as a carer for a disabled person.<sup>165</sup> Furthermore, ‘non-disabled’ people are also protected from victimisation connected to a complaint of disability discrimination.<sup>166</sup>

This is in contrast with the approach to most other protected characteristics under the Act, such as sex, race, sexual orientation, age, and religion or belief, which are protected symmetrically. For example, the ban on sex discrimination applies to both men and women. By contrast, the asymmetric nature of disability protection enables reasonable adjustments to be made for disabled people to facilitate equal participation.<sup>167</sup> If such protection were symmetrical, non-disabled people could claim discrimination when

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<sup>161</sup> Allen (n 153) 4.

<sup>162</sup> Aileen McColgan, *Discrimination Law: Text, Cases and Materials* (3<sup>rd</sup> edn, Bloomsbury Publishing 2023) 480.

<sup>163</sup> *ibid.*

<sup>164</sup> Razia Karim, ‘Protected Characteristics’ in Anthony Robinson, David Ruebain, Susie Uppal (eds), *Blackstone’s Guide to the Equality Act 2010* (4<sup>th</sup> edn, OUP 2021) 17.

<sup>165</sup> *ibid.*

<sup>166</sup> McColgan (n 162) 480.

<sup>167</sup> Karim (n 164) 17.

disabled persons are provided with additional support or aids. The reasonable adjustments provisions will be discussed in further detail in Chapter Five.

This is useful to note because, while the Act has been criticised for masking the differences between disability and the other protected characteristics, it does treat disability differently. This reflects the fact that disability discrimination is experienced exclusively by disabled people. However, as will be argued in Chapter Four, the Act does not go far enough in recognising the barriers to participation in society faced by persons with disabilities.

### 3.3.2. Definition of Disability Under the Equality Act 2010

Under Section 6 of the Equality Act:

- (1) A person (P) has a disability if –
  - (a) P has a physical or mental impairment, and
  - (b) the impairment has a substantial and long-term adverse effect on P’s ability to carry out normal day-to-day activities.

Supplementary provisions determining whether somebody will be considered disabled under the Act are contained in Schedule 1, Part 1 of the EqA 2010 and in the Equality Act 2010 (Disability) Regulations.

#### 3.3.2.1. *Physical or Mental Impairment*

The term ‘impairment’ is not exhaustively defined in the Act and must therefore be given its ordinary and natural meaning.<sup>168</sup> Schedule 1, paragraph 12, requires adjudicating

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<sup>168</sup> *McNicol v Balfour Beatty Rail Maintenance Ltd* [2002] EWCA Civ 1074; [2002] ICR 1498 CA [17]; Government Equalities Office, ‘Equality Act 2010: Guidance on Matters to be Taken into Account in Determining Questions Relating to the Definition of Disability’ (2011) <<https://www.gov.uk/government/publications/equality-act-guidance/disability-equality-act-2010-guidance-on-matters-to-be-taken-into-account-in-determining-questions-relating-to-the-definition-of-disability-html>> accessed 28 January 2025, para A3.9.

bodies<sup>169</sup> to take into account guidance they deem relevant when determining whether a person is disabled.<sup>170</sup>

The Government has issued guidance to assist in interpreting the definition of disability.<sup>171</sup> The guidance acknowledges that '[i]t is not possible to provide an exhaustive list of conditions that qualify as impairments for the purposes of the Act' and notes that '[a]ny attempt to do so would inevitably become out of date as medical knowledge advanced'.<sup>172</sup> However, it provides a non-legally binding list of impairments from which a disability can arise, which includes learning disabilities.<sup>173</sup>

### 3.3.2.2. *Substantial Adverse Effect*

Section 212 defines 'substantial' as something 'more than minor or trivial'.<sup>174</sup> In *Paterson v Commissioner of Police of the Metropolis*, the Employment Appeal Tribunal (hereafter, 'EAT') considered who the comparator should be when determining whether an impairment has a substantial adverse effect on a disabled person's capacity to carry out normal day-to-day activities.<sup>175</sup> The EAT held that, when assessing the effect of the impairment on the individual, the comparison is not with the population at large, but with how the person would carry out an activity with the impairment and without it.<sup>176</sup> This case, although decided under the DDA 1995, remains good law.<sup>177</sup>

### 3.3.2.3. *Normal Day-to-day Activities*

The Act does not provide a definition or a definitive list of normal day-to-day activities. This allows greater flexibility when determining what constitutes a normal day-to-day activity.<sup>178</sup> Furthermore, listing every activity that may be considered a normal day-to-day activity would be practically impossible. However, the Government guidance includes an illustrative and non-exhaustive list of factors that would be reasonable to regard as having

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<sup>169</sup> A court, tribunal, or a person who may decide a claim relating to a contravention of Part 6 (education).

<sup>170</sup> EqA 2010, sch 1, pt 2, para 12.

<sup>171</sup> Government Equalities Office (n 168) para A3.

<sup>172</sup> *ibid.*

<sup>173</sup> *ibid.*

<sup>174</sup> EqA 2010, s 212(1).

<sup>175</sup> UKEAT/0635/06; [2007] IRLR 763.

<sup>176</sup> *ibid* [68].

<sup>177</sup> See *Banaszczyk v Booker Ltd* UKEAT/0132/15/RN; [2016] IRLR 273 [34]-[37].

<sup>178</sup> Karim (n 164) 20.

a substantial adverse effect on such activities.<sup>179</sup> However, ‘[w]hether a person satisfies the definition of a disabled person [...] will depend upon the full circumstances of the case.’<sup>180</sup>

#### 3.3.2.4. *Long-Term Effect*

An impairment is considered long-term under Schedule 1, Part 1, paragraph 2 if it ‘(a) has lasted for at least 12 months, (b) it is likely to last for at least 12 months, or (c) it is likely to last for the rest of the life of the person affected’. Learning disabilities will satisfy this requirement, as they are lifelong conditions that cannot be cured through treatment.

This Section has outlined the statutory definition of disability under Section 6 of the EqA 2010. The definition under the British legal framework focuses on the person’s impairment and its impact on their ability to carry out normal day-to-day activities, rather than on societal barriers to participation. As will be discussed in Chapter Four, this reflects a predominantly ‘medical model’ of disability, which has been subject to significant academic criticism.

### 3.4. Prohibited Conduct

#### 3.4.1. Section 13 Direct Discrimination

Section 13 of the 2010 Act prohibits direct discrimination. This is when one person is treated less favourably than another because of a protected characteristic.

Section 13 provides that:

*(1) A person (A) discriminates against another (B) if, because of a protected characteristic, A treats B less favourably than A treats or would treat others.*

*[...]*

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<sup>179</sup> Government Equalities Office (n 168) 53–55.

<sup>180</sup> *ibid.*

*(3) If the protected characteristic is disability, and B is not a disabled person, A does not discriminate against B only because A treats or would treat disabled persons more favourably than A treats B.*

#### 3.4.1.1. *Comparator*

Direct discrimination follows a formal, symmetrical model of equality, under which likes must be treated alike.<sup>181</sup> To establish direct discrimination, the claimant (B) must compare their treatment with that of another person (the comparator) and demonstrate that they have been treated less favourably. The comparator does not need to be an actual person; it can be a hypothetical one.<sup>182</sup> However, demonstrating that a hypothetical comparator would have been treated differently can be difficult, which can create an evidential weakness.<sup>183</sup>

Section 23 of the Act provides supplementary guidance to identify an acceptable comparator. There must be no material difference between the circumstances of the claimant and the comparator.<sup>184</sup> Though it is not necessary for the circumstances to be alike in all respects, it is a question of fact and degree.<sup>185</sup>

Section 23 also states that the comparison must be made with somebody who, though not disabled, has the same abilities as the disabled claimant.<sup>186</sup> This can create difficulties when establishing a claim of disability discrimination. A disabled person may be treated in the same way as a non-disabled person and suffer a detriment because the disabled person may require additional accommodations to participate equally in society.<sup>187</sup>

#### 3.4.1.2. *Less Favourably*

The claimant must also be able to show that they have been treated less favourably than a comparator without the protected characteristic. Less favourable treatment is interpreted broadly. The person does not need to demonstrate that they have suffered a material or

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<sup>181</sup> Hepple (n 133) 68; see Chapter Four, s 2.4.

<sup>182</sup> EqA 2010, s 13(1).

<sup>183</sup> *Shamoon v Chief Constable of the Royal Ulster Constabulary* [2003] UKHL 11; [2003] 2 All ER 26; Anna Beale, 'Core Rights and Duties' in Anthony Robinson, David Ruebain, Susie Uppal (eds), *Blackstone's Guide to the Equality Act 2010* (4<sup>th</sup> edn, OUP 2021) 35.

<sup>184</sup> EqA 2010, s 23(1).

<sup>185</sup> *Hewage v Grampian Health Board* [2012] UKSC 37; [2012] 4 All ER 447 [22].

<sup>186</sup> EqA 2010, s 23(2).

<sup>187</sup> Hepple (n 133) 91.

tangible loss; depriving somebody of choice is sufficient to constitute less favourable treatment.<sup>188</sup>

#### 3.4.1.3. *Causation ('Because of')*

It is also necessary to establish causation. This is that the less favourable treatment complained of was 'because of' the person's protected characteristic. The causation test is an objective one.<sup>189</sup> Furthermore, it is not necessary to prove intention or motive on the part of the discriminator.<sup>190</sup>

#### 3.4.1.4. *More favourable treatment of disabled persons*

There is no justification for direct discrimination unless the less favourable treatment is because of age.<sup>191</sup> However, Section 13(3) of the EqA 2010 states that a person without a disability is not discriminated against simply because a person with a disability has been treated more favourably.

As established, under the Act, most protected characteristics are protected against direct discrimination symmetrically.<sup>192</sup> However, people with disabilities may require 'more favourable' treatment to participate equally; thus, the Act exclusively protects disabled people from direct disability discrimination. This provision prevents claims of direct discrimination where persons with disabilities are treated more favourably.

### 3.4.2. Section 19 Indirect Discrimination

Indirect discrimination is a separate statutory wrong with different criteria. Section 19 recognises that two groups could be subjected to a neutral practice, but the person with the protected characteristic may suffer a detriment.<sup>193</sup>

Under Section 19 EqA 2010, indirect discrimination provides:

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<sup>188</sup> *R v Birmingham City Council ex p Equal Opportunities Commission* [1989] AC 1155 (HL) 1183.

<sup>189</sup> *R (on the application of E) v Governing Body of JFS and the Admissions Appeal Panel of JFS and others* [2009] UKSC 15; [2010] 2 AC 728 [13].

<sup>190</sup> See *James v Eastleigh Borough Council* [1990] 2 AC 751 (HL); *Nagarajan v London Regional Transport* [2000] 1 AC 501; Equality Act 2010 Explanatory Notes (2010) para 59 (explaining s 13).

<sup>191</sup> EqA 2010, s 13(2).

<sup>192</sup> Beale (n 183) 38.

<sup>193</sup> *ibid* 44.

*(1) A person (A) discriminates against another (B) if A applies to B a provision, criterion or practice which is discriminatory in relation to a relevant protected characteristic of B's.*

*(2) For the purposes of subsection (1), a provision, criterion or practice is discriminatory in relation to a relevant protected characteristic of B's if—*

*(a) A applies, or would apply, it to persons with whom B does not share the characteristic,*

*(b) it puts, or would put, persons with whom B shares the characteristic at a particular disadvantage when compared with persons with whom B does not share it,*

*(c) it puts, or would put, B at that disadvantage, and*

*(d) A cannot show it to be a proportionate means of achieving a legitimate aim.*

#### 3.4.2.1. Comparative Disadvantage

A key element of indirect discrimination is the requirement to demonstrate comparative disadvantage. This requires showing that a seemingly neutral ‘provision, criterion or practice’ (hereafter, ‘PCP’) puts, or would put, the group sharing the claimant’s protected characteristic at a disadvantage compared to those who do not share it.<sup>194</sup> When identifying an appropriate comparator group, the circumstances of the individuals in one group must not be materially different to those of the other.<sup>195</sup> Both the advantaged and disadvantaged groups can be hypothetical.

#### 3.4.2.2. Justification

Unlike Section 13, indirect discrimination can be justified if the person applying the PCP can show that it is a ‘proportionate means of achieving a legitimate aim’.<sup>196</sup> The

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<sup>194</sup> EqA 2010, s 19(2)(b).

<sup>195</sup> EqA 2010, s 23(1).

<sup>196</sup> EqA 2010, s 19(2)(d).

justification, therefore, has two elements: it must be *legitimate*, and the means of achieving it must be *proportionate*. The burden of proof lies on the discriminator to justify it.<sup>197</sup>

A detailed discussion of how a discriminatory act may be justified will follow in the next section, in relation to discrimination arising from disability under Section 15. Finally, as with Section 13, indirect discrimination is unlawful regardless of any discriminatory intention or the motivation underlying the PCP.<sup>198</sup>

### 3.4.3. Section 15 Discrimination Arising from Disability

Section 15 sets out the provisions for ‘Discrimination arising from disability’:

*(1) A person (A) discriminates against a disabled person (B) if—*

*(a) A treats B unfavourably because of something arising in consequence of B's disability, and*

*(b) A cannot show that the treatment is a proportionate means of achieving a legitimate aim.*

*(2) Subsection (1) does not apply if A shows that A did not know, and could not reasonably have been expected to know, that B had the disability.*

#### 3.4.3.1. No Comparator

Section 15 replaced the earlier provisions of the DDA 1995. Under the DDA 1995, the disabled person needed to show that they had been treated less favourably than others to whom the disability-related provision did not apply.<sup>199</sup> The defendant could then argue that ‘the treatment in question is justified’ as a defence.<sup>200</sup>

The problems arising from the requirement for a comparator can be seen in the decision of the House of Lords in *London Borough of Lewisham v Malcolm*.<sup>201</sup> This case

<sup>197</sup> *R (on the application of Elias) v Secretary of State for Defence* [2006] EWCA Civ 1293; [2006] 1 WLR 3213 [131].

<sup>198</sup> Hepple (n 133) 86.

<sup>199</sup> DDA 1995, s 5(1)(a) in relation to employment; s 20(1)(a) in relation to goods, facilities, and services.

<sup>200</sup> DDA 1995, ss 5(1)(b); 20(1)(b).

<sup>201</sup> [2008] UKHL 45; [2008] 1 AC 1399.

concerned a man with schizophrenia, to whom Lewisham Council had granted a secure tenancy. A condition of his tenancy agreement prohibited subletting. Despite this, Malcolm sublet his flat without the council's consent.<sup>202</sup> It appeared that this occurred when he was not taking his medication. When the local authority discovered the subletting, they served him notice to quit and issued proceedings for possession.<sup>203</sup> Additionally, there was no evidence that the local authority was aware that Malcolm had schizophrenia.<sup>204</sup>

Under Section 22(3) of the DDA 1995, a manager of premises was precluded from discriminating against a disabled person occupying the premises by evicting them or subjecting them to any other detriment.<sup>205</sup> Malcolm argued that he was a disabled person, and the subletting was for a reason related to his disability; therefore, he had been discriminated against.<sup>206</sup>

One of the central issues at appeal to the House of Lords was whether the correct comparator was (a) persons without a mental disability who have sublet their flat, or (b) tenants who had not sublet their flat.<sup>207</sup> A majority in the Lords, with Baroness Hale dissenting, held that the correct comparator was a secure tenant without a mental illness who had sublet their flat.<sup>208</sup> Such a tenant would have received the same treatment from the local authority as Malcolm. Accordingly, there was no 'less favourable treatment' and therefore no discrimination.<sup>209</sup>

The impact of this judgment was to require 'like-for-like comparisons in disability cases' between persons with disabilities and those without.<sup>210</sup> As acknowledged by Lord Brown in *Malcolm*, the effect of taking the 'narrow' interpretation constrained the reach of disability discrimination cases brought under the DDA 1995 to acts of direct discrimination.<sup>211</sup>

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<sup>202</sup> *ibid* [43]–[44].

<sup>203</sup> *Malcolm* (n 201) [46]–[47].

<sup>204</sup> *ibid* [19] as per Lord Bingham; [91] as per Baroness Hale.

<sup>205</sup> DDA 1995, s 20(3)(c).

<sup>206</sup> DDA 1995, s 24(1)(a).

<sup>207</sup> *Malcolm* (n 201) [13] as per Lord Bingham.

<sup>208</sup> *ibid* e.g., [16]; [40].

<sup>209</sup> *ibid*.

<sup>210</sup> Hepple (n 133) 92.

<sup>211</sup> Rachel Horton, 'The End of Disability-Related Discrimination in Employment? London Borough of Lewisham v Malcolm; [2008] UKHL 43; [2008] IRLR 700' (2008) 37 ILJ 376, 379; *Malcolm* (n 201) [114].

There was considerable opposition to this decision from disability campaigners.<sup>212</sup> The House of Commons Work and Pensions Committee proposed in 2009 that the government reform the provisions for disability-related discrimination by removing the requirement for a comparator.<sup>213</sup> The government accepted this proposal and introduced Section 15, discrimination arising from disability.<sup>214</sup>

Notably, Section 15 of the Act does not require a comparator. This departs from the approach to direct and indirect discrimination under the Act. The disabled person must instead show that they were treated ‘*unfavourably because of something arising in consequence of [their] disability*’.<sup>215</sup>

Section 15 represents a positive development in the British legal framework, rectifying the position seen in *Malcolm*. It recognises that comparing a disabled person with those who are not disabled would not result in genuinely equal treatment.<sup>216</sup> Disabled people should not be compared to those without disabilities when determining whether they have been discriminated against, because they may require different treatment to experience equal outcomes.<sup>217</sup> This is another example of how anti-discrimination law in Britain recognises the difference between disability discrimination and other forms of prohibited conduct. This is particularly relevant in a healthcare context, where people with learning disabilities often have different healthcare needs from non-disabled people.

### 3.4.3.2. *Unfavourable treatment*

To satisfy the requirements of discrimination arising from disability, the claimant must show that they were treated ‘unfavourably because of something arising in consequence of [their] disability’.<sup>218</sup> ‘Unfavourable treatment’ is not defined in the Act; however,

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<sup>212</sup> See Hepple (n 133) 92–93.

<sup>213</sup> House of Commons Work and Pensions Committee, *The Equality Bill: How Disability Equality Fits within a Single Equality Act* (HC 2008–09, 158–I) para 34.

<sup>214</sup> House of Commons Work and Pensions Committee, *The Equality Bill: How Disability Equality Fits within a Single Equality Act: Government Response to the Third Report from the Committee, Session 2008–09* (HC 2008–09, 836) para 2.

<sup>215</sup> EqA, s 15(1)(a).

<sup>216</sup> Hepple (n 133) 91.

<sup>217</sup> *ibid.*

<sup>218</sup> EqA 2010, s 15(1)(a).

‘unfavourable’ is generally understood similarly to analogous concepts such as ‘disadvantage’ or ‘detriment’ found in other provisions.<sup>219</sup>

The ‘unfavourable’ treatment must also arise in consequence of the person’s disability.<sup>220</sup> However, it is not necessary for there to be a direct causal link between the disabled person’s disability and the unfavourable treatment.<sup>221</sup>

### 3.4.3.3. *Justification*

Unlike direct discrimination, discrimination arising from disability can be justified. A defendant can avoid liability if they can demonstrate that the treatment was a proportionate means of achieving a legitimate aim.<sup>222</sup> The test for justification under Section 15 is the same as that which applies under indirect discrimination.

The defence has two parts: it must be a *legitimate aim* and a *proportionate means* of achieving it. When considering whether an aim is legitimate, it must not be discriminatory in and of itself and must represent a real objective consideration.<sup>223</sup> Proportionality requires an assessment of whether the treatment is appropriate and necessary.<sup>224</sup> Necessary is taken to mean ‘reasonably necessary’.<sup>225</sup> If less discriminatory measures could have been taken to pursue the identified legitimate aim, the treatment will not be considered necessary.<sup>226</sup> The treatment must also be appropriate, meaning it must be a suitable means of achieving the identified aim.<sup>227</sup>

Furthermore, if the alleged discriminator has not made reasonable adjustments under Section 20, and doing so would have avoided the unfavourable treatment, it will be

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<sup>219</sup> *Williams v Trustees of Swansea University Pension and Assurance Scheme* [2018] UKSC 65; [2019] 2 All ER 1031 [27]–[28].

<sup>220</sup> EqA 2010, s 15(1)(a).

<sup>221</sup> *Sheikholeslami v University of Edinburgh* UKEATS/0014/17/JW; [2018] IRLR 1090 [66].

<sup>222</sup> EqA 2010, s15(1)(b).

<sup>223</sup> *R v Secretary of State for Employment ex parte Equal Opportunities Commission* [1994] UKHL 2; [1995] 1 AC 1.

<sup>224</sup> Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation [2000] OJ L 303/16, art 2(2)(b)(i).

<sup>225</sup> *Homer v Chief Constable of West Yorkshire* [2012] UKSC 15; [2012] 3 All ER 1287 [22].

<sup>226</sup> *ibid* [25].

<sup>227</sup> *ibid* [22]; Beale (n 183) 47.

very difficult to justify.<sup>228</sup> The duty to make reasonable adjustments will be discussed further in Chapter Five.

#### 3.4.3.4. *Knowledge of disability*

A person will not be liable under Section 15 if they can show that they did not know, and could not reasonably have been expected to know, that the claimant had a disability.<sup>229</sup> The defendant must demonstrate that they did not know of the disability and that they could not reasonably have been expected to find out whether the person had a disability.<sup>230</sup>

In cases where the discriminator relies on the knowledge requirement, a court or tribunal will also consider whether reasonable enquiries would have revealed that the person in question had a disability.<sup>231</sup> Only if a reasonable enquiry would not have revealed the person's disability will the knowledge requirement not be satisfied.<sup>232</sup> However, it is not necessary to show that the discriminator considered the person's disability when subjecting them to the unfavourable treatment.<sup>233</sup>

### 3.5. Models of Equality Law

This next section will explore the conceptual framework for equality law.

#### 3.5.1. Formal Equality

The first notion is formal equality. Premised on the Aristotelian principle that likes should be treated alike, this is the idea that fairness requires everyone to be treated consistently.<sup>234</sup> This model of equality best aligns with the provisions for direct discrimination under Section 13 EqA 2010.

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<sup>228</sup> *City of York Council v Grosset* [2018] EWCA Civ 1105; [2018] 4 All ER 77 [57].

<sup>229</sup> EqA 2010, s 15(2).

<sup>230</sup> *ibid.*

<sup>231</sup> *A Ltd v Z* UKCAT/0273/18/BA; [2020] ICR 199 [42].

<sup>232</sup> *ibid.*

<sup>233</sup> *Grosset* (n 228) [40].

<sup>234</sup> Fredman, *Discrimination Law* (n 130) 9.

As Fredman notes, ‘this principle has played a crucial role in dismantling express legal prohibitions in relation to particular identity groups’.<sup>235</sup> However, formal equality is limited by the fact that ‘[o]nly ‘likes’ qualify for equal treatment; there is no requirement that people be treated *differently* according to *their differences*’ [emphasis added].<sup>236</sup>

Equality, on a formal view, would require a disabled person to be treated the same as someone without a disability. However, persons with disabilities often require differential treatment to participate on an equal basis. Formal equality also relies on a symmetrical model of equality.<sup>237</sup> Accordingly, a non-disabled person could argue that they have been discriminated against if they are not provided with the same accommodations as disabled persons.<sup>238</sup>

In a healthcare context, patients with learning disabilities may need to be treated differently to access services on an equal basis as non-disabled patients. For example, they may require longer appointments, information provided in accessible formats, or personalised care plans.<sup>239</sup> Under a formal equality approach, such measures may be characterised as treating disabled persons ‘better’ than others.

### 3.5.2. Substantive Equality

Substantive equality emerges as a response to the criticisms of formal equality.<sup>240</sup> While its precise definition is contested,<sup>241</sup> one theory of equality is often attributed to it: equality of results.<sup>242</sup> Equality of results requires equal outcomes, not just consistent treatment.<sup>243</sup> Fredman argues that its strength lies in recognising that identical treatment can reinforce inequality due to historical or ongoing discrimination.<sup>244</sup>

However, equality of outcomes is an ambiguous concept that is not without controversy. One of the issues Fredman notes is that, if equality of results is used to focus

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<sup>235</sup> *ibid.*

<sup>236</sup> *ibid* 14.

<sup>237</sup> Michael Connolly, *Discrimination Law* (2<sup>nd</sup> edn, Sweet & Maxwell 2011) 5–6.

<sup>238</sup> See Hugh Collins, ‘Discrimination, Equality and Social Inclusion’ (2003) 66 MLR 16 for further criticisms of formal equality.

<sup>239</sup> Stuart Read and others, ‘Disabled People’s Experiences of Accessing Reasonable Adjustments in Hospitals: A Qualitative Study’ (2018) 18 BMC Health Services Research 931.

<sup>240</sup> Connolly (n 237) 10–12.

<sup>241</sup> Sandra Fredman, ‘Substantive Equality Revisited’ (2016) 14 ICON 712, 712–713.

<sup>242</sup> Connolly (n 237) 11.

<sup>243</sup> Fredman, *Discrimination Law* (n 130) 16.

<sup>244</sup> *ibid.*

on group outcomes, any imbalance in the representation may be taken to indicate discrimination.<sup>245</sup> This may lead to preferential treatment of an underrepresented group, regardless of whether there is evidence of discrimination.<sup>246</sup>

Equality of opportunity is often presented as a middle ground between formal equality and equality of results.<sup>247</sup> Commonly illustrated by the metaphor of competitors in a race, it argues that equality cannot be achieved if people begin the race at different starting points.<sup>248</sup> This approach rejects measures intended to redress imbalances through targets or quotas, instead choosing to ‘equalise the starting point rather than the end result’.<sup>249</sup> This view of equality has also been criticised on the basis that removing barriers to participation does not guarantee that the disadvantaged group can take advantage of opportunities.<sup>250</sup> Fredman uses the example of abolishing word-of-mouth recruitment practices or non-job-related selection criteria.<sup>251</sup> While this approach removes procedural obstacles, it does not guarantee that everyone has experienced the same opportunities and therefore meets the job-selection criteria.<sup>252</sup>

An alternative approach, developed by Fredman, understands disadvantage multidimensionally.<sup>253</sup> Fredman’s framework for measuring substantive equality is based on four dimensions: redressing disadvantage; addressing stigma, stereotyping, and prejudice; enhancing participation and voice; and accommodating difference and structural change.<sup>254</sup> One of the benefits of Fredman’s approach is its ability to address the ‘interaction between different facets of inequality’, as inequality is experienced in multiple forms in society and can interact with one another.<sup>255</sup> Fredman emphasises that these dimensions are interdependent and should not be prioritised hierarchically.<sup>256</sup>

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<sup>245</sup> *ibid* 17.

<sup>246</sup> *ibid*, Chris Armstrong, ‘Debating Opportunities, Outcomes and Democracy: Young and Phillips on Equality’ (2006) 54 *Political Studies* 349 for further criticism on equality of opportunity.

<sup>247</sup> Fredman, *Discrimination Law* (n 130) 21.

<sup>248</sup> *ibid*.

<sup>249</sup> *ibid*.

<sup>250</sup> Fredman, ‘Substantive Equality Revisited’ (n 241) 723.

<sup>251</sup> *ibid*.

<sup>252</sup> *ibid*, see Andrew Mason, ‘Equality of Opportunity and Differences in Social Circumstances’ (2004) 54 *Philosophical Quarterly* 368 for further criticism of equality of opportunity.

<sup>253</sup> Fredman, ‘Substantive Equality Revisited’ (n 241) 723.

<sup>254</sup> *ibid* 727.

<sup>255</sup> *ibid* 728.

<sup>256</sup> *ibid* 736. For criticisms of Fredman’s multi-dimensional framework for substantive equality see Catherine Mackinnon, ‘Substantive Equality Revisited: A reply to Sandra Fredman’ (2016) 14 *International Journal of Constitutional Law* 739.

People with learning disabilities undoubtedly experience structural disadvantage when assessing healthcare services, as demonstrated by discussions in Chapter Two. They are more likely to die prematurely and experience avoidable deaths.<sup>257</sup> Furthermore, this group are also likely to receive worse care in NHS England compared to the general population.<sup>258</sup>

At the same time, people with learning disabilities are likely to experience stigma, stereotyping, and prejudice; these social attitudes inform the practice of healthcare workers and can lead to discriminatory views informing care and ideas around the value of the person's life.<sup>259</sup> Disadvantage is also reflected in the lack of participation and voice that people with learning disabilities are given in decisions around their own care.<sup>260</sup> This is entrenched by the lack of representation of disabled people in decision-making processes and politics.<sup>261</sup> Additionally, the second aspect of the participative dimension is the importance of community and the ability to participate on equal terms in society.<sup>262</sup> People with learning disabilities are precluded from participating in society on equal terms with others as a consequence of poor healthcare provision. The effect of lower life expectancy and worse health outcomes is that people with learning disabilities are unable to live long and healthy lives, preventing them from participating in society on equal terms.

Finally, NHS England is an institution which perpetuates structural inequality for people with learning disabilities. This has been demonstrated by the findings in Chapter Two, which show the disparity in health outcomes for people with learning disabilities. To address health inequalities, the healthcare system must be transformed to accommodate differences.

The provisions on discrimination arising from disability under Section 15 of the EqA 2010 are more closely aligned with substantive equality. Section 15 does not rely on a formal equality model as it does not require a person with a disability to be treated the same as a person without a disability. One of Fredman's criticisms of formal equality

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<sup>257</sup> White and others (n 1) 7.

<sup>258</sup> *ibid* see 27.

<sup>259</sup> Allerton and Emerson (n 78) 926.

<sup>260</sup> Mencap, 'Treat Me Well: Simple Adjustments Make a Big Difference' (2017) <<https://www.mencap.org.uk/sites/default/files/2018-07/2017.005.01%20Campaign%20report%20digital.pdf>> accessed 28 April 2025.

<sup>261</sup> Fredman, 'Substantive Equality Revisited' (n 241) 731–732.

<sup>262</sup> *ibid*.

measures is the need to find a comparator.<sup>263</sup> Formal equality requires answering the question ‘equal to whom?’. This leads to the construction of a ‘universal individual’ for whom the person discriminated against must compare themselves to.<sup>264</sup> In the context of disability, this inevitably leads to the answer ‘equal to a non-disabled person’.<sup>265</sup> Formal equality requires comparing a person with a disability to a non-disabled person. However, this fails to recognise that persons with disabilities may require differential treatment to participate equally in society.

Furthermore, as argued by Fredman, formal equality establishes the idea that non-disability is the ‘norm’ to which disabled people must be compared.<sup>266</sup> This leads to inequalities becoming further embedded in systems, as societal structures are designed around dominant groups. Any changes to these structures are then viewed as departing from the ‘norm’, rather than creating an inclusive and accessible service. This is problematic because it has the potential to minimise the perception of inequality in healthcare services. If non-disability is the norm, then any failure to meet the needs of learning-disabled people is diminished to being an outlier or exception to the service that most people get.

The EqA 2010 also contains the duty to make reasonable adjustments under Section 20. This duty requires employers and service providers to make reasonable adjustments to prevent disabled people from being disadvantaged. This is an example of a substantive equality measure in that it does not require equal treatment of persons with disabilities and those without. The thesis will return to the discussion on reasonable adjustments in Chapter Five.

This discussion of the theoretical foundations of equality is relevant when considering how equality legislation can be reformed to improve outcomes for people with learning disabilities accessing health and social care services in NHS England. However, when a person with a learning disability has differing health and social care needs, this equal treatment can lead to unequal outcomes. Therefore, the rest of this thesis will argue in favour of substantive equality measures to eliminate the health discrimination experienced by people with learning disabilities.

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<sup>263</sup> Fredman, *Discrimination Law* (n 130) 11–14; see also Connolly (n 237) 6–8.

<sup>264</sup> *ibid* 6–8

<sup>265</sup> *ibid* 12.

<sup>266</sup> *ibid* 6–8.

As discussed in Chapter Two, the NHS England Constitution commits to promoting equality by paying particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population.<sup>267</sup> This chapter demonstrated that health outcomes and life expectancy for people with learning disabilities in England are substantially behind those of the general population.<sup>268</sup>

The NHS England Constitution can be understood as supporting a substantive equality approach to healthcare provision. It recognises that certain groups in society experience unequal health outcomes and requires attention to be paid to redressing this. A substantive equality approach in healthcare would be better suited to addressing the health inequalities faced by people with learning disabilities in England. It would encourage NHS Trusts and local authorities to remove the structural barriers that affect people with learning disabilities and contribute to poorer health outcomes. The remaining chapters of this thesis will therefore argue in favour of substantive equality reforms to the British equality framework.

### 3.6. Conclusion

By the late twentieth century, there was increasing recognition that issues affecting disabled people are not matters of welfare, but of rights. Preceding the 2010 Act, the UK had a suite of equality legislation protecting different groups. This legislation has since been subsumed into a single Equality Act.<sup>269</sup> It has been argued that harmonising the legislation may have led to worse outcomes for disabled people.<sup>270</sup> This is due to a belief that there has been a loss of focus on disability, and there are concerns that combining disability with the other eight protected characteristics masks the differences between disability and other characteristics.<sup>271</sup>

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<sup>267</sup> Department of Health and Social Care (n 15).

<sup>268</sup> E.g., White (n 1); Mencap, 'Death by Indifference: 74 Deaths and Counting: A Progress Report 5 Years On' (n 72).

<sup>269</sup> Hepple, Coussey, Choudhury (n 143).

<sup>270</sup> House of Lords Select Committee (n 129).

<sup>271</sup> *ibid* para 50.

The Chapter has provided an overview of the equality framework in Britain. It discussed the asymmetric protection of disability, ensuring that reasonable adjustments can be made for disabled people without concern that a non-disabled person may claim they have been discriminated against. Furthermore, Section 3.4. outlined the provisions for direct and indirect discrimination, as well as discrimination arising from disability under the 2010 Act. It has been shown that, unlike direct and indirect discrimination, discrimination arising from disability does not require the claimant to compare unfavourable treatment with that of someone without a disability. This reflects an understanding that achieving equality may require differential treatment. Finally, Section 2.5. explored the theoretical underpinnings of equality law, arguing in favour of a substantive equality approach to recognise the multi-dimensional approach that equality law must take to fulfil the right to equality.

The purpose of Chapter Three has been to summarise the current legislation and lay the foundations for the fourth and fifth chapters, in which recommendations will be made to improve the legislation and policies governing the operation of NHS England. Chapter Four will consider ways in which the definition of disability can be improved to lessen focus on the person's medical impairment. It will also consider reforms to NHS England's policies and practices.

## Chapter Four: A Human Rights Approach to Disability

### 4.1. Introduction

This chapter builds on Chapter Three's analysis of the current legal protections for people with disabilities in Britain. This chapter evaluates the definition of disability through competing models of disability. It begins by analysing the medical model, which conceptualises disability as a purely medical phenomenon, locating the 'problem' of disability within the person, rather than recognising the external social and environmental barriers that disable people.<sup>272</sup> It will be argued that Section 6 of the Equality Act 2010 reflects a medical model by focusing on the individual's impairment and its impact on their ability to carry out 'normal day-to-day activities'. This approach locates the 'problem' of disability within the person.<sup>273</sup>

It then contrasts this with the social model, which attributes disability to environmental and societal barriers to full participation.<sup>274</sup> However, the social model has been criticised for neglecting the lived experience of impairment, including pain and the deterioration of quality of life.<sup>275</sup> Thus, an alternative conception of disability, referred to as the human rights model of disability, has emerged. While it has been debated whether the model is an alternative to or an extension of the social model, the rights-based framework recognises disability as a part of human variation and diversity, framing disability as a human rights and justice issue.<sup>276</sup>

This conceptual framework informs two key recommendations. First, the chapter will recommend that the definition of disability and disabled person under the CRPD should be adopted into the EqA 2010. The CRPD definition takes a human rights approach to disability by recognising that disabled people are autonomous rights holders, and that disability is created by the interaction between impairment and environmental and

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<sup>272</sup> McColgan (n 162) 487.

<sup>273</sup> EqA 2010, s 6.

<sup>274</sup> Union of the Physically Impaired Against Segregation, 'Fundamental Principles of Disability' (1976) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-fundamental-principles.pdf>> accessed 05 March 2025, 3 (UPIAS).

<sup>275</sup> Theresia Degener, 'A New Human Rights Model of Disability' in Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer Publishing 2017) 47.

<sup>276</sup> Gerard Quinn and Theresia Degener, *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability* (United Nations 2002) 14.

attitudinal barriers. In adopting the CRPD definition, the health inequality experienced by people with learning disabilities would be viewed as a systemic issue in NHS England, as opposed to a consequence of the person's disability.

Second, it proposes that the fundamental rights and freedoms of the CRPD should be embedded in hospital policies and practices, as well as in the laws governing healthcare provision for people with learning disabilities. This recommendation will ensure that the fundamental human rights of people with learning disabilities are respected when accessing care through NHS England.

As examined in Chapter Three, substantive equality requires the law to recognise different ways in which disadvantage is experienced, rather than treating everyone alike. Building on this discussion, this chapter contends that the human rights model of disability provides a stronger foundation for substantive equality because it accommodates both the subjective lived experience of impairment and the structural barriers faced by disabled people.

## **4.2. Social and Medical Model of Disability**

### **4.2.1. The Medical Model**

As discussed in Chapter Three, the approach to disability adopted by Section 6 EqA 2010 is a medical one.<sup>277</sup> However, it should be noted that other aspects of the Act, in particular the asymmetrical protection afforded to disability, the recognition of discrimination by association and perception, and the recognition of deemed disabilities, also reflect a social model. Furthermore, the reasonable adjustments duty goes some way towards taking account of the institutional barriers experienced by disabled people; this will be examined in greater detail in Chapter Five.

The medical model is embedded in the medical field; it conceptualises disability solely as a medical phenomenon.<sup>278</sup> Resultingly, it presents disability as a 'personal tragedy, suggesting that disability is some terrible chance event that occurs at random to

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<sup>277</sup> McColgan (n 162) 487.

<sup>278</sup> Angelica Guevara, 'The need to Reimagine Disability Rights Law because the Medical Model of Disability Fails us all' (2021) *Wisconsin Law Review* 269, 277.

unfortunate individuals.’<sup>279</sup> The person’s impairment is treated as the reason for their limited ability to participate in society, thereby locating the ‘problem’ of disability in the person.<sup>280</sup>

This approach is reflected in the statutory definition of disability under the Equality Act 2010.<sup>281</sup> The requirement for a person to demonstrate that ‘a physical or mental impairment’ focuses on ‘functional impairment’, as opposed to the ‘impairments created by society’.<sup>282</sup> The definition relies on a medicalised assessment of disability, in which the disabled person must demonstrate that they are limited by a medical factor, the physical or mental impairment.<sup>283</sup> This assumes that any limitations to participating in society stem from the individual and their impairment.<sup>284</sup> This, in turn, focuses on the effect of the impairment on the individual, rather than on societal and environmental factors that hinder equal participation in society.<sup>285</sup>

The further requirement that the impairment have a ‘substantial and long-term adverse effect’ on the individual’s ability to carry out ‘normal day-to-day activities’ entrenches this approach.<sup>286</sup> As Bunbury argues, this requirement reinforces the EqA 2010’s reliance on the medical model. The definition only considers the effect the person’s impairment has on their capacity to carry out these activities, as opposed to the ‘social and physical environmental factors’ that restrict participation.<sup>287</sup>

As discussed in Chapter Three, the decision in *Paterson* held that, when assessing the effect of an impairment on a person with a disability, the comparison is with how the individual would carry out the same activity without the impairment.<sup>288</sup> This approach centres on the person’s disability and on whether they are unable to perform an activity generally considered ‘normal day-to-day’.<sup>289</sup> This, in turn, shifts attention away from

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<sup>279</sup> *ibid* 278.

<sup>280</sup> McColgan (n 162) 480–487; Stephen Bunbury, ‘Unconscious Bias and the Medical Model: How the Social Model May Hold the Key to Transformative Thinking About Disability Discrimination’ (2019) 19 *IJDL* 26, 28.

<sup>281</sup> Katie Wells, ‘The Impact of the Framework Employment Directive on UK Disability Discrimination Law’ (2003) 32 *ILJ* 253, 261–262.

<sup>282</sup> *ibid*.

<sup>283</sup> *ibid*.

<sup>284</sup> Woodhams and Corby (n 134) 164.

<sup>285</sup> Bunbury (n 280) 35–36.

<sup>286</sup> *ibid*.

<sup>287</sup> *ibid*.

<sup>288</sup> *Paterson* (n 175).

<sup>289</sup> Wells (n 281) 258.

remedying the environmental and societal barriers to full participation. The medicalisation of disability is also evident in the heavy reliance that tribunals and courts place on medical evidence when determining whether a person is disabled under the Act.<sup>290</sup>

#### 4.2.2. The Social Model

Since the 1960s, the medical model has been increasingly challenged by the social model of disability.<sup>291</sup> The social model has served as a major political driving force for disabled people in the UK and has helped to reduce socially created barriers to participation.<sup>292</sup> The social model of disability in the UK has its origins in the publication of *The Fundamental Principles of Disability* by the Union of the Physically Impaired Against Segregation in 1976. The document states that:

*In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society.*<sup>293</sup>

Michael Oliver's work has been central to the development of this model in academic circles.<sup>294</sup> Oliver distinguished between the social model of disability and the 'individual model of disability'.<sup>295</sup> The individual model of disability encompasses a range of issues which 'locates the 'problem' of disability within the individual and [...] sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from the disability'.<sup>296</sup> It should be noted that Oliver rejected the idea that there is a medical model of disability and instead argued that there is an individual model of disability for which medicalisation is one component.<sup>297</sup>

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<sup>290</sup> Bunbury (n 280) 35.

<sup>291</sup> *ibid* 29.

<sup>292</sup> Nick Watson, 'The Dialectics of Disability: A Social Model for the 21<sup>st</sup> Century?' in Colin Barnes and Geof Mercer (eds), *Implementing the Social Model of Disability: Theory and Research* (Disability Press Leeds 2004) 102.

<sup>293</sup> UPIAS (n 274) 3.

<sup>294</sup> See Degener, 'A New Human Rights Model of Disability' (n 275) 41; Anna Lawson and Angharad Beckett, 'The Social and Human Rights Models of Disability: Towards a Complementarity Thesis' (2021) 25 *IJHR* 348, 349.

<sup>295</sup> Michael Oliver, *The Politics of Disablement* (Macmillan Press 1990).

<sup>296</sup> Michael Oliver, 'The Individual and Social Models of Disability' (1990) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Oliver-in-soc-dis.pdf>> accessed 28 May 2025, 3.

<sup>297</sup> *ibid*.

In contrast, the social model presents disability as a problem which arises because of the relationship between the disabled person and the design and structure of society, as well as the practices and attitudes of the general population.<sup>298</sup> The social model seeks to challenge the notion that the problem with disability lies within the disabled person themselves. The model distinguishes between ‘impairment’ and ‘disability’.<sup>299</sup> Impairment relates to the functional limitation regarding the physical and/or mental condition, whereas disability is a result of the response by society, which causes a loss of opportunity.<sup>300</sup>

However, the EqA 2010 continues to reflect a medicalised understanding of disability.<sup>301</sup> By requiring disabled persons to demonstrate limitations in ‘normal day-to-day activities’, the Act implicitly relies on a fixed standard of ‘normality’.<sup>302</sup> As Morris argues, such notions of normality are value-laden and tied to ideas about ‘what is right, [...] desirable and what belongs’.<sup>303</sup> The use of ‘normality’ in legal definitions risks reinforcing exclusion by positioning disabled people as outside what is considered to ‘belong’.<sup>304</sup>

#### 4.2.3. Criticisms of the Social Model

Despite the social model's significant influence, it has been subject to significant criticism.<sup>305</sup> This section does not provide a comprehensive account of all these criticisms; instead, it focuses on one major critique of the social model of disability: that it neglects the personal experience of impairment.<sup>306</sup>

Degener argues the social model ignores the reality that people with disabilities may also experience impairments symptomatic of their disability, such as pain,

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<sup>298</sup> See UN General Assembly, *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, GA Res 48/96 (20 December 1993) para 5, cited in Doyle (n 137) 11; European Commission, *Communication to the Council and the European Parliament: Towards a United Nations Legally Binding Instrument to Promote and Protect the Rights and Dignity of Persons with Disabilities* COM (2003) 16 final (24 January 2003) cited in Wells (n 180) 260.

<sup>299</sup> Degener, ‘A New Human Rights Model of Disability’ (n 275) 42.

<sup>300</sup> *ibid.*

<sup>301</sup> Bunbury (n 280).

<sup>302</sup> *ibid.* 40.

<sup>303</sup> Jenny Morris, *Pride Against Prejudice* (The Women’s Press Ltd 1991) 15–16.

<sup>304</sup> *ibid.*

<sup>305</sup> See *ibid.*; Tom Shakespeare, ‘Cultural Representation of Disabled People: Dustbins for Disavowal?’ (1994) 9 *Disability and Society* 283; Watson (n 292); Degener, ‘A New Human Rights Model of Disability’ (n 275).

<sup>306</sup> Degener, ‘A New Human Rights Model of Disability’ (n 275) 47.

deterioration of quality of life, and shorter life expectancies.<sup>307</sup> While the social model correctly identifies societal barriers as a source of disadvantage, it risks suggesting that limitations are solely socially produced, rather than also resulting from the body.<sup>308</sup>

Morris is one of the pioneers of the criticism that the social model neglects the individual experience of disability.<sup>309</sup> She argues that while the clear separation of disability and impairment in the social model has enabled disabled people to talk about their experience of disabling barriers, it has also led to difficulties in acknowledging impairment and its effects on people's lives.<sup>310</sup> She argues that this is due to pre-existing beliefs in society that the lives of those with disabilities are inherently worth less or are pitiful. According to Morris, to overcome such beliefs, many disabled people steer clear of discussions around the intrinsic experience of impairment. However, to entirely ignore the personal experience of disability would be denying the experience of many disabled people's bodies and trying to conform to a standard of what it means to be a 'full human being'.<sup>311</sup>

Furthermore, critics such as Shakespeare argue that, in everyday life, it is difficult to distinguish between the impact of social barriers and the intrinsic limitations created by impairment, as the two are 'inextricably interconnected'.<sup>312</sup> In practice, it is difficult to distinguish between limitations arising from the body and those produced by social barriers. Treating them as entirely separate obscures the complexity of lived experience with a disability. While it is important to work towards eliminating disabling social barriers, it is also necessary to recognise the negative aspects of impairment without devaluing the life of the person with a disability.<sup>313</sup>

In response, proponents of the social model have argued that the model is not intended to neglect the experience of impairment. Oliver contends that the distinction between impairment and disability is not a denial of the pain of impairment but rather 'a

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<sup>307</sup> *ibid.*

<sup>308</sup> Tom Shakespeare, 'The Social Model of Disability' in Lennard Davis (ed), *The Disability Studies Reader* (4<sup>th</sup> edn, 2013 Routledge) 328.

<sup>309</sup> Jenny Morris, 'Impairment and Disability: Constructing an Ethics of Care that Promotes Human Rights' (2001) 16 *Hypatia* 1.

<sup>310</sup> *ibid* 9–10.

<sup>311</sup> *ibid.*

<sup>312</sup> Shakespeare, 'The Social Model of Disability' (n 308) 329.

<sup>313</sup> Mairian Corker and Sally French, 'Reclaiming Discourse in Disability Studies' in Mairian Corker and Sally French (eds), *Disability Discourse* (OUP 1999) 6.

pragmatic attempt to identify and address issues that can be changed through collective action rather than professional and medical treatment’.<sup>314</sup>

However, the defence does not fully address the critique that it is the interaction between impairment and societal barriers which produces disability. Corker and French argue that the social model presents disability and impairment as a ‘dualism or dichotomy’ in which it fails to ‘conceptualise a mutually constitutive relationship between impairment and disability which is both materially and discursively (socially) produced.’<sup>315</sup> As such, to treat the two as entirely different is to neglect the lived experiences of many people with disabilities who encounter both impairment and socially produced disability as an interconnected phenomenon.

Finally, Degener highlights that the social model does not explain why disabled persons should be recognised as people before the law with human rights capacity.<sup>316</sup> While it explains how exclusion occurs, it does not fully justify why disabled people should be afforded rights that respect their dignity and serve as a foundation for preventing exclusion in disability policy.<sup>317</sup>

#### 4.2.4. Significance of the Medical and Social Model

The limitations of the medical and social models are particularly relevant in the context of healthcare inequalities experienced by people with learning disabilities. As discussed above, one criticism of the medical model is that it presents the person’s limited ability to participate in society to be as a result of their impairment.<sup>318</sup> To address diagnostic overshadowing and poor-quality healthcare arising from stereotypical attitudes, it is necessary to move away from a medicalised understanding of disability. This approach can lead to the assumption that health inequalities experienced by people with learning disabilities are caused by their impairment, rather than inadequate care.

Conversely, the social model may neglect the personal experiences of impairment by people with learning disabilities.<sup>319</sup> It is important in healthcare that professionals

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<sup>314</sup> Oliver, *The Politics of Disablement* (n 295).

<sup>315</sup> Mairian Corker and Sally French, *Disability Discourse* (OUP 1999) 2; 6.

<sup>316</sup> Degener, ‘A New Human Rights Model of Disability’ (n 275) 43.

<sup>317</sup> *ibid.*

<sup>318</sup> Bunbury (n 280) 28.

<sup>319</sup> Degener, ‘A New Human Rights Model of Disability’ (n 275) 47.

recognise and understand the health challenges experienced by people with learning disabilities, without devaluing the person's life.<sup>320</sup> What is required is an approach that recognises both the structural barriers identified by the social model and the lived realities of impairment, while grounding disability in principles of dignity, equality, and legal rights. This is reflected in the human rights model of disability, which will be examined in the following section.

#### 4.2.5. An Emerging Human Rights Model of Disability

As a result of the criticisms of the social model, an array of alternative conceptions of disability have emerged.<sup>321</sup> One of the most influential being the human rights model.<sup>322</sup> While there is no single definition of this model of disability, proponents generally agree that it focuses on 'the inherent dignity of the human being', acknowledging that all people possess 'inherent self-worth'.<sup>323</sup> The model frames disability as a matter of rights and justice, while continuing to locate the 'problem' of disability outside of the person and within society.<sup>324</sup>

Degener argues that the human rights model recognises impairment as part of human variation and diversity.<sup>325</sup> As discussed, the social model has been criticised for neglecting the experiences of pain, early death, and the deterioration of quality of life associated with impairment. According to Degener, the human rights model acknowledges these experiences alongside societal barriers to participation and requires that both be acknowledged.<sup>326</sup> By recognising disability as a part of human diversity, the model incorporates the experience of impairment while maintaining that persons with disabilities are entitled to human rights and freedoms on an equal basis with others. Furthermore, while the human rights model, like the social model, locates the 'problem' of disability

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<sup>320</sup> Michael Brown and others, 'Learning disability Liaison Nursing Services in South-East Scotland: A Mixed-Methods Impact and Outcome Study' (2012) 56 *Journal of Intellectual Disability Research* 1161.

<sup>321</sup> See Sophie Mitra, 'The Capability Approach and Disability' (2006) 16 *Journal of Disability Policy Studies* 236; Anne Waldschmidt, 'The Cultural Model of Disability as an Analytical Tool' in Anne Waldschmidt, Hanjo Berressem, Moritz Ingwersen (eds), *Culture - Theory - Disability* (Transcript Verlag 2017).

<sup>322</sup> Lawson and Beckett (n 294) 349.

<sup>323</sup> Quinn and Degener (n 276) 14; see also Michael Stein and Penelope Stein, 'Beyond Disability Civil Rights' (2007) 58 *Hastings Law Journal* 1203, 1223.

<sup>324</sup> *ibid.*

<sup>325</sup> Degener, 'A New Human Rights Model of Disability' (n 275) 47.

<sup>326</sup> *ibid* 47–49; see also Theresia Degener, 'Disability in a Human Rights Context' (2016) 5 *Laws* 35, 40–42.

outside the individual, it reconceptualises this problem as stemming from ‘a lack of responsiveness by the State and civil society to the difference that disability represents’.<sup>327</sup>

The exact role of the human rights model is contested.<sup>328</sup> Some argue that it extends and improves upon the social model, while Lawson and Beckett argue that the two models are complementary and play distinct roles in advancing the rights of disabled people.<sup>329</sup> However, these debates fall beyond the scope of this thesis. For the following discussion, it is sufficient to note that the human rights model introduces a disability rights framework that focuses on reducing societal barriers to participation and recognises persons with disabilities as autonomous, rights-bearing individuals.<sup>330</sup>

### 4.3. The United Nations Convention on the Rights of Persons with Disabilities

Building on the discussion of the different models of equality, the thesis will argue that the CRPD takes a human rights approach by recognising that persons with disabilities are entitled to the same human rights protections as those without. This analysis will lead to the first recommendation of the thesis: that the current definition of disability under the EqA 2010 should be revised to incorporate the CRPD’s human rights-focused definition. This is relevant to healthcare provision for people with learning disabilities, as the CRPD definition of disability acknowledges the experience of impairment while recognising that people with learning disabilities still have fundamental human rights. These rights include equal access to healthcare and health outcomes.<sup>331</sup>

#### 4.3.1. The Human Rights Model Under the CRPD

The CRPD was adopted on 13 December 2006.<sup>332</sup> It is the first international human rights treaty to comprehensively codify and consolidate the universal rights of persons with

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<sup>327</sup> *ibid.*

<sup>328</sup> *ibid.*

<sup>329</sup> Lawson and Beckett (n 294) 349–350.

<sup>330</sup> Andrea Broderick and Delia Ferri, *International and European Disability Law and Policy: Text, Cases and Materials* (CUP 2019) 24.

<sup>331</sup> See Emerson and others (n 4) 2–5.

<sup>332</sup> Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) UNGA Res 61/106, Annex I (CRPD).

disabilities.<sup>333</sup> To date, 191 countries have signed and ratified the CRPD, and 107 have ratified its Optional Protocol.<sup>334</sup> The UK ratified the Convention and its Optional Protocol on 9 June 2009, thereby committing to revising domestic law to achieve compliance with the Convention's provisions.<sup>335</sup> However, the UK operates a dualist system, meaning that ratification of an international treaty does not, by itself, make it a part of domestic law. Accordingly, although the UK has ratified the CRPD, it has not been incorporated into the domestic legal framework.

The adoption of the CRPD is widely regarded as marking a shift in attitude from a medical to a human rights approach to disability rights protection.<sup>336</sup> Although the text of the CRPD does not explicitly refer to a 'human rights model', many proponents of the model identified a connection between the CRPD and this framework.<sup>337</sup> As discussed, the medical model conceptualises disability as an individual problem and exclusion is seen as resulting from the person's impairment. Whereas the CRPD Committee notes that the human rights model views disability as socially constructed, while also acknowledging the impact of impairment on the person.<sup>338</sup>

During negotiations for the CRPD, it was agreed that the medical model would not be a suitable approach for the drafting of the Convention.<sup>339</sup> Kayess and French explain that this is because it frames disability as an individual affliction requiring cure or treatment, with the aim of assimilating the person into society.<sup>340</sup> This approach was

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<sup>333</sup> Coomara Pyaneandee, *International Disability Law: A Practical Approach to the United Nations Convention on the Rights of Persons with Disabilities* (Routledge 2019) xxiii.

<sup>334</sup> Optional Protocol to the Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) UNGA Res 61/106, Annex II; See also United Nations Human Rights Office of the High Commissioner, 'Status of Ratification: Convention on the Rights of Persons with Disabilities' <<https://indicators.ohchr.org/>> accessed 15 April 2025.

<sup>335</sup> Wayne Martin and others, 'Achieving CRPD Compliance: Is the Mental Capacity Act of England and Wales Compatible with the UN Convention on the Rights of Persons with Disabilities? If Not, What Next?' (Essex Autonomy Project 2014) <<https://repository.essex.ac.uk/13624/1/EAP-Position-Paper-FINAL-copy.pdf>> accessed 19 March 2026, 1.

<sup>336</sup> Broderick and Ferri (n 330).

<sup>337</sup> See Degener, 'Disability in a Human Rights Context' (n 326); Stein and Stein (n 323).

<sup>338</sup> Committee on the Rights of Persons with Disabilities, 'General Comment No. 6 (2018) on Equality and Non-Discrimination' (26 April 2018) UN Doc CRPD/C/GC/6, paras 9, 73(b).

<sup>339</sup> See Rosemary Kayess and Phillip French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 Human Rights Law Review 1.

<sup>340</sup> *ibid* 5.

considered incompatible with the Convention's purpose of recognising persons with disabilities as 'subjects of rights'.<sup>341</sup>

The social model of disability heavily influenced the negotiations of the CRPD. However, Degener argues that while the social model explains the exclusion of disabled people from society, it does not provide 'moral principles or values as a foundation for disability policy'.<sup>342</sup> In contrast, the human rights model recognises persons with disabilities as autonomous rights holders, grounded in universal rights that are not contingent upon 'a certain health status or condition of functioning'.<sup>343</sup> Accordingly, disability policy is justified by the person's status as a human being.<sup>344</sup>

The human rights approach to disability in the CRPD is reflected in Article 1, which states that the purpose of the Convention is:

*to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.*

Thus, the CRPD affirms the status of persons with disabilities as rights holders. As mentioned in section 4.2.5., this thesis does not seek to resolve whether the human rights model replaces or complements the social model. However, it clearly demonstrates that the CRPD adopts a fundamentally different approach to disability from that of the EqA 2010. Whereas the Act reflects a medical model, the Convention recognises persons with disabilities as rights-bearing individuals entitled to the same fundamental freedoms and protections as those without disabilities.

#### **4.3.2. The (Non-)Definition of Disability**

During the negotiation phase of the CRPD, the question of whether disability should be defined was contested. The International Disability Caucus ('IDC') was established to unify and coordinate NGOs representing persons with disabilities throughout the drafting

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<sup>341</sup> *ibid* 3.

<sup>342</sup> Degener, 'Disability in a Human Rights Context' (n 326) 38.

<sup>343</sup> *ibid*.

<sup>344</sup> *ibid*.

of the Convention.<sup>345</sup> Many European states and NGOs argued that it would be impossible to come to a consensus on a definition, and that any definition would risk becoming outdated or excluding certain groups of persons with disabilities.<sup>346</sup> A large number of states were also concerned that too broad a definition would compel them to recognise impaired groups not traditionally understood as persons with disabilities in domestic legislation.<sup>347</sup> For example, persons with psycho-social disabilities and those with blood-borne organisms causing disease, such as HIV/AIDs.<sup>348</sup>

Furthermore, the IDC argued that any definition would derive from the medical model of disability.<sup>349</sup> It emphasised that understandings of ‘disability’ as a social category evolve over time and vary between societies. Incorporating a definition of disability ran the risk of ‘time-locking the CRPD and imposing a western view of disability on non-western cultural systems’.<sup>350</sup>

Despite these concerns, it was determined that a definition of disability would be necessary. Proponents of a definition argued that, without it, national definitions of disability would prevail, potentially leaving large groups of persons with disabilities without protection under the Convention in countries with more restricted definitions.<sup>351</sup>

As discussed, the EqA 2010 adopts a medicalised definition of disability under Section 6. In contrast, the CRPD relies on a less prescriptive and open-ended definition.<sup>352</sup> The Convention defines disability in the Preamble (which is not legally binding) and in Article 1.<sup>353</sup> The Preamble, at recital (e), provides that:

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<sup>345</sup> Stefan Tromel, ‘A personal perspective on the drafting history of the United Nations Convention on the Rights of Persons with Disabilities’ in Gerard Quinn and Lisa Waddington (eds), *European Yearbook of Disability Law* (1<sup>st</sup> edn, Intersentia 2009) 117.

<sup>346</sup> *ibid* 121.

<sup>347</sup> Kayess and French (n 339) 23.

<sup>348</sup> *ibid*.

<sup>349</sup> *ibid*.

<sup>350</sup> *ibid*.

<sup>351</sup> Tromel (n 345) 121.

<sup>352</sup> Broderick and Ferri (n 330) 65.

<sup>353</sup> Rachele Cera, ‘Preamble’ in Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer Publishing 2017) 80.

*...disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.*

The Preamble makes a clear reference to the human rights model of disability.<sup>354</sup> It defines disability as the product of the interaction between ‘persons with impairments’ and ‘environmental barriers’ which hinder ‘full and effective participation in society’. Moreover, the Preamble accedes to the IDC’s notion that disability is ‘an evolving concept’, enabling the Convention to adapt to changing understandings of disability.<sup>355</sup>

The definition of disability is provided under the second paragraph of Article 1 of the Convention:

*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*

While agreement on the Preamble was relatively straightforward, reaching agreement on the definition of ‘persons with disabilities’ proved more challenging.<sup>356</sup> Initially, the IDC argued in favour of a very long and non-exhaustive list of disabilities, including ‘physical, sensory, psychosocial, intellectual, neurological, and medical impairments and conditions’.<sup>357</sup> However, this proposal was unsuccessful.

During the drafting stages, there was general agreement that, if a definition of disability were to be included in the Convention, it should reflect the social model rather than the medical model.<sup>358</sup> However, Degener argues that the Convention goes beyond the social model and ‘codifies a human rights model of disability’.<sup>359</sup> Furthermore, according to Della Fina, this approach has been reiterated by the CRPD Committee in several

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<sup>354</sup> *ibid* 84.

<sup>355</sup> Valentina Della Fina, ‘Article 1 [Purpose]’ in Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer Publishing 2017) 97.

<sup>356</sup> Tromel (n 345) 122.

<sup>357</sup> Della Fina, ‘Article 1 [Purpose]’ (n 355) 98.

<sup>358</sup> *ibid* 95; World Health Organization, ‘Towards a Common Language for Functioning, Disability and Health: ICF – The International Classification of Functioning, Disability and Health: Introduction’ (World Health Organization 2002) <<https://cdn.who.int/media/docs/default-source/classification/icf/icfbeginnersguide.pdf>> accessed 15 November 2025, 8–9.

<sup>359</sup> Degener, ‘A New Human Rights Model of Disability’ (n 275) 42.

concluding observations. In these, the Committee has identified that some States Parties rely on definitions of disability that do not conform to the Convention's 'human rights-based model of disability'.<sup>360</sup>

The wording of Article 1 makes it clear that it is to be interpreted as a non-exhaustive list, as the second paragraph 'contains an open description or non-definition of disabilities'.<sup>361</sup> The Convention therefore adopts a broader approach to disability than the EqA 2010, which limits disability to 'physical or mental impairment'. Nonetheless, it is not self-evident which other categories of impairment fall within this definition.<sup>362</sup> Moreover, like the EqA 2010, the Convention is limited in that it only considers 'long-term' impairments.<sup>363</sup> Notwithstanding these limitations, the Convention still represents a significant improvement to the Section 6 EqA 2010 definition of disability, as it departs from the medical model and follows a human rights-based approach to disability.

#### 4.3.3. Recommendation One: Adopt the CRPD Definition of Disability

Building on this discussion, the first recommendation of the thesis is to adopt the definitions of disability and persons with disabilities under the CRPD into the EqA 2010.<sup>364</sup> The CRPD definition moves away from the medical model on which Section 6 of the EqA 2010 relies. Instead, it recognises the inherent dignity and human rights of people with disabilities. Establishing that an individual falls within the statutory definition of disability under the Equality Act 2010 is a prerequisite to bringing disability discrimination claims under the Act, thereby making the statutory definition an important consideration.

Adopting a human rights model of disability has the potential to improve health outcomes for people with learning disabilities. Furthermore, shifting the legal framework from an exclusive focus on impairment to an understanding that social and environmental barriers also disable people can play an important role in shaping systemic and social attitudes to people with learning disabilities. As argued by Sunstein, legal rules can change

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<sup>360</sup> Della Fina, 'Article 1 [Purpose]' (n 355) 98; see also Committee on the Rights of Persons with Disabilities, 'Concluding observations on the initial report of China' (15 October 2012) UN Doc CRPD/C/CHN/CO/1, para 9; Committee on the Rights of Persons with Disabilities, 'Concluding observations on the initial report of Azerbaijan' (12 May 2014) UN Doc CRPD/C/AZE/CO/1, para 9.

<sup>361</sup> Marianne Schulze, *Understanding the UN Convention on the Rights of Persons with Disabilities: A Handbook on the Human Rights of Persons with Disabilities* (3<sup>rd</sup> edn, Handicap International 2010) 34.

<sup>362</sup> Kayess and French (n 339) 23–24.

<sup>363</sup> Della Fina, 'Article 1 [Purpose]' (n 355) 98.

<sup>364</sup> CRPD, preamble recital (e), art 1.

attitudes by signalling what society regards as acceptable or unacceptable.<sup>365</sup> Therefore, reforming the definition of disability has the potential to reshape societal attitudes and institutional cultures towards disability.<sup>366</sup>

This change would affect how health and social care services in NHS England understand disability and disadvantage. Adopting the CRPD definitions recognises that disadvantage is not solely medically determined but also arises from service designs that fail to consider the needs of persons with learning disabilities. Furthermore, a human rights approach would reinforce that equal access to healthcare for people with learning disabilities is a fundamental right. As such, health and care service providers in NHS England would need to consider this when designing and operating services. Failures in healthcare provision would therefore be understood not merely as service failures, but as breaches of fundamental rights.

#### **4.4. Rights and Obligations Under the CRPD**

While the first recommendation has the potential to shift attitudes and approaches to healthcare provision, it is unlikely to be sufficient on its own to improve health outcomes for people with learning disabilities in NHS England. Definitional reform itself will not impose substantive duties and obligations on health and social care providers. As such, this section recommends that the rights and obligations guaranteed by the Convention be more effectively reflected in healthcare policy, practice, and the domestic legal framework regulating healthcare decision-making for people with learning disabilities.

Chapter Three presented findings from the Select Committee on the Equality Act 2010, which concluded that incorporating disability within a single Act alongside other protected characteristics has led to a loss of focus on disability and risks obscuring its distinct nature.<sup>367</sup> Although the report recognised the impracticality of creating separate legislation, incorporating the rights and obligations set out in the CRPD into healthcare policy could address this loss of visibility for people with disabilities, particularly those

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<sup>365</sup> Cass Sunstein, 'On the Expressive Function of Law' (1995) 144 *University of Pennsylvania Law Review* 2021.

<sup>366</sup> Richard McAdams, 'A Focal Point Theory of Expressive Law' (2000) 86 *Virginia Law Review* 1649.

<sup>367</sup> House of Lords Select Committee (n 129) 5.

with learning disabilities.<sup>368</sup> This would ensure that their fundamental rights are treated as a central consideration in legislation and policy.

The Equality Act 2010 focuses on protection from discrimination, including direct, indirect, and disability-related discrimination. However, it provides little by way of guaranteeing substantive rights or freedoms for people with disabilities. By contrast, the CRPD not only protects persons with disabilities against discrimination but also establishes a framework of enforceable rights and obligations. As discussed in Chapter Three, many claims under the Equality Act 2010 depend upon comparing the treatment of a disabled person with that of a non-disabled comparator.<sup>369</sup> By contrast, the CRPD does not require persons with disabilities to establish less favourable treatment through a comparator. Instead, the Convention focuses on whether they are able to enjoy their fundamental rights and freedoms on an equal basis with others, reflecting its human rights focus.

#### **4.4.1. CRPD Rights and Obligations in Healthcare**

Of particular relevance to healthcare provision for those with learning disabilities are: the right to life (Article 10), liberty and security of the person (Article 14), protecting the integrity of the person (Article 17), equal recognition before the law (Article 12), and health (Article 25).

##### **4.4.1.1. Article 10: Right to Life**

Article 10 of the CRPD provides that ‘every human being has the inherent right to life and [state parties] shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others’. Bruno emphasises that the ‘inherent’ nature of the right to life reflects that the right is not conferred on individuals by society or the State; it is intrinsic to one’s humanity.<sup>370</sup> Therefore, the State should take all necessary measures to ensure the effective enjoyment of the right to life.<sup>371</sup>

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<sup>368</sup> *ibid* para 50.

<sup>369</sup> Although disability-specific provisions such as section 15 depart from this approach.

<sup>370</sup> Giovanni Carlo Bruno, ‘Article 10 [Right to Life]’ in Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer Publishing 2017) 250.

<sup>371</sup> *ibid*.

In the context of the significant health inequalities experienced by people with learning disabilities in England, this obligation extends beyond protection from harm to include positive measures. It requires States to take preventative measures to ensure that persons with disabilities can enjoy equitable health outcomes and the right to life on an equal basis with others.<sup>372</sup>

#### 4.4.1.2. Articles 12, 14 and 17

Article 14 protects the right to liberty and security of the person. Importantly, the article prevents the unlawful and arbitrary deprivation of liberty, and the existence of a disability shall in no case justify such a deprivation.<sup>373</sup> It also requires that, where deprivation of liberty occurs, persons with disabilities are afforded the same human rights protections as others.<sup>374</sup>

Article 14 assumes a special importance for any person with learning disabilities because this group often require a broad range of services to exercise their legal capacity and to live in the community.<sup>375</sup> Furthermore, those with learning disabilities are more likely to be subject to unlawful or arbitrary detention.<sup>376</sup>

Article 14 is further legitimised by Article 17, protecting the integrity of the person. It provides that '[e]very person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others'. As Keys notes, 'mental health laws generally legitimise state intervention by permitting coercive treatment and other forms of restrictive practices while providing some safeguards for the person'.<sup>377</sup> These mental health laws do so by relying on substitute decision-making to override the person's legal capacity.<sup>378</sup> An example of this is the Mental Capacity Act 2005 (hereafter, 'MCA'), which will be discussed further in the next section.<sup>379</sup>

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<sup>372</sup> See Department of Health and Social Care (n 15).

<sup>373</sup> CRPD, art 14(1)(b).

<sup>374</sup> CRPD, art 14(2).

<sup>375</sup> Francesco Seatzu, 'Article 14 [Liberty and Security of Person]' in Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer Publishing 2017) 297.

<sup>376</sup> *ibid.*

<sup>377</sup> Mary Keys, 'Article 17 [Protecting the Integrity of the Person]' in Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer Publishing 2017) 330–331.

<sup>378</sup> *ibid.*

<sup>379</sup> Applying to England and Wales.

Likewise, Article 12, which concerns equal recognition before the law, has cast further doubt on current national mental health laws.<sup>380</sup> It echoes the Preamble, affirming the importance of inherent dignity, freedom of choice, and autonomy.<sup>381</sup> As argued by Keys, these ‘principles are respected through the equal recognition of the legal capacity of all persons with disabilities’.<sup>382</sup> Of relevance to the thesis is Article 12(4), which requires appropriate and effective safeguards to ensure respect for the ‘rights, will, and preferences’ of disabled persons in matters relating to the exercise of legal capacity.

#### 4.4.1.3. *The Mental Capacity Act 2005 (MCA)*

A full analysis of the MCA is beyond the scope of this thesis.<sup>383</sup> This section instead highlights one area in which the MCA is not fully compliant with the CRPD. This example will demonstrate the importance of aligning domestic law with the Convention to improve health outcomes for people with learning disabilities.

The MCA provides the legal framework for determining whether a person lacks the capacity to make a particular decision and for deciding which medical decisions should be made on their behalf.<sup>384</sup> However, the Essex Autonomy Project, commissioned by the Ministry of Justice, found that the MCA is not compliant with the CRPD.<sup>385</sup> It was argued that the MCA is currently non-compliant with the CRPD, particularly, the definition of ‘mental incapacity’ under Section 2(1).<sup>386</sup>

Under Section 2(1) MCA, a person lacks capacity if ‘he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain’. Notwithstanding this, the MCA presumes capacity unless it is established otherwise.<sup>387</sup> However, as argued by the Essex Autonomy

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<sup>380</sup> Fiona Morrissey, ‘The United Nations Convention on the Rights of Persons with Disabilities: A New Approach to Decision-Making in Mental Health Law’ (2012) 19 *European Journal of Health Law* 423, 425.

<sup>381</sup> Mary Keys, ‘Article 12 [Equal Recognition Before the Law]’ in Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer Publishing 2017) 265.

<sup>382</sup> *ibid.*

<sup>383</sup> See Kay Wheat, ‘The Law Relating to Mental Capacity and Mental Health’ in Tom Denning and others (eds), *Oxford Textbook of Old Age Psychiatry* (3<sup>rd</sup> edn, OUP 2020); Anna Smajdor and others, *Oxford Handbook of Medical Ethics and Law* (OUP 2021).

<sup>384</sup> NHS, ‘Mental Capacity Act’ (2024) <<https://www.nhs.uk/social-care-and-support/making-decisions-for-someone-else/mental-capacity-act/>> accessed 26 March 2026.

<sup>385</sup> Martin and others (n 335).

<sup>386</sup> *ibid* at executive summary.

<sup>387</sup> MCA 2005, s 1(2).

Project, the MCA's definition of incapacity seems to treat people differently based on certain cognitive impairments.<sup>388</sup> The definition relies on the presence of a disability, constituting 'discrimination against those with disabilities that impair cognitive performance'.<sup>389</sup>

Bartlett further argues that the presence of a disability as a reason to determine incapacity is theoretically problematic, as people may hold false beliefs for a variety of reasons.<sup>390</sup> However, why should it be the case that a false medical belief held due to a mental disability should not be respected when an equally indefensible reason, such as online misinformation, would result in the decision being respected?<sup>391</sup> As such, the MCA treats people with disabilities, specifically those with learning disabilities, differently under the law. Under Article 12 CRPD, this raises concerns about unequal treatment before the law. It has been recommended that this approach be abandoned in favour of a statutory test that does not focus on the presence of a disability.<sup>392</sup>

Empirical research also highlights significant gaps in health and social care professionals' understanding of mental capacity in assessments of people with learning disabilities.<sup>393</sup> Furthermore, although the MCA operates on the presumption of capacity unless otherwise established, a study of support workers found that this presumption is not upheld in practice.<sup>394</sup> For people relying on specialist services for everyday support, many routine decisions were made on their behalf and justified by 'unmitigated constructions of service users lacking capacity'.<sup>395</sup> This suggests systemic issues in both compliance and the correct use of the MCA in NHS England for patients with learning disabilities.

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<sup>388</sup> Martin and others (n 335) 3–4.

<sup>389</sup> *ibid*; see also Peter Bartlett, 'The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law' (2012) 75 MLR 696, 762.

<sup>390</sup> Peter Bartlett, 'Re-thinking the Mental Capacity Act 2005: Towards the Next Generation of Law' (2023) 86 MLR 599, 687.

<sup>391</sup> *ibid*.

<sup>392</sup> Bartlett, 'The UN CRPD and Mental Health Law' (n 385) 762–764.

<sup>393</sup> Daniel Ratcliff and Melanie Chapman, 'Health and Social Care Practitioners' Experiences of Assessing Mental Capacity in a Community Learning Disability Team' (2016) 44 British Journal of Learning Disabilities 259; Indermeet Sawhney, 'Mental Capacity Act 2005: Views and Experiences of Learning Disability Psychiatrists' (2018) 33 Psychiatric Bulletin 234.

<sup>394</sup> Treena Jingree, 'Duty of Care, Safety, Normalisation and the Mental Capacity Act: A Discourse Analysis of Staff Arguments about Facilitating Choices for People with Learning Disabilities in UK Services' (2015) 25 Community and Applied Social Psychology 138.

<sup>395</sup> *ibid* 148.

There has been an ongoing debate over whether substitute decision-making is compatible with the CRPD at all.<sup>396</sup> In General Comment No. 1, the Committee on the Rights of Persons with Disabilities makes clear that compliance with Article 12 requires States Parties to abolish all substitute decision-making regimes.<sup>397</sup> Although General Comments are not legally binding, they can be influential in developing policy positions.<sup>398</sup> Substitute decision-making occurs where one person makes a decision on behalf of another who is deemed to lack mental capacity in relation to that decision.<sup>399</sup> However, others have argued that removing such frameworks would be unworkable, as in some situations a person may lack the capacity to make a decision, even with support. In such cases, it may be necessary, in the interests of the person, to make a decision.<sup>400</sup>

This thesis does not seek to resolve this debate. Rather, it highlights an example of how the current legal framework treats people with learning disabilities unequally before the law, raising concerns about compliance with the CRPD.

#### 4.4.1.4. *Article 25: Health*

Finally, Article 25 of the Convention recognises the right to health. As discussed, people with learning disabilities experience disproportionately worse health outcomes in England and have a significantly lower average age at death. Article 25 recognises ‘that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability’. Additionally, persons with disabilities should be provided with the health services they require, ‘specifically because of their disabilities’.<sup>401</sup> This is also in line with the aims of NHS England’s Constitution, discussed in Chapter Two, to promote equality through service provision. It reflects the Constitution’s requirement to pay particular attention to groups whose health and life expectancy are not keeping pace with the rest of the population.<sup>402</sup>

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<sup>396</sup> See Bartlett, ‘The UN CRPD and Mental Health Law’ (n 385).

<sup>397</sup> Committee on the Rights of Persons with Disabilities, ‘General Comment No. 1 (2014): Article 12: Equal Recognition before the Law’ UN Doc CRPD/C/GC/1, 11 April 2014, paras 3, 27–28.

<sup>398</sup> Helen Keller and Leena Grover, ‘General Comments of the Human Rights Committee and their Legitimacy’ in Helen Keller and others (eds), *UN Human Rights Treaty Bodies: Law and Legitimacy* (CUP 2012) 128–129.

<sup>399</sup> Mary Keys, ‘Article 12 [Equal Recognition Before the Law]’ (n 377) 269–270

<sup>400</sup> Martin and others (n 335) 28.

<sup>401</sup> CRPD, 25(b).

<sup>402</sup> Department of Health and Social Care (n 15).

Consistent with the CRPD's shift away from a medical model and towards a rights-based model of disability, it is recognised in the Convention that health and disability are not 'mutually exclusive'.<sup>403</sup> It should not be assumed that because a person has a disability, they should experience worse health outcomes or care.<sup>404</sup> In practice, this means that health and care services in NHS England have an obligation to ensure that people with learning disabilities can access healthcare free from discrimination or stigmatisation.<sup>405</sup> Moreover, they must work towards achieving equal health outcomes for people with learning disabilities that are equal to those of the general population.

This obligation is particularly salient in light of findings that people with learning disabilities face inequitable access to organ transplantation on the basis of their disability and perceived inability to make decisions.<sup>406</sup> As such, recognising the importance of equal health outcomes is necessary to ensure that patients with learning disabilities have equal opportunity to receive lifesaving treatments and interventions that can substantially improve their quality of life.<sup>407</sup>

#### **4.4.2. Recommendation Two: Implementation of the CRPD Rights and Obligations into the UK Legal Framework**

Definitional reform, as proposed in Recommendation One, is unlikely on its own to bring about the changes necessary to address the health inequalities experienced by people with learning disabilities in NHS England. Therefore, the second recommendation is to implement the CRPD rights into the national legal framework. As it currently stands, the UK's dualist system means that, despite ratifying the Convention, it has little effect within the legal system due to the lack of incorporation. To prevent these rights from remaining merely aspirational, it is necessary to incorporate them into the national legal framework. The CRPD's rights-based framework, which guarantees fundamental rights and obligations, should serve as guiding principles for determining NHS policies and practices, as well as for lawmakers when designing statutes governing healthcare practice.

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<sup>403</sup> Ilja Richard Pavone, 'Article 25 [Health]' in Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer Publishing 2017) 475–476.

<sup>404</sup> *ibid.*

<sup>405</sup> *ibid* 478.

<sup>406</sup> Rebecca Thom and others, 'Inequitable Access to Transplants: Adults with Impaired Decision-Making Capacity' (2022) 35 *Transplant International* 10084.

<sup>407</sup> *ibid.*

This section has provided one example, the MCA, to demonstrate how the current framework discriminates against people with learning disabilities. However, there are many further examples within health and care services that require consideration.<sup>408</sup>

In light of Fredman's four-dimensional framework of substantive equality discussed in Chapter Three, more effective implementation of CRPD rights and obligations has clear transformative potential.<sup>409</sup> By embedding the fundamental human rights of people with learning disabilities into healthcare law and practice, this approach requires the restructuring of systems and institutions that currently produce disadvantage.<sup>410</sup> In this way, healthcare practices would need to be redesigned to accommodate the needs of learning disabled patients, rather than expecting them to conform to existing structures. As such, this recommendation can be understood as a substantive equality measure.

#### 4.5. Conclusion

This chapter has advanced a case for a rights-based approach to disability discrimination. It began by examining competing models of disability and equality, criticising the medical model for locating the 'problem' of disability within the person, rather than recognising disability as a socially constructed phenomenon. It then considered the social model, which distinguishes between impairment and disability, and emphasises the role of attitudinal and environmental barriers in producing disadvantage. This provided the foundation for a human rights approach that reframes disability as a rights and justice issue.<sup>411</sup> This approach also reinforces the substantive equality framework discussed in Chapter Three. Unlike the medical and social models, the human rights model accommodates both the lived and subjective experience of impairment and the structural barriers that disadvantage people with disabilities. In doing so, it provides a stronger basis for achieving substantive equality.

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<sup>408</sup> E.g., The Mental Health Act 1983, amended in 2007; Sheila Hollins and others, 'The Case for Removing Intellectual Disability and Autism from the Mental Health Act' (2019) 215 *British Journal of Psychiatry* 633. Both statutes have now been replaced by the Mental Health Act 2025, full implementation will be phased over eight to ten years.

<sup>409</sup> Fredman, 'Substantive Equality Revisited' (n 241) 732.

<sup>410</sup> *ibid.*

<sup>411</sup> Quinn and Degener (n 276) 14; Stein and Stein (n 323) 1223.

Building on this theoretical framework, the chapter analysed the CRPD. It recommended that the medical-model-based definition of disability in Section 6 of the EqA 2010 should be replaced with the CRPD's definition of disability and persons with disabilities.<sup>412</sup> The CRPD adopts a human rights-based approach, understanding disability as arising from the interaction between impairment and environmental barriers, while affirming the fundamental rights of persons with disabilities. Reframing disability in this way has the potential to improve healthcare provision for people with learning disabilities by shifting the focus from individual impairment to the structural and attitudinal barriers that generate health inequalities.

The chapter then advanced the second recommendation, that NHS policies, practices, and the legal framework governing healthcare should more fully reflect the rights and obligations set out in the CRPD. This approach aligns with a substantive equality framework by requiring not only formal recognition of rights but also the transformation of institutional structures that disadvantage people with learning disabilities.

Chapter Five extends this analysis by examining the reasonable adjustments duty under section 20 of the EqA 2010. It argues that the duty reflects a substantive equality approach and makes the case for its more effective implementation within healthcare settings.

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<sup>412</sup> CRPD, preamble recital (e), art 1.

## Chapter Five: The Duty to Make Reasonable Adjustments

### 5.1. Introduction

This chapter builds on the recommendations from the previous chapter on ways to reduce the health inequalities experienced by people with learning disabilities. It argues that, while the duty to make reasonable adjustments has the potential to achieve substantive equality in healthcare for people with learning disabilities, this is not realised in practice. This failure is attributed to the inconsistent application and underuse of the duty within NHS England. Drawing on interdisciplinary medical research, the chapter proposes a series of reforms aimed at strengthening its effective implementation.

The chapter has three clear aims. First, it maps the legal framework of the reasonable adjustments duty under the EqA 2010.<sup>413</sup> Second, it examines how the duty is used within NHS England in relation to people with learning disabilities. Third, it advances recommendations to improve the implementation of the duty in health and social care services, with the aim of enhancing health outcomes for people with learning disabilities. The recommendation will also propose practical ways to use the duty effectively, informed by relevant medical research.

The chapter also briefly considers the duty of reasonable accommodation under the CRPD.<sup>414</sup> It argues that the duty to make reasonable adjustments under the EqA 2010 extends further in the context of services and public functions. Whereas the CRPD requires individualised, case-specific reasonable accommodation, the EqA 2010 imposes an anticipatory duty. This anticipatory duty represents a more effective approach, as it requires healthcare providers to anticipate the needs of people with learning disabilities in advance, rather than responding once a need has arisen.

### 5.2. The Duty to Make Reasonable Adjustments

As discussed in Chapter Three, the duty to make reasonable adjustments is contained in Section 20 of the EqA 2010. It imposes a positive obligation on employers, service

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<sup>413</sup> EqA 2010, s 20.

<sup>414</sup> CRPD, art 5(3).

providers, public authorities, and other organisations to take action to modify barriers to the equal participation of disabled people in the areas of life covered by the Act.<sup>415</sup> One of the most significant differences between the duty to make reasonable adjustments and the prohibition on indirect discrimination and discrimination arising from disability is that a failure to comply with the duty cannot be justified.<sup>416</sup> Furthermore, there is no requirement for a comparator, unlike in indirect discrimination.

As argued by Monaghan, the duty reflects a more social model of disability by recognising that disability is created by ‘attitudinal, environmental, and social barriers’.<sup>417</sup> She does, however, acknowledge that the less-than-social model definition of disability undermines this under Section 6 of the EqA 2010.<sup>418</sup> Furthermore, Chapter Three discussed different models of equality, arguing that the provisions preventing direct discrimination under the EqA 2010 align more closely with formal equality, while Section 15 (discrimination arising from disability) reflects a substantive equality approach. The duty to make reasonable adjustments is a further example of a substantive equality approach. It seeks to remove barriers that disadvantage disabled people, thereby enabling their full participation in society.<sup>419</sup>

The duty may arise in three forms. First, where a provision, criterion, or practice places a disabled person at a substantial disadvantage in relation to a relevant matter compared with non-disabled persons, reasonable steps must be taken to avoid that disadvantage.<sup>420</sup> Second, where a physical feature puts a disabled person at a substantial disadvantage in relation to a relevant matter in comparison with non-disabled persons, reasonable steps must be taken to avoid that disadvantage.<sup>421</sup> Third, reasonable steps must be taken to provide auxiliary aids and services where a disabled person would otherwise be at a substantial disadvantage in relation to a relevant matter in comparison with non-

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<sup>415</sup> Karon Monaghan KC, *Monaghan on Equality Law* (2<sup>nd</sup> edn, OUP 2013) 400.

<sup>416</sup> EqA 2010, s 19 and 15.

<sup>417</sup> *ibid.*

<sup>418</sup> Monaghan (n 415) 283–286; see also citation 1020.

<sup>419</sup> Anna Lawson, ‘Disability Equality, Reasonable Accommodation and the Avoidance of Ill Treatment in Places of Detention: The Role of Supranational Monitoring and Inspection Bodies’ (2012) 16 *IJHR* 845, 847–848.

<sup>420</sup> EqA 2010, s 20(3).

<sup>421</sup> EqA 2010, s 20(4).

disabled people.<sup>422</sup> The terms ‘provision’, ‘criterion’, and ‘practice’ are not defined, but are intended to carry the same meaning as in the indirect discrimination provisions.<sup>423</sup>

Under EqA 2010, Section 21, failure to comply with the duty to make reasonable adjustments for a person with a disability constitutes discrimination against them. The common threshold for all three of the requirements is ‘substantial disadvantage’. As discussed in Chapter Three, ‘substantial disadvantage’ is a disadvantage which is more than minor or trivial.<sup>424</sup> The disabled person must be disadvantaged in comparison with other persons. However, this is a more general comparison as to whether the person was put at a substantial disadvantage compared to a non-disabled person. This is not the same as the individual, ‘like-for-like’ comparisons required in cases of direct discrimination.<sup>425</sup> Therefore, there is no requirement to identify a comparator or comparator group.<sup>426</sup> Furthermore, as with indirect discrimination, the comparison exercise does not require separate proof that the disability causes the substantial disadvantage suffered.<sup>427</sup>

Those subject to the duty are obligated to take such steps ‘as is reasonable to have to take’ to avoid disadvantage. ‘Reasonable’ is not qualified further by the Act. Whether or not it is reasonable for a particular adjustment to be made will depend on the facts of the circumstances of the case, and will vary according to the type of service, the nature and size of the service provider, the resources available to it, and the effect of the disability on the disabled person.<sup>428</sup> Unlike indirect discrimination, a failure to make an adjustment deemed ‘reasonable’ cannot be justified.

Although the duty is a single, overarching obligation applicable to all unlawful acts created by the EqA 2010, to understand the impact of the duty on specific activities, reference must be made to the relevant schedules: services and public functions (Sch 2), premises (Sch 4), work (Sch 8), education (Sch 13), and associations (Sch 15). For the purpose of this thesis, the focus is on services and public functions because health and social care will fall within the scope of a service or public function.<sup>429</sup> There is no

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<sup>422</sup> EqA 2010, s 20(5).

<sup>423</sup> Beale (n 183) 48.

<sup>424</sup> See definition of ‘substantial’ in s 212(1).

<sup>425</sup> *Fareham College Corporation v Walters* [2009] IRLR 991.

<sup>426</sup> Beale (n 183) 49.

<sup>427</sup> *Sheikholeslami v University of Edinburgh* [2018] UKEAT/0014/17/0510, [2018] IRLR 1090 [53].

<sup>428</sup> Equality and Human Rights Commission, ‘Services, Public Functions and Associations: Statutory Code of Practice’ (2011) <<https://www.equalityhumanrights.com/equality/equality-act-2010/codes-practice/services-public-functions-and-associations-code-0>> accessed 03 December 2025, para 7.29.

<sup>429</sup> See EqA 2010, s 29(1) and (7), sch 2 para 1.

comprehensive definition of ‘service’ in the 2010 Act. Section 29 provides that a service is something provided to the public or a section of the public, whether for payment or not.<sup>430</sup> The *Statutory Code of Practice on Services, Public Functions and Associations* provides a non-exhaustive illustrative list, which includes hospitals and clinics.<sup>431</sup>

The effect of the Schedules is that the duty applies differently depending on the activity concerned.<sup>432</sup> In certain areas covered by the Act, the duty is anticipatory. These include services, public functions, and associations.<sup>433</sup> Where a duty is anticipatory, it requires the duty bearer to take reasonable steps to overcome barriers that may put disabled people at a substantial disadvantage. In contrast, in other areas of activity covered by the Act, such as work, the duty is reactive.<sup>434</sup> This means the duty is triggered only when a disabled person faces a substantial disadvantage, and the person upon whom the duty is imposed knows of the disabled person.

In this thesis on the provision of healthcare services for people with learning disabilities, it is important to consider that the duty is anticipatory, as it falls within the scope of services and public functions. This means that when a person with a learning disability accesses these public services, service providers may not wait for a disabled person to use the service before considering reasonable adjustments; they must make the service accessible in advance.<sup>435</sup>

This section has shown that the reasonable adjustments duty is a positive obligation to reduce barriers to equal participation. The duty reflects a social model of disability; however, it is limited by the less-than-social-model definition of disability under Section 6 of the Act. Moreover, this section has argued that the duty aligns with a substantive equality approach. When considering health and social care services, the duty to make reasonable adjustments is anticipatory. This means that adjustments in health and social care facilities should be made before the person with a learning disability needs to access them.

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<sup>430</sup> Chris Fry, ‘Services, Public Functions, and Transport’ in Anthony Robinson, David Ruebain, Susie Uppal (eds), *Blackstone’s Guide to the Equality Act 2010* (4<sup>th</sup> edn, OUP 2021) 84.

<sup>431</sup> Equality and Human Rights Commission, *Services, Public Functions and Associations* (n 424) para 11.3.

<sup>432</sup> Monaghan (n 415) 403.

<sup>433</sup> E.g., EqA 2010, sch 2 para 2(2).

<sup>434</sup> E.g., EqA 2010, sch 8 para 20.

<sup>435</sup> Monaghan (n 415) 403.

The next section will briefly discuss the duty to provide reasonable accommodation under the CRPD. It will argue that the reasonable adjustments duty under the EqA 2010 goes further than the duty to reasonably accommodate under the CRPD, because it is an individualised, reactive duty. In contrast, reasonable adjustments are anticipatory for certain activities.

### 5.3. Reasonable Accommodation under the CRPD

The UN convention, along with the national equality framework, places a responsibility on all public services, including hospitals and care services, to make reasonable adjustments to ensure that people with learning disabilities are not disadvantaged.<sup>436</sup> The CRPD requires states parties to prohibit discrimination on the basis of disability, and defines such discrimination to include a failure to provide reasonable accommodation.<sup>437</sup>

The Convention defines reasonable accommodation as being ‘necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case...’.<sup>438</sup> Article 2 of the CRPD defines the duty as arising ‘where needed in a particular case’, emphasising its individualised nature.<sup>439</sup> As argued by Lawson and Orchard, the duty is akin to the reactive reasonable adjustments duty under the EqA 2010, rather than the anticipatory duty.<sup>440</sup> In contrast, the reasonable adjustments duty requires the duty bearer to anticipate necessary adjustments in some circumstances and make them prior to the person requiring adjustments.

This is a positive example of the EqA 2010 going further than the CRPD to ensure equal participation in society for persons with disabilities.<sup>441</sup> However, the reasonable accommodation duty exists within the broader human rights framework of the CRPD, ensuring that the Convention’s specified rights and obligations are implemented in

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<sup>436</sup> Mairead Moloney, Therese Hennessy, and Owen Doody, ‘Reasonable Adjustments for People with Intellectual Disability in Acute Care: A Scoping Review of the Evidence’ (2021) 11 *BMJ Open* <<https://bmjopen.bmj.com/content/11/2/e039647>> accessed 16 February 2026, 2.

<sup>437</sup> CRPD, art 5(3).

<sup>438</sup> CRPD, art 2.

<sup>439</sup> Broderick and Ferri (n 330) 104.

<sup>440</sup> Anna Lawson and Maria Orchard, ‘The Anticipatory Reasonable Adjustment Duty: Removing the Blockages?’ (2021) 80 *CLJ* 308, 315.

<sup>441</sup> *ibid.*

practice. In moving towards a human rights approach to disability discrimination, the British equality framework should maintain its anticipatory approach to reasonable adjustments while also better recognising the CRPD's broader human rights framework for persons with disabilities.

The next section will make recommendations on how the reasonable adjustments duty can be used to decrease the health inequalities experienced by people with learning disabilities. It argues that the duty is underused in health and care settings, and better use of the duty can help to reduce health inequality for people with learning disabilities.

#### 5.4. Underuse of Reasonable Adjustments in Healthcare

Despite national and international legislation requiring health and social care providers to make reasonable adjustments to ensure that services are accessible to those with learning disabilities, there continue to be many barriers to accessing these services.<sup>442</sup> A report by the Equality and Human Rights Commission found that people with learning disabilities face several barriers when accessing healthcare.<sup>443</sup> These include failures to identify people with learning disabilities in health systems so that reasonable adjustments can be made in advance. The report also identified discriminatory attitudes, a lack of expertise on the part of healthcare staff, and failures to make reasonable adjustments in light of the literacy and communication difficulties experienced by many people with a learning disability. Additionally, it highlighted the persistence of diagnostic overshadowing.<sup>444</sup> Furthermore, a scoping review by Moloney, Hennessy, and Doody found a lack of research on the practice and implementation of reasonable adjustments in acute care settings.<sup>445</sup>

While the reasonable adjustments duty has the potential to overcome the disadvantage experienced in accessing and receiving health and care services, it is clear that in England, the adjustments are not being utilised to the best of their ability to reduce disadvantage in this setting.<sup>446</sup> *The Independent Inquiry into Access to Healthcare for*

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<sup>442</sup> Equality and Human Rights Commission, 'Being Disabled in Britain: A Journey Less Equal' (3 April 2017) <<https://www.equalityhumanrights.com/our-work/our-research/being-disabled-britain-journey-less-equal>> accessed 20 February 2026, 96–100.

<sup>443</sup> *ibid.*

<sup>444</sup> *ibid* 96–97.

<sup>445</sup> Moloney, Hennessy, and Doody (n 436).

<sup>446</sup> Lawson and Orchard (n 440) 308; Heslop and others (n 2) 4.

*People with Learning Disabilities* (Michael Inquiry) concluded that there are risks inherent in the care system for people with learning disabilities and that they are largely due to a failure to make reasonable adjustments to services.<sup>447</sup> Following the Michael Inquiry, a 2018 qualitative study by Read and others on disabled people's experiences of accessing reasonable adjustments in hospitals reported mixed findings about whether and how reasonable adjustments were provided.<sup>448</sup> The study found that while some participants shared positive examples of good practice, others spoke about difficult encounters and few adjustment provisions.<sup>449</sup>

Furthermore, the Michael Inquiry found that people with learning disabilities, on average, have higher unmet needs, most of which were in primary care settings.<sup>450</sup> The Inquiry noted that primary care is the place where most health promotion and ill health prevention measures are delivered, and most people with learning disabilities live in the community rather than within specialised services.<sup>451</sup> Therefore, the findings of unmet primary care needs are of great significance when considering the evidence of poor health outcomes for people with learning disabilities.

This, coupled with findings of healthcare professionals' stereotypical-based attitudes on healthcare provision, is contributing to the health discrimination experienced by those with learning disabilities in NHS England and unequal health outcomes.<sup>452</sup> Therefore, this chapter recommends that to address the health inequalities experienced by those with learning disabilities, reasonable adjustments should be better utilised at both system-level and individual-level.<sup>453</sup>

At the system-level, reasonable adjustments are when 'health and social care service providers have planned and taken a strategic approach to addressing the barriers that could potentially impede disabled people from accessing a service'.<sup>454</sup> Whereas,

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<sup>447</sup> Michael (n 66).

<sup>448</sup> Read and others, 'Disabled People's Experiences of Accessing Reasonable Adjustments in Hospitals' (n 239).

<sup>449</sup> *ibid.*

<sup>450</sup> Michael (n 66) 8.

<sup>451</sup> *ibid.*

<sup>452</sup> Mencap, 'Death by Indifference: 74 Deaths and Counting: A Progress report 5 Years on' (n 72); White and others (n 1); Allerton and Emerson (n 78) 926.

<sup>453</sup> Moloney, Hennessy, and Doody (n 436) 2.

<sup>454</sup> Pauline Heslop and others, 'Implementing Reasonable Adjustments for Disabled People in Healthcare Services' (2019) 34 *Nursing Standard* 29, 31-32.

individual-level adjustments are tailored to a specific disabled person's needs.<sup>455</sup> The need for a person to have reasonable adjustments made to their care may be identified in a discussion with them or on their behalf by a carer or healthcare professional. Once a person's need for reasonable adjustments is identified, their hospital records may be 'flagged' to alert healthcare staff to the need to provide them.<sup>456</sup>

### **5.5. Recommendation Three: Improve Access to Reasonable Adjustments**

The academic literature on reasonable adjustments in medical research presents a series of recommendations for implementing adjustments to improve health and care provision for people with learning disabilities. The following measures outlined in this thesis focus on adjustments identified in research as improving the quality of care and health outcomes for patients with learning disabilities.

#### **5.5.1. Individual-Level Changes**

##### **5.5.1.1. *Cultural Change and Education***

One of the commonly cited challenges of implementing reasonable adjustments in healthcare settings relates to the way they are perceived and enacted by healthcare staff.<sup>457</sup> Research has found that there is a need for learning disability education and awareness training for healthcare professionals to understand effective healthcare strategies for people with learning disabilities.<sup>458</sup> A study of twenty-one semi-structured interviews held with disabled people of their experiences accessing reasonable adjustments in hospitals found that one of the most commonly reported recommendations was the need for 'culture

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<sup>455</sup> *ibid.*

<sup>456</sup> *ibid.*

<sup>457</sup> See White and others (n 1).

<sup>458</sup> Mairead Moloney and others, 'Exploring Implementation of Reasonable Adjustments in Hospitals for People with Intellectual Disability: Using a Realist Lens' (2025) 18 JAN 7707, 7719.

change’ within the NHS.<sup>459</sup> Participants in the study reported that staff values and attitudes impacted their practice and the care they received.<sup>460</sup>

There is a greater need for training and awareness of reasonable adjustments among healthcare staff. This will ensure healthcare workers can identify and implement reasonable adjustments when supporting patients with learning disabilities. Furthermore, training should incorporate awareness of bias and prejudice, ensuring that healthcare professionals do not act on assumptions or preconceptions about people with learning disabilities when delivering care.

#### 5.5.1.2. *Communication*

Another commonly cited adjustment in the literature centres around communication and the provision of information. Clear, direct, and consistent communication ensures that healthcare staff and people with learning disabilities can clearly understand each other, reducing anxiety and stress in healthcare environments.<sup>461</sup> Furthermore, improving communication can be particularly important for obtaining consent to treatment.<sup>462</sup>

Information should be provided in accessible formats for the person’s needs.<sup>463</sup> Examples include large print and easy-read materials.<sup>464</sup> Information should also be provided using different formats, such as using symbols to help people with communication difficulties understand and express their opinions.<sup>465</sup>

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<sup>459</sup> Read and others, ‘Disabled People’s Experiences of Accessing Reasonable Adjustments in Hospitals’ (n 239) 935.

<sup>460</sup> *ibid.*

<sup>461</sup> Joana Moyle and others, ‘Role of Reasonable Adjustments in Improving Care: A Case Study’ (2015) 18 *Learning Disability Practice* 32, 34.

<sup>462</sup> Linda Philips, ‘Learning Disabilities: Making Reasonable Adjustments in Hospital’ (2019) 115 *Nursing Times* 38, 40.

<sup>463</sup> Read and others, ‘Disabled People’s Experiences of Accessing Reasonable Adjustments in Hospitals’ (n 239) 937.

<sup>464</sup> *ibid.*

<sup>465</sup> Moyle and others (n 461) 34.

### 5.5.1.3. *Identification of Needs and Hospital Passports*

The academic literature on reasonable adjustments has recommended improvements in identifying and recording the needs of people with learning disabilities.<sup>466</sup> The World Health Organisation identified transitions in care between facilities, sectors, and support staff to be a key patient safety concern, as they increase the potential for communication errors when key information is not transferred with the patient.<sup>467</sup> For this reason, it is important that details of reasonable adjustments and the patient's needs are accurately recorded and easily accessible to healthcare staff.

An important part of this is the proper use of hospital passports, which provide essential information about the person and their health needs.<sup>468</sup> Hospital passports in the UK contain useful information about a person, such as communication needs, personal care, and any other reasonable adjustments they may need.<sup>469</sup> However, Northway and others in a review of 60 hospital passports for people with learning disabilities in the UK found considerable variation between patient passports.<sup>470</sup> The findings showed that some passports omitted important information on allergies, risk assessment, and the need for reasonable adjustments.<sup>471</sup> The study recommended greater standardisation of documents with input from key stakeholders, including people with learning disabilities, their families, carers, and hospital staff.<sup>472</sup>

### 5.5.1.4. *Hospital Experience*

Additionally, Philips outlines a series of person-centred adjustments to improve care experiences for people with learning disabilities.<sup>473</sup> Examples include allowing extra time for appointments, providing a quiet waiting area, and inviting patients to pre-admission

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<sup>466</sup> *ibid*; Stuart Read and others, 'Hospital Passports, Patient Safety and Person-Centred Care: A Review of Documents Currently Used for People with Intellectual Disabilities in the UK' (2018) 18 *BMC Health Services Research* 931, 937.

<sup>467</sup> Aziz Sheikh and others, 'The Third Global Patient Safety Challenge: Tackling Medication-Related Harm' (2017) 95 *Bulletin World Health Organisation* 546.

<sup>468</sup> NHS, 'Support if You Are Going into Hospital – Learning disabilities' (2025) <<https://www.nhs.uk/conditions/learning-disabilities/going-into-hospital/>> accessed 31 March 2026.

<sup>469</sup> *ibid*.

<sup>470</sup> Ruth Norway and others, 'Hospital Passports, Patient Safety and Person-Centred Care: A Review of Documents Currently Used for People with Intellectual Disabilities in the UK' (2017) 26 *Journal of Clinical Nursing* 5160.

<sup>471</sup> *ibid*.

<sup>472</sup> *ibid* 5167.

<sup>473</sup> Philips (n 462) 40.

visits so they can familiarise themselves with the environment and know what to expect.<sup>474</sup> Furthermore, giving people appointments at the start or end of clinics and ensuring they are first on the theatre list for surgery helps to reduce waiting time, thereby creating a predictable and less stressful experience.<sup>475</sup>

### 5.5.2. System-level Implementation

Moloney and others conducted empirical research into the factors influencing the implementation of reasonable adjustments in hospitals for people with intellectual disabilities.<sup>476</sup> The findings of the research showed that while healthcare professionals support the provision of reasonable adjustments in hospitals as a person-centred approach to caring for people with intellectual disability, there is little evidence of ‘strategic system-level implementation’.<sup>477</sup> What this means in practice is that reasonable adjustments are applied inconsistently, on a case-by-case basis, and require individual healthcare staff to identify adjustment needs and implement them, rather than relying on systemic change.<sup>478</sup> This creates a system that is overly reliant on individual effort rather than on organised structures and policies to guarantee reasonable adjustments.

Implementation of reasonable adjustments at the system-level for healthcare provision is an evidence-based way to address health inequalities experienced by those with learning disabilities.<sup>479</sup> The findings from Moloney and others’ research indicate a need to adopt hospital-wide, coordinated, structured policies and procedures that ensure the consistent application of reasonable adjustments.<sup>480</sup>

Furthermore, there were broader system-level failures due to the lack of integrated care pathways.<sup>481</sup> Integrated care systems are broad alliances of partners who all have a role in improving local health, care, and wellbeing. These may also include social care

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<sup>474</sup> *ibid.*

<sup>475</sup> *ibid.*

<sup>476</sup> Moloney and others (n 458) 7707.

<sup>477</sup> *ibid.*

<sup>478</sup> See also Marcus Redley and others, “‘Reasonable Adjustments’ under the UK’s Equality Act 2010: An Enquiry into the Care and Treatment to Patients with Intellectual Disabilities in Acute Hospital Settings’ (2019) 32 *Applied Research in Intellectual Disabilities* 1412.

<sup>479</sup> Moloney and others (n 458) 7717.

<sup>480</sup> *ibid.*

<sup>481</sup> *ibid* 7714.

providers, voluntary organisations, and community and enterprise sectors.<sup>482</sup> The findings by Moloney and others show that there is a need to ensure clear communication between the organisations responsible for providing health and care services at the community/primary care level and in acute hospital settings. This will ensure staff can adequately support those with learning disabilities who may depend on several health and care services.

As discussed in Chapter Two, Connor Sparrowhawk's post-death investigation found that there was weak teamworking in the NHS care facility and with the community learning disability team.<sup>483</sup> The fragmented nature of his care led to standalone decisions that were neither coordinated nor validated by colleagues across services. His case demonstrates why it is important to have coordinated, system-level policies and procedures for the care of people with learning disabilities.

Additionally, an independent inquiry recommended a series of system-level changes to improve the provision of healthcare services for those with learning disabilities.<sup>484</sup> One recommendation was to revise the *Core Standards for Better Health*, a set of standards introduced by the Department of Health as a basis for inspection and regulation in the NHS. The inquiry recommended that the standards be amended to reflect the requirement to make reasonable adjustments to services to ensure they are accessible to people with learning disabilities.<sup>485</sup>

The Core Standards were replaced in 2014 with the *Fundamental Standards of Care*, introduced and enforced by the Care Quality Commission.<sup>486</sup> The Fundamental Standards now include the requirement to provide person-centred care, defined as care tailored to the individual, meeting their needs, and reflecting their preferences.<sup>487</sup> While this is a positive step, it falls short of explicitly recognising the legal duty to make reasonable adjustments to services for disabled people. Explicit recognition of the duty to make reasonable adjustments to ensure services are accessible to people with learning disabilities would enable better leadership and direction-setting. If NHS trusts are assessed

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<sup>482</sup> NHS England, 'What are Integrated Care Systems?' <<https://www.england.nhs.uk/integratedcare/what-is-integrated-care/>> accessed 01 March 2026.

<sup>483</sup> Verita (n 81) paras 3.23–3.24.

<sup>484</sup> Michael (n 66).

<sup>485</sup> *ibid* Recommendation 6 at 46.

<sup>486</sup> Care Quality Commission, 'The Fundamental Standards of Care' (2026) <<https://www.cqc.org.uk/about-us/fundamental-standards>> accessed 06 March 2026.

<sup>487</sup> *ibid*.

against this standard, those involved in setting policies and procedures are more likely to implement system-level changes rather than rely on individual healthcare staff to make changes in an ad hoc manner.

While the legal framework for reasonable adjustments presents a significant opportunity to remedy health inequalities experienced by people with learning disabilities, it is underutilised as it currently stands. The combined effect of adopting a human rights model of disability under the EqA 2010, the rights and obligations outlined in the CRPD, and encouraging health and social care providers to adopt reasonable adjustments at both system and individual levels has the potential to improve the quality of care and health outcomes for those with learning disabilities in NHS England.

## 5.6. Scarcity and Reasonable Adjustments

Chapter Two discussed the cost constraints the NHS faces as populations grow, life expectancy increases, and the range of available treatments expands.<sup>488</sup> The NHS now faces the challenge of promoting equality while ensuring cost-effectiveness and the efficient distribution of scarce resources.<sup>489</sup> It is therefore important to make recommendations that take into account the challenges and limitations of NHS England.

It may be a consequence of these recommendations that local councils and NHS England will have to provide additional funding to implement these changes. Notwithstanding, this thesis contends that the recommendations made are best able to address health and care inequalities experienced by those with learning disabilities while balancing the need to distribute scarce resources effectively.<sup>490</sup> This approach is also consistent with the human rights principle of core minimum obligations, which recognises that, although resources are limited, States must nevertheless ensure minimum essential levels of healthcare. According to this principle, resource constraints should not justify a failure to provide the reasonable adjustments necessary for people with learning disabilities to access healthcare on an equal basis with others.

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<sup>488</sup> See Jackson (n 44) 38–39.

<sup>489</sup> *ibid.*

<sup>490</sup> Department of Health and Social Care (n 15).

Furthermore, the reasonable adjustments duty allows account to be taken of factors such as the type of service being provided, available resources, and the effect of the disability on the person.<sup>491</sup> Therefore, it provides the necessary flexibility to meet the needs of those with learning disabilities while also accounting for the financial and resource limitations that health and care providers in NHS England face.

Health inequalities arise from an interaction of social, economic, environmental, and healthcare factors. For example, influences such as housing quality, education, and socioeconomic status are all determinants of someone's health outcomes. Therefore, attaining the highest standard of health is multi-faceted. Notwithstanding this, one factor contributing to poor health outcomes for people with learning disabilities relates to the provision of primary and secondary medical care in the UK. Grounding the recommendations in this thesis in medical research ensures they reflect the practical realities of what will be effective in remedying these health inequalities for people with learning disabilities. As such, the adjustments recommended are more likely to distribute scarce resources efficiently.

## 5.7. Conclusion

The final recommendation in this thesis is to improve access to reasonable adjustments in health and care services for people with learning disabilities. This chapter began by arguing that the duty to make reasonable adjustments under the EqA 2010 is a central mechanism for achieving substantive equality in healthcare for people with learning disabilities. It has been shown that, while the British framework goes further than the CRPD by imposing an anticipatory duty, this potential is not being realised in practice. Research on the application of the reasonable adjustments duty in healthcare demonstrates that adjustments are inconsistently applied and often underused, contributing to unmet health needs and ongoing barriers to accessing healthcare.

On this evidence, the chapter has recommended that more effective implementation of the duty is required at both the individual and system levels in healthcare to improve health equality for people with learning disabilities. It has made a series of individual-level

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<sup>491</sup> Lawson and Orchard (n 440) 320; Equality and Human Rights Commission, *Services, Public Functions and Associations* (n 428) paras 7.29–7.30.

recommendations, including cultural change, improved communication, better identification of needs, consistent use of hospital passports, and improvements to appointment practices. Furthermore, at the system level, it has recommended the development of coordinated, system-wide policies and procedures to ensure reasonable adjustments are applied consistently in healthcare settings.

Finally, this chapter drew on the discussion from Chapter Two regarding resource and funding constraints in the NHS. One of the aims of this thesis has been to develop practical recommendations to improve health outcomes for people with learning disabilities while accounting for the challenges faced by NHS England. While resource constraints remain a relevant consideration, the flexibility in the reasonable adjustments duty allows these measures to be implemented in a proportionate and cost-effective way.

The final concluding chapter will bring together the recommendations from Chapters Four and Five to conclude that, if equality in healthcare for people with learning disabilities is to be fully realised, substantial legal reform is required.

## Chapter Six: Conclusion

### 6.1. Contribution

The motivation for writing this thesis came from it being a relatively underdeveloped research area within legal scholarship. While medical research and reports demonstrate the health inequalities experienced by people with learning disabilities in England, there is comparatively little discussion on this issue in the legal field. The thesis sought to address this gap by bringing together theoretical frameworks of disability and equality with doctrinal analysis. It relied on interdisciplinary sources to evidence the lived experience of people with learning disabilities. In this way, the legal recommendations advanced build upon an existing body of work and research on the health inequalities experienced by people with learning disabilities. It is hoped that the thesis can inspire further discussions within legal scholarship on how the law can be reformed to ensure more equitable health and social care provision for people with learning disabilities.

The aim of the thesis has been to advance legal recommendations to address health inequalities experienced by people with learning disabilities in NHS England. The overarching vision for the equality rights and resulting healthcare provision of learning-disabled people is to reduce premature and avoidable deaths as well as to improve experiences of accessing health and social care for people with learning disabilities.

The recommendations focus on developing a healthcare system that recognises the inherent dignity and human rights of people with learning disabilities. In this way, failures to provide equitable healthcare services for people with learning disabilities are not reduced to deficiencies in service delivery. Instead, they are understood as violations of fundamental human rights, thereby raising the standard expected of health and social care services in England. Outside of clinical outcomes, it is hoped that the recommendations will enable people with learning disabilities to lead longer, healthier, and happier lives, thereby engendering a society in which everyone is equally able to reach their full potential regardless of disability.

Chapter Two began by contextualising the nature and extent of health inequalities experienced by people with learning disabilities in England. This chapter was structured around two clear themes. Firstly, it discussed the historical origins of the NHS, which

sought to address inequalities in healthcare provision. It then demonstrated that this aim continues to be reflected in the NHS Constitution today, alongside the need to balance high service demand and scarce resources.

Secondly, notwithstanding the aim of equality in healthcare, there continues to be inequality in the provision of healthcare services for people with learning disabilities in the. Drawing upon past and recent research in England, the chapter discussed institutional discrimination and health inequalities experienced by people with learning disabilities in the NHS. It particularly focused on rates of premature mortality and avoidable deaths. Furthermore, it discussed the case of Connor Sparrowhawk, whose death drew widespread attention to the health discrimination and inequality experienced by people with learning disabilities. Despite increased awareness of this, inequalities in healthcare provision and outcomes continue to persist, highlighting the need for legal reform in this area.

Chapter Three was broader in scope; it examined the legal framework governing disability discrimination in England. This chapter had three central aims. Firstly, it sought to provide a historical overview of the development of equality law in England to demonstrate that there has been a shift in attitude from a welfare-based approach to a rights-based framework in the twentieth century. The chapter also considered criticism of the harmonisation of equality legislation under the 2010 Act, which was claimed to mask the differences between disability and the other protected characteristics.

Secondly, the chapter provided an overview of the equality law governing disability discrimination in England. It discussed the definition of disability under Section 6, noting that it focuses on the person's functional impairment. Furthermore, it showed that the definition provides asymmetrical protection for disabled people. It then outlined the different forms of discrimination under the Act: direct discrimination, indirect discrimination, and discrimination arising from disability. It demonstrated the differing approach to discrimination arising from disability, which does not require the person to compare their treatment to that of a non-disabled person. Therefore, the British legal framework does, in some respects, recognise the distinct experience of disability compared to other protected characteristics.

Finally, Chapter Three discussed the theoretical underpinnings of equality law. It argued that formal equality, requiring all persons to be treated the same, would be an inadequate approach to disability discrimination. The model has been widely criticised as

failing to address structural disadvantage. For people with disabilities, this would be particularly problematic, given the inherent differences between the experiences of disabled and non-disabled people. The chapter considered different conceptions of substantive equality, arguing in favour of Fredman's four-dimensional approach of aims and objectives, which looks to address different facets of inequality.<sup>492</sup> It concluded that a substantive approach should be used when proposing reforms to the healthcare provision for people with learning disabilities.

Bringing together the discussions in Chapters Two and Three, Chapter Four argued in favour of a human rights approach to disability, framing disability discrimination as a rights and justice issue. The chapter made two key recommendations.

Chapter Four began by exploring the theoretical frameworks underpinning disability discrimination law. It criticised the medical model for locating the 'problem' of disability within the individual, rather than the attitudinal and environmental factors that hinder full participation in society. It demonstrated that the current definition of disability under Section 6 EqA 2010 is overly reliant on a medical model, due to its focus on functional impairment. The chapter then examined the social model of disability, demonstrating that it offers an alternative understanding of disability by focusing on the ways in which disability is created through attitudinal and societal barriers. However, the social model has also been criticised as failing to recognise the lived experience of impairment and the realities of pain, shorter life expectancy, and deterioration of quality of life. Accordingly, the chapter looked to the human rights model of disability. A relatively new conception, it views disabled people as autonomous rights-holders and recognises their right to dignity, autonomy, and inclusion. As such, the human rights approach acknowledged the lived experience of impairment while still recognising social and structural barriers.

This criticism led to the first recommendation of the thesis, to implement the CRPD's definition of disability and disabled person into the national legal framework. It has been argued that CRPD takes a human rights approach to disability by affirming the fundamental freedoms and human rights of persons with disabilities and promoting their inherent dignity.<sup>493</sup> The definition of disability and disabled person under the Act focuses on the interaction between persons with impairment and societal barriers that limit

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<sup>492</sup> Fredman, 'Substantive Equality Revisited' (n 241).

<sup>493</sup> CRPD, art 1.

participation. Implementing a human rights model of disability under the national framework has the potential to reduce health inequality experienced by people with learning disabilities. It ensures that those responsible for delivering care and overseeing standards recognise their responsibility to eliminate discrimination caused by institutional barriers in NHS England.

Secondly, Chapter Four recommended that the rights and obligations guaranteed by the Convention should be better recognised in NHS England's healthcare policies and practices. Definitional reform alone is unlikely to address health inequalities experienced by people with learning disabilities. Accordingly, embedding the rights and obligations set out in the CRPD into NHS England's healthcare policy and practices ensures that persons with learning disabilities are guaranteed equal health outcomes as human rights.

Finally, Chapter Five discussed the duty to make reasonable adjustments. It argued that while the duty has the potential to improve health care delivery and outcomes for people with learning disabilities, in practice, it is underutilised. The third recommendation was to improve the use and implementation of reasonable adjustments across NHS England. Relying on medical research conducted in NHS hospitals, it proposed both individual and system-level changes to implement planned and strategic approaches across NHS England to adjust service delivery and provide person-centred care.

## **6.2. The Future**

Looking to the future, the government should hold a full and comprehensive consultation on healthcare inequality affecting people with learning disabilities. The consultation should bring together a range of stakeholders, including health and social care providers, local authorities, healthcare workers, charities, and carers. Importantly, at the centre of the research should be the perspectives and lived experiences of people with learning disabilities. The research should examine all aspects of healthcare service delivery and the legal frameworks that govern them, to inform comprehensive reform of healthcare for people with learning disabilities.

Furthermore, existing medical research on reasonable adjustments is limited by the small sample sizes used. Future research would benefit from large-scale studies examining people with learning disabilities' experiences in accessing reasonable adjustments. Such

research would provide a more reliable evidence base for identifying shortcomings in current provision and informing necessary improvements in delivery.

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