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Is it Illegal to be Autistic?

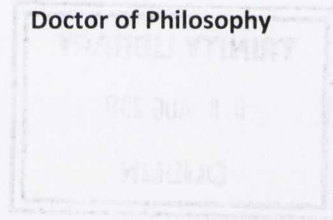
An analysis of whether the rights situation in different jurisdictions is
leading to a silent genocide of autistic persons

A thesis submitted to the

University of Dublin, Trinity College

for the degree of

Doctor of Philosophy



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**"The problem is not the problem.
The problem is your attitude about the problem."**

(Captain Jack Sparrow, *Pirates of the Caribbean*)

Table of Contents

Summary.....11

Acknowledgements13

PART I: INTRODUCTION15

Chapter 1: Introduction.....15

1.1 Defining the 'Problem'.....16

1.1.1 Viewing Autism as a Medical Condition16

1.1.1.1 International Guiding Texts – ‘Disorder/ Condition’ not Disease.....17

1.1.1.2 The DSM-5 ‘Earthquake’ - The Text Revisions.....19

1.1.2 Viewing Autism as Non-Medical – Neurodivergence.....20

1.1.2.1 Disabilities in terms of the Medical Model21

1.1.2.2 Shift towards a Social Model of Disability.....23

1.1.2.3 The Emergence of an Autistic Identity25

1.1.3 Clash of Worlds – Indistinguishability and Cure28

1.1.3.1 Claiming Breach of Rights – The Auton Saga28

1.1.3.2 Same Breach – Different Perception31

1.1.4 They Say It’s Genocide36

1.1.4.1 Defining Genocide.....40

1.1.4.2 Adapting the Concept – Interpretation and Widening42

1.1.4.3 Israel Charny's Definition43

1.1.4.4 Beyond Mass Murder44

1.2 Thesis Overview and Research Questions44

1.2.1 Thesis Overview44

1.2.2 Research Questions.....47

PART II: THE WAR ON AUTISM – A WAR ON PERCEPTIONS.....49

Chapter 2: Autism – Perceptions and Reality.....49

2.1 Introduction49

2.2 Illness or Aberrance from the Norm49

2.2.1 Identifying Aberrance from the Medical Norm.....49

2.2.2 Seeking a Cure for this Aberrance.....51

2.2.3 Autism – What is it?53

2.3 The Issue of Perception: Why is Autism Wrong?55

4

2.3.1	Autism – 'The Enemy' Within	55
2.3.2	Other Side of the Coin	57
2.3.3	All about choices	60
2.4	Autistic Behaviour and the Communication Link	61
2.4.1	Behavioural Therapies – Communication vs Conditioned Responses	62
2.4.1.1	Background	62
2.4.1.2	Using Aversion... To Improve Communication	64
2.4.1.3	Reconditioning – Behaviourist for Assimilation	66
2.5	Conclusion	69
Chapter 3: Stifling Communication – Stifling Identities		71
3.1	Introduction	71
3.2	Monolingualism to Multilingualism – Language and Identity	71
3.2.1	Introduction	71
3.2.2	Assimilation and 'Extirpation' of Difference	72
3.2.3	Changing Perceptions and Initial Reforms	76
3.2.3.1	United Kingdom	76
3.2.3.2	Spain	77
3.2.3.3	Turkey	78
3.2.4	Conclusions	80
3.3	Different Processing and Communication Styles	83
3.3.1	Behavioural Therapies and the Right to Education	84
3.3.1.1	O' Cuanachain v. Minister for Education	84
3.3.1.2	Autism-Europe v. France	87
3.3.1.3	AEH v. France	89
3.3.2	Activist Anger	91
3.3.3	Reality Nowadays and Need for Middle Ground	94
3.3.4	Legislating for Change: The Current Maltese Scenario	98
3.3.4.1	Early Intervention and Therapies – Legislation and Policy	98
3.3.4.2	Subsidiary Legislation	99
3.3.4.3	Enabling Participation vs Mandating Normalisation	101
Chapter 4: Wrong Behaviour or Undesirable Behaviour?		103
4.1	Introduction	103
4.2	Social Views: From Gender Deviance to Gender Diversity	104

4.3	The Decriminalisation of Sodomy – Hart-Devlin Redux.....	108
4.3.1	The Actual Debate	108
4.3.2	Redux – Then and Now	110
4.3.3	Analogous Scenarios	111
4.3.4	But Do All Roads Lead to Rome?	112
4.4	Sodomy in Court – Bowers v. Hardwick	114
4.5	Drawing Parallels: Africa.....	115
4.5.1	Zimbabwe	116
4.5.2	Botswana	119
4.6	Rehabilitating Behaviours – Lawrence v. Texas.....	120
4.7	From Public Morality to Constitutional Morality	124
4.8	Doing Away with Tyranny.....	128
Chapter 5: Shifts in Disability Perception: The Situation and the Struggle		129
5.1	Introduction	129
5.2	From Protection to Empowerment: Lessons from Children’s Rights	130
5.2.1	The English Scenario.....	130
5.2.2	From Rights Declaration to Rights Convention	132
5.2.3	Involvement of Civil Society/ Beneficiaries in UNCRC Drafting	134
5.2.4	Presumption of Relevant Competence	136
5.2.4.1	EU Activists’ Recommendations – Competence and Legal Capacity	140
5.2.4.2	Comparative Advocacy: The CRPD and the UN’s SDGs	140
5.3	Shifting Perspectives at the ECJ: From Medical to Social Models.....	141
5.3.1	A Medicalised Approach: The Chacón Navas Saga.....	142
5.3.2	Towards the Social Model: The HK Danmark Cases.....	144
5.4	At the UN – from Handicapped Persons to Persons with Disabilities	148
Chapter 6: ‘Pro-Cure’ vs ‘Anti-Cure’– Medical Model vs Social Model?		149
6.1	Introduction	149
6.2	‘Pro-Cure’ Groups: Researching the Cause of the Aberrance	150
6.2.1	The Search for the Autism Gene	152
6.2.2	The ‘Vaccines Cause Autism’ Controversy	153
6.3	Autistic Advocates – From Focus Group to Rights Movement	155
6.3.1	Early Steps.....	156
6.3.2	Identity and Personhood – Reappropriation of Terminology (Example) ...	157

6.3.3	Moving Towards External Advocacy.....	158
6.3.3.1	‘Infiltrating the Mainstream’	159
6.3.3.2	Autistics Going Solo.....	162
6.4	Concluding Remarks.....	164
PART III: WAR ON AUTISM: ELIMINATION OR ASSIMILATION		167
Chapter 7: Genocide, Writ Large		167
7.1	Introduction	167
7.2	The Notion of a 'Protected Group'	168
7.2.1	Going Beyond the Convention’s Categories	169
7.3	Beyond Protected Groups – Genocide as a Concept in Jus Cogens.....	170
7.3.1	The Court’s Definition of Genocide.....	171
7.3.2	Eichmann’s Objections and the Notion of Jus Cogens.....	173
7.4	Elements of Action and Intention.....	177
7.4.1	Broadening the Concept of Actus Reus.....	177
7.4.2	Re-Classification and Re-Calibration of Crimes	178
7.4.2.1	Rape as Torture.....	179
7.4.2.2	The Concept of Genocidal Rape.....	181
7.4.2.2.1	Re-Classification at the ICTR	184
7.4.3	Defining the Mens Rea for Genocide	188
7.4.3.1	Croatia v. Serbia	188
7.4.3.2	The Srebrenica (Popovic and other joined) Cases	191
7.4.3.3	The Genocide Case, Krstic, and murkier waters	194
7.4.4	The Concept of Justifiable Genocide.....	196
Chapter 8: Genocide – From Theory to Practice.....		198
8.1	Introduction	198
8.2	‘We Charge Genocide’: Testing the Waters	198
8.2.1	Killing of Members of the Group	201
8.2.2	Intent to Destroy a Group	202
8.2.3	Incitement and Complicity to Genocide	203
8.2.4	Conclusion regarding Petition and Snowball Effect.....	204
8.3	Irreparable Damage done by Lemkin.....	206
8.4	Recapitulating the Flexible Concept of Genocide.....	212
8.4.1	Qualifying Groups	212

8.4.2	Element of Actus Reus	213
8.4.3	Element of Mens Rea	213
8.4.4	Conclusions	214
Chapter 9: The Pre-Natal Sphere – Prevention and Termination		217
9.1	Introduction	217
9.1.1	Use of Mental Illness/ Mental Disability-related materials	219
9.2	The Issue of Genetic Research	220
9.2.1	Cases in Point? – The Autism Genome Project	221
9.2.2	Mass abortions in the case of autism?	224
9.2.2.1	Discovery of Autism ‘Genetic Signature’	225
9.2.2.2	Western Australia – Authorisation of Autism Detection Genetic Tests	227
9.2.2.3	UK – Evaluation concerning allowing Autism Screening	230
9.2.3	International/ European Legislation pertinent to this Scenario	232
9.3	Disability-Specific Abortion Legislation	233
9.3.1	Review by the CRPD Committee	234
9.3.2	Initiatives at CRPD-Compliant Law Reform	239
Chapter 10: The Post-Natal Sphere – Cure, Remission or Normalisation		243
10.1	Introduction	243
10.2	Research into a Cure	244
10.3	The Issue of Euthanasia	246
10.4	Specific Therapies	247
10.4.1	Certain Applications of Behavioural Therapies	248
10.4.2	Science-based and Pseudo-science-based ‘Curative’ Therapies	249
10.4.2.1	‘Le Packing’	251
10.4.2.2	Stem Cell Therapy	251
10.4.2.3	Chelation Therapy	253
10.4.2.4	Hyperbaric Oxygen Therapy	255
10.4.2.5	Bleach Enemas/ MMS	257
10.4.2.6	Nutritional and Chemical Supplements	258
10.5	The Role of the Media and Personalities	260
10.6	The Right Not To Be Abused – International Instruments	262
10.6.1	Physical and Mental Abuse	262
10.6.2	Freedom from Pharmaceutical Abuse	264

10.6.3	Recent Movements at European Level	266
10.6.3.1	Lacking Guarantees: Autism, Detention and Sterilisation?	267
Chapter 11: The Word on the Street – Awareness or Acceptance?.....		271
11.1	Introduction	271
11.2	Use of Medicalised Language – The EU Situation	272
11.2.1	EU Legal Basis for Autism Initiatives.....	272
11.2.2	Medicalised Language in EU Initiatives	273
11.2.3	Conclusion.....	274
11.3	The DSM-5 Revisions – Perpetuating the Medical Model?	277
11.3.1	Window-Dressing Gone Wrong	278
11.3.2	What the Neurodiversity Community wanted	279
11.3.3	What the DSM Committee Wanted.....	279
11.3.4	What Really Happened.....	280
11.4	The Importance of Awareness: EU Awareness Frozen In Time.....	280
11.5	Beyond Medicalisation?.....	282
11.5.1	The United States and Canada.....	282
11.5.2	Northern Ireland: A Novel Approach.....	284
11.5.3	Malta: Awareness versus Acceptance	286
PART IV: CONCLUSION.....		289
Chapter 12: Conclusions & Recommendations.....		289
12.1	Introduction	289
12.2	Possible Genocidal Nature of Actions and Omissions.....	290
12.2.1	The Pre-Natal Sphere – Prevention and Termination.....	290
12.2.2	The Post-Natal Sphere – Cure, Remission or Normalisation	293
12.2.2.1	Researching an Aetiology/ Cure	293
12.2.2.2	Euthanasia	293
12.2.2.3	‘Curative’ Therapies	294
12.2.2.4	Certain Applications of Behavioural Therapies.....	297
12.2.3	The Word on the Street – Awareness or Acceptance?	300
12.2.4	Notes of Genocide – And the Way Forward?.....	303
12.3	Ending the Madness: The Need to Talk to the Other Side.....	304
12.3.1	The Canadian Fracas	305
12.3.2	The United Kingdom (England) – A Concerted Approach.....	307

12.3.2.1	Towards the Autism Act: A Grassroots Approach	307
12.3.2.2	Hammering out a Compromise	309
12.3.2.3	Perception and the Roadblock.....	310
12.4	The Problem (and Solution) to Self-Advocates' 'Militant Tendencies'	312
12.4.1	Shakespeare and Watson: 'Absolutist Sacred Cow' Problem	312
12.4.2	Beyond the Social Model and the 'Enemy on the Other Side'	314
12.5	The Role and Obligations of the State	315
12.5.1	To Listen and To Regulate	315
12.5.2	To Participate in a Tripartite Approach Towards Empowerment	316
12.6	Beyond Rights: Equal Partners for Autistic Justice	319
12.6.1	Not Rights But Justice	319
12.6.2	Through Interdependence, Towards Justice	321
BIBLIOGRAPHY		323

Summary

The aim of this thesis is to investigate a claim made by certain autistic rights activists, that present-day treatment by society of autistic persons amounts to genocide. This is to be viewed especially in conjunction with a specific proposal by activist Nick Walker, that prosecutions under the United Nations' Genocide Convention should be allowed, through a broad interpretation of legal protection mechanisms.

This thesis establishes that autistic persons are, in fact, subjected to an ongoing 'war' on autism, stemming from a power dichotomy in which the majority 'neurotypical' body of the population enforces its status quo views of normalcy, against an autistic minority. This is based on perceptions of 'good and bad' and 'right and wrong', also fuelled by an incorrect understanding of autism, as well as social prejudices towards mental disabilities as traditionally defined.

The core of such perceptual bias stems from communication and behaviour in autism diverging from accepted norms, as well as the current mainstream societal perception that such divergence is to be addressed through normalisation/ indistinguishability, and prevention of autism if possible. This rather than trying to understand autism for what it really is, and understanding the root cause of such communication and behavioural 'deficits', in line with autistic persons' identity and personhood.

The points above are validated through case studies covering linguistic and ethnic minorities, as to 'good and bad' communication and identity, as well as LGBTQI persons, as to 'right and wrong' behaviour and identity. Both case studies are developed in the context of a dominant-minority power dichotomy, with the issues of competence and capacity at times arising in autism addressed through comparison with the children's rights scenario.

A shift from protection to empowerment in legislative and policy focus is further strengthened by examining the shift from the medical to the social models of disability. The fact that such a shift towards acceptance and inclusion can occur, following a shift in perceptions, is used to point to the fact that treatment of persons within a social group prior to such shift could constitute mistreatment and result in rights breaches.

Possible rights breaches in main areas relating to autism are then examined, covering the pre-natal, post-natal and knowledge and awareness sectors. The applicability and possible extension of the concept of genocide to autistic persons as a group is then examined, by analysing statutes, and especially authors and case law where such did indeed happen in the case of other groups. Reasons for failure of claims are also discussed.

Possible breaches identified are then tested against a concept of genocide extended to autistic persons, whereby it is concluded that actions or omissions by states and supranational bodies could constitute genocide in a number of instances. The thesis then concludes by discussing how to break the deadlock posed by such scenarios, and move towards a rights-based approach, citing authors, activists and real-life examples.

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PART I: INTRODUCTION

Chapter 1: Introduction

One can speak of a large public outrage following the Second World War concerning mass killings of persons of different racial, ethnic and religious backgrounds.¹ In conjunction with this, the subsequent racial theories behind such actions – as well as associated movements such as eugenics, and areas of 'specialisation' such as the study of racial hygiene – could be said to have started to die down, in many cases. However, the situation concerning persons with disabilities, and particularly persons with what were considered to be mental illnesses or disabilities, was quite different.

Anything considered racist was repealed, and the organisations propagating such ideas banned by post-war governments, as in the case of the Nazi Party in Germany,² as well as practically any movement standing for racist, fascist or national socialist ideologies. Other countries such as the United States, whose citizens were physically distanced from the horrors of the Holocaust and its sub-components such as Aktion T4,³ could be said to have taken a bit longer, but eventually also desegregated their institutions and daily life in general by the 1960s.⁴ Even if 'cracks' were present, such as that allowing hate speech to still make it past the sieve of the US Constitution's First Amendment,⁵ the situation could be said to be generally comparable to that in Europe.

¹ These criteria were the main elements upon which the Convention on the Prevention and Punishment of the Crime of Genocide (hereinafter Genocide Convention), G.A. Res. 260, U.N. GAOR 3, U.N. Doc. A/810 (1948), adopted 9 December, 1948; entered into force 12 January 1951, 78 U.N.T.S. 277, was built following the end of the Second World War.

² Law No. 2 of 10 October 1945 'Providing for the Termination and Liquidation of the Nazi Organisations' (CONL/P(45)44), reported in Allied Control Council Laws, Volume I, at 131.

³ *'Handicapped: Victims of the Nazi Era, 1933-1945'*, published by the United States Holocaust Memorial Museum, used with permission by 'A Teacher's Guide to the Holocaust', available online at <http://fcit.usf.edu/HOLOCAUST/PEOPLE/USHMMHAN.HTM>.

⁴ The turning point in this regard was the United States District Court judgement in *Browder v. Gayle* (decided by the United States District Court for the Middle District of Alabama, per Johnson, Lynne and Rives JJ, on 5 June 1956, 142 F. Supp. 707.), subsequently upheld by the Supreme Court (on 13 November 1956, 352 U.S. 903), which declared racial segregation on buses in Alabama unlawful and unconstitutional, by virtue of violating the Fourteenth Amendment to the United States Constitution guaranteeing equal protection before the law, and which was shortly followed by the Supreme Court decision in *Oliver Brown, et al. v. Board of Education of Topeka, et al.*, per Warren CJ joined by Black, Reed, Frankfurter, Douglas, Jackson, Burton, Clark and Minton JJ, 17 May 1954, 347 U.S. 483 (*Brown v. Board of Education*) that desegregated education using the same premise.

⁵ This Amendment was adopted together with the United States Bill of Rights on 15 December 1791, in an effort to strengthen civil liberties, and among other matters states that "Congress shall make no law [...] abridging the freedom of speech, or of the press; or the right of the people peaceably to assemble [...]".

1.1 Defining the 'Problem'

1.1.1 Viewing Autism as a Medical Condition

The main issue at stake can be definitely said to be one of public opinion. Both mental illnesses and disabilities, as traditionally defined,⁶ can be traced to medical diagnoses to this very day. These are to be made following largely standard guidelines laid out in documents such as the World Health Organisation (WHO)'s ICD-10⁷ on the international level, and the American Psychiatric Association (APA)'s DSM-IV or DSM-5⁸ on a regional level. Practical wisdom has long dictated that any medical illness should be treated in order to relieve symptoms and, if possible, eradicated. This is the approach currently being used in notable matters such as the fight against cancer and Acquired Immunodeficiency Syndrome (AIDS), which have caught most headlines over the past few decades. Successful eradication of a 'scourge' along these lines has been met with unprecedented satisfaction, the most recent instance of such being the WHO's declaration concerning the eradication of smallpox in 1979.⁹

⁶ This category includes the category of mental illnesses, more recently described as mental health difficulties, and nowadays seen within the purview of psychosocial disabilities, see, for example, 'Psychosocial Disability: one of the most misunderstood areas of disability', Disability Rights Fund, accessed online at <http://www.disabilityrightsfund.org/our-impact/insights/psychosocial-disability/>, as well as; the category of that correlate with the American Psychiatric Association (APA)'s category of 'Neurodevelopmental Disorders', defined as "a group of conditions with onset in the developmental period[, that] typically manifest early in development, often before the child enters grade school, and are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning" in the 5th edition of the APA's *Diagnostic and statistical manual of mental disorders*, American Psychiatric Association, American Psychiatric Publishing, Arlington, VA, 2013 (hereinafter DSM-5), and with the category of 'Mental, Behavioral and Neurodevelopmental disorders' in the World Health Organisation (WHO)'s *International Statistical Classification of Diseases and Related Health Problems* (10th Revision), World Health Organisation, Geneva, 1992 (hereinafter 'ICD-10'). This broad category also includes Intellectual Disabilities, previously referred to as 'Mental Retardation', as well as Autism, the neurodevelopmental component of which can be said to be neurobehavioural, as further discussed in Section 2.2.3 of this thesis.

⁷ ICD-10, op. cit.

⁸ *Diagnostic and statistical manual of mental disorders* (Revised 4th ed.) (hereinafter DSM-IV-TR), American Psychiatric Association, American Psychiatric Publishing, Arlington, VA, 2000, and; DSM-5, op. cit. While the DSM-5 is now the diagnostic manual of record in the United States, one still finds continued adherence to the DSM-IV in many other parts of the world also following the DSM criteria, such as in Ireland, especially in the field of autism due to, for example, the DSM-5's 'elimination' of the category of Asperger Syndrome, as stated by practitioners such as Michael Fitzgerald at the 'Challenging DSM-5' Conference, organized by Aspire: Asperger Syndrome Association of Ireland, at Trinity College Dublin, 8-9 November, 2013.

⁹ World Health Organisation, 'Declaration of global eradication of smallpox', *Weekly Epidemiological Record*, Volume 55, 1980, at 148.

One might then posit, along the same lines, that persons given a diagnosis of an Autism Spectrum Condition (ASC)¹⁰ or Autism Spectrum Disorder (ASD)¹¹ are also afflicted by a medical illness having its roots in a generally-recognised medical diagnosis, and that similar efforts should be made to alleviate the symptoms laid down in such diagnostic criteria. One might further add, in such a scenario that, just as with smallpox, and hopefully in future as the case would also be with cancer and AIDS, that one would also see the end of such conditions affecting 'sufferers' and their families, in the hope of making the world a better place in the process.

This is to be seen in conjunction with public opinion concerning mental disabilities and mental illness, traditionally defined, in which the first thought that comes to most persons' minds is that of a grossly unstable individual who is locked up as a matter of public policy, or else of a person who does not have what it takes to participate in a 'normal' manner in the world around them, stemming from a lack of intellect and capacity to act independently. This, together with the feeling that the world around most persons would be both a better as well as, possibly, a safer place, should the issues around such persons be addressed, with these persons being viewed with derision, pity, or a mixture of both.

1.1.1.1 International Guiding Texts – 'Disorder/ Condition' not Disease

The medical community currently defines autism pathologically. The main yardsticks for diagnosis and reference for the past years were the WHO's ICD-10 Manual, as well as the APA's DSM-IV, now superseded by the DSM-5, with the relevant scenario in this regard tackled shortly ahead. Both texts speak of autism, and of its variants, as a disorder,¹² and offer clinical guidelines of symptoms that can lead to a diagnosis.

The approach and categorisations currently favoured by both the WHO and the APA can be seen to encourage fertile ground for the 'pro-cure' approach to autism described later in this thesis, much to the ire of a good number of disability and especially autistic self-

¹⁰ This term is currently favoured in the United Kingdom.

¹¹ This term is currently favoured in the United States of America and many other countries.

¹² The ICD-10, in section F84, speaks of a "group of disorders characterized by [...] abnormalities", while section 299 of the DSM-IV-TR uses terminology such as "marked impairment", "abnormal functioning" and "disturbance".

advocates.¹³

The main characteristics of autistic persons were traditionally seen to be three – generally referred to as the ‘triad of impairments’.¹⁴ Repetitive, restrictive and stereotyped behaviours and interests;¹⁵ significant delays and impairments in communication,¹⁶ and; impairments in social interaction.¹⁷ In what is considered to be ‘high-functioning autism’, as in the case of Asperger Syndrome, issues with communication are stated in diagnostic criteria not to be present.¹⁸

This diagnosis takes its name from Austrian physician Hans Asperger who, starting in the 1930s, labelled certain children in his care at the Vienna University Children’s Hospital as ‘little professors’.¹⁹ These children still exhibited deficits in comparison to then-contemporary societal norms in social interaction, as well as rigidity in behavioural patterns, albeit to much lesser extents than the individuals described by Kanner.

However, conversely, they exhibited no similar restraints on their cognitive abilities, demonstrating instead average or even above-average Intelligence Quotients (IQs), hence Asperger’s description. Such individuals were later classified as having Asperger syndrome, nowadays considered in certain circles to be the highest-functioning form of autism a person can be diagnosed with, i.e. that which allowed a person to function as closely as possible to societal standards deemed ‘normal’.²⁰

When not all the characteristics for a diagnosis of autism or Asperger Syndrome are met, a diagnosis of Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) is returned, under the WHO criteria, as well as the APA criteria applied up until the DSM-IV-

¹³ See Section 6.2 of the thesis for a further discussion of the topic.

¹⁴ This term was introduced by Lorna Wing, in ‘The Definition and Prevalence of Autism: A Review’, *European Child and Adolescent Psychiatry*, Vol.2, Issue 2, April 1993, at 61-74.

¹⁵ ICD-10, op. cit., at F84.0 (b); DSM-IV-TR at 299.00 A (3).

¹⁶ ICD-10, op. cit., at F84.0 (b); DSM-IV-TR at 299.00 A (2).

¹⁷ ICD-10, op. cit., at F84.0 (b); DSM-IV-TR at 299.00 A (1).

¹⁸ ICD-10, op. cit., at F84.5; DSM-IV-TR at 299.80 D.

¹⁹ Hans Asperger (trans. and annot. by Uta Frith), ‘Autistic psychopathy’ in childhood’, in Uta Frith, *Autism and Asperger syndrome*, Cambridge University Press, 1991, at 37–92.

²⁰ Doreen Bradley Satter, ‘Understanding Asperger’s Syndrome – The Mildest and Highest Functioning Form of Autism’, suite101.com, 17 May 2007, available online at http://autism-types.suite101.com/article.cfm/understanding_aspergers_syndrome. Diagnostic criteria in ICD-10, at section F84.5; DSM-IV, at section 299.80.

TR revision.²¹

The picture became even more complicated when the notion of an 'Autistic Spectrum', rather than simply a one-size-fits-all diagnosis of Autism, was suggested.²² This has been read, in medicalised terms, as a spectrum placing Kanner's description of autism at one end of a scale, with varying degrees of 'impairment' being observed by different researchers along a continuum, with a form of 'High Functioning Autism' being present at the other end.²³

However, the Autistic Spectrum is seen by autistic activists as a very fluid concept, with no fixed points on the line, and persons able to be on different points of it at different times, depending on their actual state and environmental input.²⁴

1.1.1.2 The DSM-5 'Earthquake' - The Text Revisions

The APA published its revision of the DSM Manual on May 18th, 2013,²⁵ after a long-drawn consultation and compilation process chaired by a panel of experts. Autism has now been unified under one category, that of 'Autism Spectrum Disorder',²⁶ doing away with sub-categories such as Asperger Syndrome and PDD-NOS, and instead recommending diagnosis of symptoms anywhere across the continuum under this heading.

It further added a 3-level classification system, depending on whether the 'patient' would

²¹ ICD-10, op. cit., at F84.9 et.; DSM-IV-TR at 299.80/10.

²² Ami Klin, 'Autism and Asperger syndrome: an overview', *Revista Brasileira de Psiquiatria*, Vol. 2, suppl.1, São Paulo, May 2006, English translation available online at http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1516-44462006000500002&lng=en&nrm=iso&tlng=en.

²³ See, for example, Romana Tate, 'What's the Difference Between High Functioning and Low Functioning Autism?', Autism Women's Network, accessed online at <http://autismwomensnetwork.org/whats-the-difference-between-high-functioning-and-low-functioning-autism/>, for the main points usually raised when the terms 'high-functioning' and 'low-functioning' are discussed within the context of autism.

²⁴ As to this topic, see the relevant Position Statements of the Autistic Self Advocacy Network (ASAN), a self-advocacy group run by and for autistic persons, further described in Section 6.3 of this thesis, at <http://autisticadvocacy.org/home/about-asan/position-statements/>, and ASAN's views on Autism, which echo those of the majority in the self-advocacy community, at <http://autisticadvocacy.org/home/about-asan/about-autism/>, where relevant views about the Autistic Spectrum are also described.

²⁵ DSM-5, op. cit.

²⁶ DSM-5 at 299.00 (F84.0).

require merely ‘support’, ‘substantial support’ or ‘very substantial support’²⁷ – ushering in new assessments based on whether the autism in question is judged to be ‘mild’, ‘moderate’ or ‘severe’.²⁸ The ‘triad’ has been reformed, in that social and communication issues have been paired into the same category,²⁹ with repetitive and restrictive interests making up the other.³⁰

The former diagnosis of PDD-NOS has been absorbed into the new Social (Pragmatic) Communication Disorder diagnosis, technically separate from Autism under the DSM-5,³¹ while Sensory issues have been included into diagnostic criteria for the first time.³²

A ‘grandfathering clause’ permits previously diagnosed persons to retain their diagnosis made under earlier DSM revisions, even if it was under categories that have now been removed/ reformed.³³ Comorbidity of autism with other neurodevelopmental conditions such as ADHD, intellectual or language ‘impairments’, catatonia or other known medical or genetic conditions or environmental factors, has also been allowed by way of diagnosis, by the new text.³⁴

1.1.2 Viewing Autism as Non-Medical – Neurodivergence

There is also an alternative argument for viewing persons with mental disabilities, traditionally defined, as ‘neurodivergent’. One might or might not debate the presence of a disability in such persons. However, even in the latter case, this is seen in conjunction with certain characteristics that result in that person approaching the world in a different manner, so the relevant discourse shifts to understanding such approaches, and making relevant accommodations for such persons.

This approach emphasises these criteria as principal points, rather than just viewing these persons as simply being in some way impaired, in contrast to the larger ‘neurotypical’ body

²⁷ Ibid., at Table 2.

²⁸ Fred Volkmar, comment made during ‘Setting the Scene – The Background to DSM-5’ presentation at ‘Challenging DSM-5’ international conference, op. cit.

²⁹ DSM-5, op. cit., at 299.00 A.

³⁰ Ibid., at 299.00 B.

³¹ Ibid., at 315.39 (F80.89).

³² Ibid., at 299.00 B (4).

³³ Ibid., at Note to 299.00.

³⁴ Ibid., at Direction to Specify comorbidities in diagnosis.

of the population.³⁵ This notion would thus replace the still-generally prevalent notion that mental disability is a horrible disease which affects persons badly, making them less than 'normal', a phenomenon nobody desires also nowadays, and which must be eradicated.

The concept of neurodiversity and autistic emancipation were products of the winds of change blowing following the advent of the social model of disability, once these also reached the field of Intellectual and Developmental Disabilities (I/DDs).

1.1.2.1 Disabilities in terms of the Medical Model

In the medical model of disability, public opinion lay at the core of the notion of over-medicalising disabilities. The 'medical model' of disability is generally taken to be that which emphasises functional limitation as the main element around which a person's disability centres, due to such an element being emphasised by the medical community, such as through the World Health Organisation's definitions of 'impairment', 'disability and handicap'.³⁶

Although major shifts to the social model of disability, discussed shortly, have been attempted, both supranationally and in various countries, this approach, or certain elements of it, to varying degrees, is still alive and well in many instances and places, as will also be described further throughout the course of this thesis.

This mindset can be illustrated through the actions of comedian Jerry Lewis, who caused uproar following his comments in the context of a disability fundraising telethon in 1990. When trying to 'empathise' with persons with muscular dystrophy, Lewis stated he following:

"I decided after 41 years of battling this curse that attacks children of all ages, I would put myself in that chair, that steel imprisonment that long has been deemed the dystrophic child's plight. . . . I realize my life is half, so I must learn to do things

³⁵ The term, coined by Judy Singer, according to Andrew Solomon in 'The Autism Rights Movement', *New York Magazine*, 25 May 2008, was first used by Harvey Blum in 1998 in an article entitled 'Neurodiversity', *The Atlantic*, 30 September 1998.

³⁶ 'Models of Disability', carried on the website of the Connections for Community Leadership programme at <http://www.copower.org/leader/models.htm>.

halfway. I just have to learn to try to be good at being half a person."³⁷

As regards autistic persons specifically, this can be seen in the 1988 film 'Rain Man',³⁸ in which one of the lead characters, Charlie Babbitt, trying to trace the beneficiary of part of an inheritance his late father had placed in trust, is directed to a mental asylum, where he discovers that his long-lost brother Raymond is actually residing there, and is also the beneficiary of the said trust.

In trying to make sense of all this, in a conversation with the director of the institution, Dr. Bruner, he tries to figure out 'what is going on' with his brother as follows:

Charlie Babbitt - What is he, crazy?

Dr. Bruner - No.

Charlie Babbitt - Is he retarded?

Dr. Bruner - Not exactly.

Charlie Babbitt - Not crazy or retarded, but he's here.

This modelling of a system on similar lines to animal welfare legislation, with a mentality of protecting those who were perceived as too vulnerable to stand on their own two feet, rather than empowering them to be able to take control of their lives, and perhaps also give a meaningful contribution to the society they also formed part of, was later identified as the medical model of disability by certain authors,³⁹ with a tragedy/ charity model being devised to 'deal' with it.⁴⁰

³⁷ Jerry Lewis, 'What if I had Muscular Dystrophy?', *Parade* magazine, 2 September 1990, as quoted in Mary Johnson, 'A Test of Wills: Jerry Lewis, Jerry's Orphans, and the Telethon', *The Disability Rag*, September/ October 1992, available online at <http://www.ragged-edge-mag.com/archive/jerry92.htm>.

³⁸ Barry Levinson, *Rain Man*, United Artists, Century City (California), 1988. It was, however, later pointed out by several persons that Kim Peek, the real-life person on whom Raymond Babbitt's character was based, was not autistic, but rather a savant, defined as "a person with a developmental disability, such as an autism spectrum disorder, [who] demonstrates profound and prodigious capacities or abilities far in excess of what would be considered normal" in LK Miller, 'The savant syndrome: Intellectual impairment and exceptional skill', *Psychological Bulletin*, Volume 125, Issue 1, at 31, with his savantism due to agenesis of the corpus callosum, a separation of the brain's hemispheres that allows a person to simultaneously, for example, read both pages of an open book and retain the information, as stated by Berit Brogaard in 'The Brain of the Real Rain Man', *The Superhuman Mind*, *Psychology Today*, 17 March 2013, accessed online at <https://www.psychologytoday.com/blog/the-superhuman-mind/201303/the-brain-the-real-rain-man>.

³⁹ 'Models of Disability', op. cit.

⁴⁰ Ibid.

1.1.2.2 Shift towards a Social Model of Disability

Although in the case of mental disabilities as traditionally defined, including in the case of autism, matters moved much more slowly, the 1970s saw the advent of proponents of a social model of disability. These proponents put forward the view that individuals with a disability were different in some way, but this could be accommodated by appropriate structural and, most importantly, conceptual changes in society.

This marked the start of the formal shift in thinking within academic circles from a charity-based Approach, embodied by the medical/ charity-tragedy model of disability, to a rights-based approach to disability, embodied by what was to become known as the social model.

The charge was led by disabled British academic Mike Oliver, within the framework of research and lobby group UPIAS (Union of the Physically Impaired Against Segregation). This paved the way for the movement that was later embodied by the rallying cry “Nothing About Us Without Us”,⁴¹ which eventually became the cornerstone of the new UN Convention on the Rights of Persons with Disabilities (CRPD) adopted in 2006.⁴²

Frances Hasler termed the social model ‘the big idea’ of the British disability movement.⁴³ UPIAS’ initial efforts from the 1970s were given academic credence by authors such as Vic Finkelstein in the 1980s,⁴⁴ and later Colin Barnes⁴⁵ in the 1990s. The most seminal pieces, however, remain those penned by Mike Oliver.⁴⁶

⁴¹ The term has its roots in the Latin phrase *Nihil novi nisi commune consensu* (trans. ‘Nothing new without the common consent’), the title of constitutional legislation adopted by the Polish Sejm (Parliament) in 1505, transferring legislative power, saving in a number of reserved matters, from the King to representatives of the nobility seated in the Sejm, ushering in the Polish-Lithuanian ‘Commonwealth of the Nobility’ (*Rzeczpospolita Szlachecka*), as detailed in W.J. Wagner, ‘May 3, 1791, and the Polish constitutional tradition’, *The Polish Review*, Volume 36, Issue 4, 1992, at 383. The term entered disability activism in 1998, through Jack Charlton’s eponymous book (University of California Press, Los Angeles (CA)), the author having heard the term being discussed at a conference by South African disability activists, the latter having in turn heard it from an activist from Eastern Europe.

⁴² Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, U.N. GAOR, 61st Sess., U.N. Doc. A/Res/61/106 (Dec. 13, 2006) (hereinafter ‘UN CRPD’).

⁴³ Frances Hasler, ‘Developments in the disabled people’s movement’, in J. Swain et al., *Disabling Barriers, Enabling Environments*, Sage, London, 1993, at 284.

⁴⁴ See, for example: *Attitudes and Disabled People*, World Rehabilitation Fund, New York (NY), 1980; ‘To Deny or Not to Deny Disability’, in A. Brechin et al. (eds.), *Handicap in a Social World*, Hodder and Stoughton, Sevenoaks, 1981.

⁴⁵ *Disabled People in Britain and Discrimination*, Hurst and Co., London, 1991.

⁴⁶ In particular, see *The Politics of Disablement*, Macmillan, Basingstoke, 1990; *Understanding*

Shakespeare and Watson describe the social model as having now become “the ideological litmus test of disability politics in Britain, used by the disabled people’s movement to distinguish between organisations, policies, laws and ideas which are progressive, and those which are inadequate.”⁴⁷

The core definition of the British social model is derived from the UPIAS document ‘Fundamental Principles of Disability’,⁴⁸ the main tenets of which are distilled in the following three paragraphs quoted:

“... 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. Disabled people are therefore an oppressed group in society.

To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called ‘disability’, of people with such impairment.

Thus we define impairment as lacking all or part of a limb, or having a defective limb, organism or mechanism of the body and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.”⁴⁹

Shakespeare and Watson summarise the three main claims made in this manifesto’s definition as follows:

- Disabled people are an oppressed social group
- There is a distinction between the impairments that people have, and the oppression

Disability: From Theory to Practice, Macmillan, Basingstoke, 1996.

⁴⁷ Tom Shakespeare and Nicholas Watson, ‘The social model of disability: an outdated ideology?’, *Research in Social Science and Disability*, Volume 2, Issue 9, 2002, at 3, 10.

⁴⁸ An edited version of the Principles (‘Fundamental Principles of Disability’) are reprinted in Mike Oliver, ‘Understanding Disability: From Theory to Practice’, *Journal of Sociology & Social Welfare*, Vol. 23, Issue 3, 1996, Article 24, at 22.

⁴⁹ Ibid.

which they experience

Most importantly, ‘disability’ should be defined as the social oppression, not the form of impairment.⁵⁰

Lisa Waddington states that the social model is based on a socio-political approach, which argues that disability stems primarily from the failure of the social environment to adjust to the needs and aspirations of people with impairments.

This rather than from the inability of people with impairments to adapt to the environment, which one could term the central mantra of the medical model. The argument here, according to her, is that it is discrimination, in the physical and attitudinal environment, prejudice, stigmatisation, segregation and a general history of disadvantage, which is the major problem.⁵¹

1.1.2.3 The Emergence of an Autistic Identity

In view of these winds of change, it was eventually not only parent and guardian activists who decided to alter their stance but, most importantly, self-advocates who were autistic themselves. These persons decided to finally speak up, and foster awareness and wider acceptance of autism, dispelling commonly-held myths, while fighting for their rights – and their lives.

They campaigned to no longer be abused, locked up, silenced, stripped of legal capacity, forced to adapt to inaccessible situations, and in general demonised. The focus of their activism was placed on shifting society’s viewpoint: one that looked into how and why they were broken, and on how the situation could be fixed or prevented, rather than on recognising that they were members of society like everybody else.

⁵⁰ Shakespeare et., op. cit., at 4.

⁵¹ Lisa Waddington, ‘Case C-13/05, *Chacón Navas v. Eurest Colectividades SA*, judgement of the Grand Chamber of 11 July 2006’, *Common Market Law Review*, Volume 44, Issue 2, 2007, at 487, 491.

Human beings with challenges but also with abilities, including that of being productive members of society. They advocated for investing instead in supports and services, just like for other members of society, allowing autistic persons to likewise lead healthy and happy lives, with them being able to run their own lives and be in control of their own destinies, as far as possible, just like any other person.

The seminal piece that kicked off the autistic self-advocacy movement is usually traced back to being Jim Sinclair's 'Don't Mourn for Us,'⁵² where Sinclair laid out what were to be the movement's main tenets. Here, Sinclair pushed forward on issues of social justice, as well as issues of labelling and terminology, most prominently on the use of identity-first language over person-first language. The latter move was also being undertaken by other disabled self-activists pushing to bring about the social model into being, as a statement of empowerment and of taking back control over their lives.

This point can also be marked as the birth of the Neurodiversity movement, the term being coined by Judy Singer,⁵³ and first used by Harvey Blum in 1998 in an eponymous article in *The Atlantic*.⁵⁴ The concept attempted to dispel the deeply ingrained concepts of 'normal' and 'other', making the case instead for different persons with different neurological profiles, who were all part of the same human family nonetheless. Therefore, within this context, autism was simply one of many different neurological expressions of the human norm.

This led to the autistic rights movement taking on the mantle of neurodiversity, with autistic persons identifying as 'neurodivergent', and referring to persons falling within the socially accepted standard neurological norm, those who are currently portrayed or identify as the social majority, as 'neurotypical'.⁵⁵ This term was also extended further to covering other neurodivergent conditions by certain self-advocates.⁵⁶

⁵² Jim Sinclair, 'Don't Mourn for Us', *Our Voice*, Autism Network International newsletter, Volume 1, Number 3, 1993, available online at http://www.autreat.com/dont_mourn.html. The introduction states that the article is an outline of the presentation Sinclair gave at the 1993 International Conference on Autism in Toronto, and is addressed primarily to parents.

⁵³ Solomon, op. cit.

⁵⁴ Blum, op. cit.

⁵⁵ Ibid.

⁵⁶ The notion of neurodiversity has also been extended further than simply encompassing the autistic spectrum by some activists. Some activists, such as Savannah Logsdon-Breakstone, in *Autistic*, 'Allistic, Neurodiverse, and Neurotypical: Say what?', *Cracked Mirror in Shalott Blog*, 12 April

While this new means of identifying was and still is empowering and liberating for many members of the autistic community, allowing them to ‘come out’, live their lives, and express who they really are, it nonetheless poses the threat of being used for drawing ‘them and us’ battle lines.⁵⁷ This phenomenon can manifest itself in the same way as it already has in the case of many other diverse groups, such as with LGBTQI persons.

However, issues still remained following the advent of such movement, particularly concerning those members of the autistic community who could not speak for themselves, or independently care for or support themselves – individuals described as ‘low-functioning’ in certain spheres, as mentioned earlier.

Such situations at times posed major challenges to the argument that disabled persons and autistic persons are in their current situation, simply and exclusively because they are so disabled by society. These concerns are sometimes raised, both in activism⁵⁸ as well as in

2013, available online at <http://crackedmirrorinshalott.wordpress.com/2013/04/12/autistic-allistic-neurodiverse-and-neurotypical-say-what/>, and Andrew Main, going by the pseudonym Zefram, in ‘allism: an introduction to a little-known condition’, fysh.org, 30 January 2003, available online at http://www.fysh.org/~zefram/allism/allism_intro.txt, and cited by Logsdon-Breakstone, insist on the fact that the neurodiverse spectrum encompasses not only autism, but also all of its so-called ‘autistic cousins’, such as ADHD and dyslexia, and that, therefore, these two terms are not as interchangeable as many make them out to be.

Logsdon-Breakstone argues, in this regard, that ‘neurotypical’ is short for ‘neurologically typical,’ and this within the typical range for human neurology. Consequently, she argues that it would not hold water to state that a person with definitively atypical neurology was neurologically typical “just because their atypicality wasn’t that they were autistic.” She also mentions the use of the neurotypical/ neurodiverse dichotomy by segments of the Mental Health consumers/ survivors communities being based on this reasoning. For this reason, she discussed new identifiers proposed by Zefram as regards autism, the dichotomy of being ‘autistic’ as opposed to ‘allistic’.

Some might argue, though, that such terminology reinforces the ‘them and us’ approach, as further discussed in Section 3.3 and Chapter 6 of this thesis, both concerning autistic advocacy, as well as concerning radical disability advocacy within the context of the social model of disability.

However, Logsdon-Breakstone emphasises that the use of this terminology is not meant to “indicate ally-hood or opponent-hood. It just means that someone is not autistic.” She later specifies that this dichotomy mirrors the same concept applied in the area of gender, when viewing the relationship between the terms ‘transgender’ and ‘cisgender’.

⁵⁷ See Sections 6.3 and 12.4 of this thesis for a further discussion.

⁵⁸ Here, one can point to the recent controversy concerning non-verbal self-advocate Amy Sequenzia, and comments made by other self-advocates that her facilitator, helping to relay her communication through spoken language, within the context of Adaptive and Assistive Communication (AAC), was not in fact relaying the information which Sequenzia was entering through her Facilitated Communication device, and that she was simply being abused as a poster-girl by ASAN, of whom she is a Board Member. Following this incident between her team and other self-advocates, at a conference in Geneva in late 2016, Sequenzia authored a blog post on *Ollibean* entitled ‘Bigots’, at <http://ollibean.com/bigots>, aimed at the self-advocates making these accusations, however, the self-advocates, who prefer to remain anonymous for the purposes of this thesis, but who are easily identified within the self-advocacy community, have expressed doubt as to whether such post, and other posts, were actually authored by Sequenzia herself.

the academic realm,⁵⁹ in particular when discussing issues such as accessibility and Assistive and Adaptive Communication (AAC),⁶⁰ as well as in extreme cases when a person suffers from comorbidities or has motor coordination issues.

These discussions also lead to major moral and ethical debates in the autism prevention vs autism acceptance and cure matter.⁶¹ Such scenarios will also be discussed further later in this thesis.

1.1.3 *Clash of Worlds – Indistinguishability and Cure*

The competing notions outlined above, have led to a specific debate, and major tensions between self-advocates and other advocates, mainly parent and professional (P&P) advocates, as to the twin issues of indistinguishability and cure in the case of autism.

1.1.3.1 Claiming Breach of Rights – The *Auton* Saga

In the former case, the most notable situation espousing such matters was the court proceedings in *Auton et al. v. Attorney General of British Columbia*.⁶² These proceedings resulted from an appeal by the Canadian federal government from the decision handed

⁵⁹ See, for example, Andrew Fallon's comments on the issue of impairments and related requirements of care, in Section 12.4.2 of this thesis.

⁶⁰ Although, as outlined in Footnote 58 above, the issue of AAC within autism and in general is controversial, it is, nonetheless, promoted by a number of organisations, such as autism advocacy group AutCom in the United States, as explained by Barbara Stern Delsack, an activist for the organisation with a background in the educational sector, during an Interview, in Washington, DC, in May 2011, as well as in Malta, where the National Commission for the Rights of Persons with Disabilities (KDPD) promotes and facilitates the use of such technologies, through a partnership with the Foundation for Information Technology Accessibility (FITA), through its Sonia Tanti Independent Living Centre (STILC).

⁶¹ See, for example, Virginia Bovell, *Is the prevention and/or cure of autism a morally legitimate quest?*, DPhil thesis, University of Oxford, 2015; Virginia Bovell, Presentation during the 'Cure vs Acceptance of Autism' Panel Discussion, XI Autism-Europe International Congress, Edinburgh, 16 September 2016.

⁶² *CONNOR AUTON, an Infant by his Guardian Ad Litem, MICHELLE AUTON, and the said MICHELLE AUTON in her personal capacity, MICHELLE TAMIR, an Infant, by her Guardian Ad Litem SABRINA FREEMAN, and the said SABRINA FREEMAN in her personal capacity, JORDAN LEFAIVRE, an Infant by his Guardian Ad Litem, LEIGHTON LEFAIVRE, and the said LEIGHTON LEFAIVRE in his personal capacity, RUSSELL GORDON PEARCE, an Infant, by his Guardian Ad Litem, JANET GORDON PEARCE, and the said JANET GORDON PEARCE in her personal capacity v. THE ATTORNEY GENERAL OF BRITISH COLUMBIA and THE MEDICAL SERVICES COMMISSION OF BRITISH COLUMBIA*, Supreme Court of Canada, per McLachlin CJ and Major, Bastarache, Binnie, LeBel, Deschamps and Fish JJ, 9 June 2004, Docket: 29508 [2004] 3 SCR 657, 2004 SCC 78 (*Auton et al. v. Attorney General of British Columbia*).

down by the Supreme Court of British Columbia in *Anderson et al. v. Attorney General of British Columbia*.⁶³ They culminated in a final decision handed down by the Supreme Court of Canada, which was possibly the longest-running litigation in connection to autism-related services ever to take place.

In this matter, parent advocates argued before provincial and eventually federal courts, that Canadian government actions, on both federal and provincial levels, withheld funding for necessary therapies for their children. They additionally specified that such therapies were proven to be both necessary and effective, this argumentation having been also accepted by various lower courts. In addition, the parents also submitted that their children were being denied their rights, under the CRPD and under the Canadian Charter of Human Rights.

⁶³ Ryan Anderson, an infant, by his Guardian ad Litem, the said Judy Anderson in her personal capacity; Ryan Anthony, an infant, by his Guardian ad Litem, Karen Anthony, and the said Karen Anthony in her personal capacity; Christian Aquilini, an infant, by his Guardian ad Litem, Paolo Aquilini, and the said Paolo Aquilini in his personal capacity; Cameron Bridges, an infant, by his Guardian ad Litem, David Bridges, and the said David Bridges in his personal capacity; Pearson Chan, an infant, by his Guardian ad Litem, David Chan, and the said David Chan in his personal capacity; Lawrence Dabbagh, an infant, by his Guardian ad Litem, Anita Dabbagh, and the said Anita Dabbagh in her personal capacity; R.D., an infant, by his Guardian ad Litem, Y.D., and the said Y.D. in her personal capacity; Hayden Ewing, an infant, by his Guardian ad Litem, Arleene Ewing, and the said Arleene Ewing in her personal capacity; Nicholas Frank, an infant, by his Guardian ad Litem, Debbra Mackie, and the said Debbra Mackie in her personal capacity; P.G., an infant, and J.G., an infant, both by their Guardian ad Litem, R.G., and the said R.G. in her personal capacity; Gary Matthew Groenke, an infant, by his Guardian ad Litem, Gary Groenke, and the said Gary Groenke in his personal capacity; Clinton Kam, an infant, and Brendan Kam, an infant, both by their Guardian ad Litem, Janny Kam, and the said Janny Kam in her personal capacity; Aaron Lewis, an infant, by his Guardian ad Litem, Jean Lewis, and the said Jean Lewis in her personal capacity; Matt Rowan, an infant, by his Guardian ad Litem, Mark Rowan, and the said Mark Rowan in his personal capacity; Allison Marshall, an infant, by her Guardian ad Litem, Beverley Sharpe, and the said Beverley Sharpe in her personal capacity; Alexander McLeod, an infant, by his Guardian ad Litem, Barbara McLeod, and the said Barbara McLeod in her personal capacity; Derek Paciejewski, an infant, by his Guardian ad Litem, Barbara Paciejewski, and the said Barbara Paciejewski in her personal capacity; Tessa Spiller, an infant, by her Guardian ad Litem, Franca Pastro, and the said Franca Pastro in her personal capacity; Kyle Pike, an infant, by his Guardian ad Litem, Kim Pike, and the said Kim Pike in her personal capacity; McKenzie Querns, an infant, and Nolan Querns, an infant, both by their Guardian ad Litem, Douglas Querns, and the said Douglas Querns in his personal capacity; Ariel Raskin, an infant, by her Guardian ad Litem, Avery Raskin, and the said Avery Raskin in his personal capacity; Adam Schertzer, an infant, by his Guardian ad Litem, Ruth Wingerin, and the said Ruth Wingerin in her personal capacity, and John Lyons Walter, an infant, by his Guardian ad Litem, Robert Walter, and the said Robert Walter in his personal capacity v. The Attorney General of British Columbia, Supreme Court of British Columbia, per Pitfield J, 22 August 2003, 2003 BCSC 1299, Docket: L0305662003 (Vancouver), (*Anderson et al. v. Attorney General of British Columbia*).

A very vocal battle in this regard had been initiated and was led by the organisation FEAT (Families for Early Autism Treatment), spearheaded by activists Norah Whitney and Sabrina Freeman, who also received personal threats due to their efforts,⁶⁴ while other Canadian disability activists shared the same sentiments about their government.⁶⁵

The main issue at stake was the use of ABA/ IBI treatment. The particular methodology being sought by the parents, was portrayed in court documents as promoting the ultimate goal of ‘indistinguishability’ of children from their peers,⁶⁶ and made statements as to how these children and their parents were ‘suffering’ due to their current state.

The aim was to have access similar to that afforded by, for example, US legislation, where specific laws in different states also cover the area of insurance law,⁶⁷ which was particularly crucial in the funding of emerging new therapies in the field.

While challenging coverage under the Canada Health Act,⁶⁸ specific focus was made on public national insurance schemes, such as the provincially-implemented Medicare programme.⁶⁹ Here, lack of access to children and their parents, as opposed to access granted to groups falling under other diagnostic criteria, was claimed as the main factor by the petitioners, based on their interpretation of ‘necessary and effective’ treatments.⁷⁰ They based their claim on the Supreme Court’s earlier decision in *Eldridge et al. v. Attorney General of British Columbia*,⁷¹ which classified necessary disability-specific interventions as “core” medical services in terms of the Act, and thus qualifying for coverage under such.

⁶⁴ Interview with Norrah Whitney, Founder of FEAT (Families for Early Autism Treatment) Ontario and Co-Petitioner in *Auton*, on behalf of her son Lucas (Toronto, July 2013).

⁶⁵ This sentiment was echoed in, for example, by Canadian parent and autism activist Harold Doherty, in a phone interview, in July 2011.

⁶⁶ *Auton et al. v. British Columbia*, Supreme Court of Canada, op. cit., at 658; Interview with Norah Whitney, op. cit.

⁶⁷ Such as the South Carolina Autism Insurance Reform Law, South Carolina Code of Laws, Title 38 (Insurance), Chapter 71 (Accident and health insurance), known as Ryan's Law, after Ryan Unumb, son of Autism Speaks board member, lawyer and activist Lorri Shealy Unumb, who pushed for such legislation in order to secure funding for her son's early intervention programmes, as discussed during an Interview with Unumb in New York, in May 2011, and also further detailed in Lorri Shealy Unumb and Daniel R Unumb, *Autism and the Law: Cases, Statutes, and Materials*, Carolina Academic Press, Durham (NC), 2011.

⁶⁸ Canada Health Act (R.S.C., 1985, c. C-6).

⁶⁹ *Auton et al. v. British Columbia*, Supreme Court of Canada, op. cit., at 667; Interview with Norah Whitney, op. cit.

⁷⁰ *Auton et al. v. British Columbia*, Supreme Court of Canada, op. cit., at 672, 674; Interview with Norah Whitney, op. cit.

⁷¹ *Robin Susan Eldridge, John Henry Warren and Linda Jane Warren v. The Attorney General of British*

Such difference in treatment also constituted the basis of their claims concerning discrimination and rights breaches, which they also claimed in terms of the Canadian Charter of Rights and Freedoms.⁷²

This was particularly due to the fact that, in the case of ABA/IBI therapy, which parents deemed to be an ‘effective regimen,’⁷³ bills ran into thousands of dollars. This treatment was seen as a necessity, not only by many in the medical community,⁷⁴ but in particular by parents of young children, especially those children considered to be ‘non-verbal’.

1.1.3.2 Same Breach – Different Perception

The political line of successive Liberal and Conservative governments had been that the petitioners’ claims, as well as proposed federal legislation⁷⁵ aimed at addressing such claims, was *ultra vires*. They argued that such was the situation, since petitioners’ desired outcome was to confer special rights on a specific group of persons, as to accessing benefits under the Canadian National Health Insurance system, discriminating against all other groups.⁷⁶

The activists in question, on the other hand, insisted instead that the main motivation of successive governments all along was to save money, for treatments that actually worked, at the expense of their children.⁷⁷ They insisted that their motivations were nothing more

Columbia and the Medical Services Commission, Supreme Court of Canada, per Lamer CJ and La Forest, L’Heureux-Dubé, Sopinka, Gonthier, Cory, McLachlin, Iacobucci and Major JJ, 24 April 1997, Docket: 24896, [1997] 3 SCR 624 (*Eldridge et al. v. Attorney General of British Columbia*); Justice Christopher Hinkson, counsel for petitioners during the various stages of the *Auton* proceedings, during an Interview in Vancouver, in May 2011, stressed petitioners’ reliance on *Eldridge* in their claims, and that the volte-face by the Supreme Court equated to ‘bad law’.

⁷² Also, citing *Eldridge*, the petitioners in *Auton* claimed a breach of Article 7 of the Charter, this also being stated by Norrah Whitney when interviewed, op. cit.

⁷³ Interview with Norrah Whitney, op. cit.

⁷⁴ The petitioners buttressed their claim before the Supreme Court, by providing a paper by Eric V. Larsson, of the Lovaas Institute in the United States, titled ‘Analysis of the Evidence Base for ABA and EIBI for Autism’, as part of evidence submitted by said plaintiffs during the proceedings.

⁷⁵ The main legislative efforts, introduced and re-introduced in successive Canadian legislatures, have been Bill C-304, which failed repeatedly to pass the House because, apart from advocating a National Autism Strategy, it also mentioned funding for ABA/IBI treatment under the Canada Health Act, and: An Act to provide for a National Strategy for the Treatment of Autism and to amend the Canada Health Act, and; Bill C-218: An Act to Amend the Canada Health Act (Autism Spectrum Disorder).

⁷⁶ Canadian Government submissions in *Auton et al. v. Attorney General of British Columbia*, Supreme Court of Canada, op. cit., at 659; Telephone interview with Geoffrey Cowper, State Counsel in *Auton* before the Supreme Court of Canada, June 2011; Interview with Christopher Hinkson, op. cit.

⁷⁷ Interview with Norrah Whitney, op. cit; Phone Interview with Peter Stoffer MP, Sponsor and

than financial considerations, even in the face of reports that disproved that their claims were couched in terms of concrete facts.⁷⁸

They also further insisted that the Canadian government has subsequently also pulled out all the stops, in order to make sure that the children's rights, through their parents as their guardians, were denied by the Supreme Court of Canada, on the basis of legal technicalities.⁷⁹

The sentiment that human rights in Canada were not a government priority was also echoed by disability activists in other fields. Commenting on the outgoing Canadian government during a conference in July 2015, Canadian former President of Inclusion International Diane Richler stated, when discussing the CRPD, that "in Canada, we have a government that does not respect human rights."⁸⁰

But while different Canadian activists echoed the same sentiments as to breaches of human rights, some activists disagreed with others as to what constituted such breaches. On the self-advocacy front, the main face of activism was Michelle Dawson, who also made submissions to the Supreme Court, after the Canadian Human Rights Commission had found against a Canadian public service and in her favour in an earlier separate case.⁸¹

Supporter of Bills C-304 & C-218 on behalf of the National Democratic Party, May 2011.

⁷⁸ This was especially due to the fact that the Canadian government chose to ignore, both generally, and also specifically within the context of the *Auton* proceedings, the conclusions of *Pay Now or Pay Later: Autism Families in Crisis, Final Report on the Enquiry on the Funding for the Treatment of Autism*, prepared by the Standing Committee on Social Affairs, Science and Technology of the Senate of Canada, Ottawa, March 2007. This report was also cited in a Phone Interview with Sabrina Freeman, Co-Founder of FEAT (Families for Early Autism Treatment) Ontario and Co-Petitioner in *Auton*, on behalf of her daughter Michelle Tamir, in May 2011, in the Interview with Norrah Whitney, op. cit, and in the Phone Interview with Peter Stoffer MP, op. cit, as well as by Tom Insel, Director of the US National Institute of Mental Health (NIMH), during the Opening Panel, at the Autism Society of America Annual Conference, Pittsburgh, 12 July 2013, where he discussed the Report's conclusions within the US context.

⁷⁹ *Auton et al. v. Attorney General of British Columbia*, Supreme Court of Canada, op. cit., at 683; Sabrina Freeman, 'Science for Sale in the Autism Wars', SKF Books, Langley (BC)/ Lynden (WA), 2003; Interview with Sabrina Freeman, op. cit; Interview with Norrah Whitney, op. cit. Following the Supreme Court's decision in *Auton*, new decisions by lower courts in Canada followed the same line taken by the lower courts in *Auton*, see, for example, *Wynberg et al. v. Her Majesty the Queen in Right of Ontario*; *Deskin et al. v. Her Majesty the Queen in Right of Ontario*, Court of Appeal for Ontario, per Goudge, Simmons and Gillese JJ.A., 7 July 2006, Docket: C43425, [2006] OJ No 2732 (QL) (*Wynberg v. Ontario*).

⁸⁰ Point raised during the 'Civil Society and the CRPD' panel, at the Beit Issie Shapiro 6th International Conference on Disabilities, Ra'anana, Israel, 10 July 2015.

⁸¹ *Michelle Dawson v. Canada Post Corporation*, Canadian Human Rights Tribunal, 2008 CHRT 41 (CanLII). The following synopsis is given by Canadian lawyer and parent advocate Harold J Doherty,

Before the Supreme Court, Dawson argued that allowing certain therapies to be applied to children by the Canadian government was a violation of their rights.⁸²

Unfortunately, this simply played into the hands of the Canadian government because, although Dawson's motivation was to point out the pitfalls of certain therapies and the way they were being applied – these therapies as applied being the central therapies that the petitioners were pushing the Canadian government to fund through their action – the Canadian government got away with simply not having to fund any therapies or structure for autism. The government got away with a technicality, rather than being required to lay the basis, in some way, for rights in the autism sphere, and then work out the details, in consultation with different parties, as to what would work best and how.

However, the different views of both sides concerning the nature of autism, as well as to how such a phenomenon should be approached and addressed, are at the centre of the main dilemmas tackled by this thesis.

in a response posted on 1 June 2016 to 'Again the question of neurodiversity and "human rights"', a blog post by Jonathan Mitchell, on Autism's Gadfly, published on 31 May 2016 and accessed at <http://autismgadfly.blogspot.ie/2016/05/again-question-of-neurodiversity-and.html>:

Dawson brought a complaint under the Canadian Human Rights Act against her former employer Canada Post, alleging that Canada Post had discriminated against her and harassed her on the basis of her autism disability, contrary to the provisions of the Canadian Human Rights Act. The Human Rights Tribunal found that she had substantiated most of her claims and found that Canada Post had contravened sections 7 and 14 of the Act.

A complaint pursuant to the Canadian Human Rights Act is brought under one of the grounds listed in section 3 of the Act. The Tribunal decision listed the grounds as race, national or ethnic origin, colour, religion, age, sex, sexual orientation, marital status, family status, disability and conviction for which a pardon has been granted.

In Dawson's case she alleged discrimination, harassment and retaliation against her by Canada Post on the basis of disability [,,] autism [,,] as set out in several paragraphs of the CHRT decisions:

" [2] In her complaint, dated August 9, 2002, Ms. Dawson alleges that the Respondent discriminated against her on the basis of disability, in breach of section 7 of the Canadian Human Rights Act in that it failed to accommodate her disability (autism).

[86] Ms. Dawson testified that autism is a neurological disability and that people generally do not have a good understanding of this reality.

.....

[90] Ms. Dawson testified that autistic persons compared to non-autistic people process information very differently, at a very basic profound level, really low level.

[95] In her testimony, Ms. Dawson also referred to people with Down Syndrome. She testified that Down Syndrome is in the same classification as autism. They are both developmental disorders or neuro-developmental disabilities."

⁸² Intervener's Factum by Michelle Dawson, in *Auton et al. v. Attorney General of British Columbia*, Supreme Court of Canada, op. cit.

Norrah Whitney, the main driver behind the whole effort, stated that she believed that autism was a medical condition, and that autism resulted in aberrations from the norm that had a deleterious effect on both the children affected, as well as on their families.⁸³ This echoed the sentiment of Members of Parliament such as Peter Stoffer, from the opposition National Democratic Party. Stoffer dismissed arguments of neurodiversity, stating instead that autism was a matter that should be dealt with under the Canada Health Act, and that in terms of it being an epidemic or otherwise, his view was that it was “equally up there” with other conditions such as diabetes and coeliac disease.⁸⁴

Although Whitney did not speak of seeking a cure, the pursuit of IBI therapy for these aims would be tantamount to seeking one, as described further in Section 10.4.1 of this thesis. Other persons who hold such medicalised views, however, do advocate for such, and have stated their willingness to pursue such cure pre- or post-natally, if the cure and mechanisms such as pre-natal autism identification were available.⁸⁵

The search for such cure is carried out through the vehicle of genetic research, the ‘holy grail’ for a long time in this area having been the search for an autism gene. Stated aims of locating such genetic markers have been achieving the possibility of ‘turning off’ such ‘problem’ genes or treating them, for example, in a chemical manner⁸⁶ – or simply terminating the pregnancy once such genes had been identified pre-natally – once such

⁸³ Interview with Norrah Whitney, op. cit.

⁸⁴ Phone Interview with Peter Stoffer MP, op. cit.

⁸⁵ See, for example, the views of former Autism-Europe President and current Vice-President Evelyne Friedel, who expressed agreement with finding a cure for autism, as well as for disability-specific abortion should pre-natal testing for autism become available, stating that ‘if I could know beforehand, I would not want to give my child such a ‘present’’, during an Interview in Budapest, in September 2013, and former Autism-Europe President and current Council of Administration member Donata Vivanti, whose comments are reported in the next Footnote.

⁸⁶ The gene in question, when ‘turned off’ in live animal subjects, was observed to lead to symptoms of autism no longer being manifested by said subjects. In Jason J. Yi, Janet Berrios, Jason M. Newbern, William D. Snider, Benjamin D. Philpot, Klaus M. Hahn, Mark J. Zylka, ‘An Autism-Linked Mutation Disables Phosphorylation Control of UBE3A’, *Cell*, Volume 162, Issue 4, at 795. The same tests in question were also performed on human cell lines, but not on live human subjects. This study was also cited by Donata Vivanti, former President and current Council of Administration member of Autism-Europe, during an Interview in Geneva, in August 2015, as an example of scientific research into the aetiology of autism that Autism-Europe supports and publicises as part of its mission.

A newer 2016 study, similarly performed on mice, claims to have ‘reversed’ autism in said test subjects by manipulating a single gene: Yuan Mei, Patricia Monteiro, Yang Zhou, Jin-Ah Kim, Xian Gao, Zhanyan Fu & Guoping Feng, ‘Adult restoration of Shank3 expression rescues selective autistic-like phenotypes’, *Nature*, Issue 530, 25 February 2016, at 481. It was carried by the *Nature* journal, which had termed autism an ‘epidemic’ on its front cover in 2008.

genes would have been discovered. The main inspiration for this was the discovery of Chromosome 21 causing Down's Syndrome,⁸⁷ and the hypothesisation that autism could result from a similar etiological basis.

On the one hand, it was such medicalised language, apart from the use of 'indistinguishability' therapies and the search for a cure, that irked activists such as Dawson.

On the other hand, the prevailing situation was also a reflection of the frustration and helplessness felt by activists such as Jean and Michael Lewis, of the Autism Society of British Columbia and the Autism Society of Canada. In this regard, the latter had stated that it would be difficult to think of how a person like Dawson could even state she is autistic,⁸⁸ when she has no idea as to what it is like to have a child running around, banging their head against everything, and constantly smearing faeces onto walls.⁸⁹

Michael Lewis also emphasised his view that Asperger syndrome, the specific autism diagnosis applied to Dawson, was not autism, and that, at the time, the DSM-5 Committee was considering removing Asperger syndrome from within the purview of an autism diagnosis.⁹⁰

However, the resulting fracas highlights the Canadian government's massive abdication of responsibility regarding autism rights because, with an unfolding situation in which two different sides to the advocacy sphere were raising major concerns, matters should have been investigated further, both as to the nature and efficacy of the therapies in question –

⁸⁷ This topic is dealt with eloquently in 'The Uncertain Rationale for Prenatal Disability Screening', an article by solicitor David Wasserman and the late noted disability rights activist Adrienne Asch, in *Virtual Mentor: Ethics Journal of the American Medical Association*, Volume 8, Number 1, January 2006, at 53, and in Armand Marie Leroi, 'The future of neo-eugenics. Now that many people approve the elimination of certain genetically defective fetuses, is society closer to screening all fetuses for all known mutations?', *EMBO Reports*, Volume 7, Issue 12, December 2006, at 1184.

See also Chapter 9 of this thesis, for a further discussion of this topic from a rights-based perspective.

⁸⁸ Interview with Jean and Michael Lewis, activists and former Presidents of the Autism Society of Canada and the Autism Society of British Columbia, and co-petitioners in *Auton v. British Columbia* on behalf of their son Aaron, West Vancouver, May 2011.

⁸⁹ Ibid

⁹⁰ Ibid; See also discussion in Section 11.3 of thesis covering also the 'removal' of Asperger Syndrome from the DSM-5.

rather than pulling out all stops to cut funding, from a purely financial point of view – and also looking into concerns raised by self-advocates in elaborating this exercise.

Not having carried out such exercise, especially as litigation in the field gained momentum, was already a violation of both plaintiffs', as well as self-advocates', rights under the UN CRPD, as to them being consulted,⁹¹ as well as to nature and efficacy of treatments.⁹²

It is the main topics emerging from the discussion above, as well as the responsibilities of states in such situations, and the consequences of their abdication of such, that shall be examined in further detail in this thesis.

1.1.4 They Say It's Genocide

This is being done in order to analyse the claims put forward by autistic activists such as Zach Richter⁹³ and the initiators of the 'Autistic Genocide Clock' internet page, and more recently through self-advocacy organisations such as ESH in Germany⁹⁴ as well as through discussions by self-advocates on online message boards.⁹⁵ The claims in question relate to a genocide being perpetrated against autistic persons through current societal practices, and such will be examined both within the definition of genocide laid out in Article 2 of the United Nations Genocide Convention,⁹⁶ as well as within a wider context.

⁹¹ UN CRPD, op. cit., at art. 4(3).

⁹² Ibid., at art. 15.

⁹³ Zach Richter, Facebook Comment in response to 'Autism Breakthrough as Genetic Signature in Babies as Young as a Year Found; Blood Test in the Works', 8 August 2013.

⁹⁴ Martin Schöngarth, founder of German autistic self-advocacy organisation ESH (Enthinderungsselbsthilfe von Autisten für Autisten (und Angehörige), enquired about the possibilities of prosecutions within or against the German state for genocide with respect to autistic persons, this having been relayed through Erich Kofmel, Founder and President of autistic self-advocacy organisation Autistic Minority International, during a meeting with the author, in Geneva, in August 2015.

As Founder and President of Enthinderungsselbsthilfe von Autisten für Autisten (und Angehörige) (ESH), he authored a shadow report to the German government's first State Report to the CRPD, the translation of which is entitled 'Autism – without it the normality would be disordered', Alternative Report under the UN-CRPD for Germany, last edited in February 2014, accessed online at http://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/PDF-Dateien/Pakte_Konventionen/CRPD_behindertenrechtskonvention/crpd_state_report_germany_1_2011_Parallel_ESH_en.pdf, which, at 20, states that "In this point, we consider the situation in Germany as a running genocide and as a planning of a broader genocide in the future affecting more minorities."

⁹⁵ One such thread on Reddit is entitled 'Finding a cure for autism is genocide', accessed online at https://www.reddit.com/r/TumblrInAction/comments/2bnlga/finding_a_cure_for_autism_is_genocide/.

⁹⁶ Convention on the Prevention and Punishment of the Crime of Genocide (hereinafter 'Genocide Convention'), G.A. Res. 260, U.N. GAOR 3, U.N. Doc. A/810 (9 December, 1948; entered into force

While authors such as Troy Duster have spoken of pre-natal testing techniques as a 'backdoor to eugenics',⁹⁷ the other activists and organisations have made much more forceful statements, using the word 'genocide' to emphasise their argument. This phenomenon has also been seen in other disability communities, such as the deaf community.⁹⁸

This sentiment was also described in Virginia Bovell's doctoral thesis.⁹⁹ Bovell, mother of an autistic child, and recipient of an OBE in 2008 for 'voluntary services to autistic children',¹⁰⁰ discussed this topic when analysing the ethics of the acceptance versus cure debate in this sphere, in the midst of what she describes, quoting Laurance, as an increasingly 'bitter ideological war'.¹⁰¹

However, although the above persons might have used the term 'genocide' for emphasis, without specific regard for its exact import and consequences, autistic activist and academic Nick Walker has written more specifically about associating the concept of genocide, within the terms of the Genocide Convention, with the current plight of autistic persons.¹⁰²

Walker writes that "[a]nyone involved in seeking or implementing prenatal tests for autism or any other sort of prenatal prevention of autism should be prosecuted in international court under the Genocide Convention, which classifies as genocide any attempt to prevent births within a targeted group."¹⁰³

12 January 1951)78 U.N.T.S. 277, entered into force Jan. 12, 1951.

⁹⁷ As further discussed in this thesis in Section 9.2.

⁹⁸ See, for example, Harlan Lane, Ethnicity, Ethics, and the Deaf-World, *Journal of Deaf Studies and Deaf Education*, Volume 10, Issue 3Pp, at 291, who delves into the culture linked with the 'Deaf World', to which parallels with the Autistic community and similar issues of identity can be drawn, and discussed the issues of cochlear implants, which are seen by some in the Deaf World as bringing on ethnocide or cultural genocide for their community.

⁹⁹ Virginia Bovell, *Is the prevention and/or cure of autism a morally legitimate quest?*, op. cit.

¹⁰⁰ Queen's Birthday Honours List 2008, Cabinet Office, UK Government Online – Publications, accessed online at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/416587/BD_2008.csv/preview.

¹⁰¹ Jeremy Laurance, 'Autism: What are the ethics of treating disability?', *The Independent*, 16 November 2007, as also cited in Virginia Bovell's Presentation during the 'Cure vs Acceptance of Autism' Panel Discussion, XI Autism-Europe International Congress, op. cit.

¹⁰² Nick Walker, 'Five Steps Toward Autism Acceptance', *Neurocosmopolitanism: Nick Walker's Notes on Neurodiversity, Autism and Cognitive Liberty*, 16 June 2014, accessed online at <http://neurocosmopolitanism.com/five-steps-toward-autism-acceptance/>.

¹⁰³ Ibid.

Walker here is not simply making emphasis, but actually invoking a legal notion on the basis of an international humanitarian law instrument, and advocating for legal prosecution based on such. Therefore, while one might want to investigate further the claims made by other activists and organisations from equality/ non-discrimination and breach of rights perspectives, within the framework of a more urgent overtone to the situation, Walker's comments call for a different approach. They call, rather, for further investigation into the actual purview of the legal concept of genocide, its possible applicability in the case of autism, whether the Genocide Convention could be applied in the case of autism, and whether such prosecutions as he suggests would be possible in terms of such.

In this regard, however, Walker does hint at a widening of concepts, when he speaks of "[i]nterpret[ing] those legal protections as broadly as possible, and rigorously enforc[ing] them."¹⁰⁴ However, Walker uses this reasoning while speaking of equality/ non-discrimination and breach of rights on the one hand, and prosecutions under Genocide Convention on the other hand, in the same breath.

Walker states that "[w]hen an Autistic person is abused for acting Autistic, prosecute it as a hate crime. Anytime an ABA "therapist" grabs an Autistic child's hands to stop her from moving like an Autistic person, prosecute it as criminal assault and as a hate crime."¹⁰⁵ Least restrictive interpretation of legal provisions could well be an effective mechanism in such scenarios.

However, Walker then continues by proposing that "[i]ndividuals and organizations that speak of autism as a "disease" or "tragedy," and that talk of "curing" it, should be prosecuted for hate speech and incitement to violence, just as if they were advocating a "Final Solution to the Jewish Problem."¹⁰⁶ Here, the prosecution of hate speech and incitement within the scenario of a least restrictive interpretation is being blended with overtones of crimes of a genocidal nature being prosecuted within the same scenario.

¹⁰⁴ Ibid.

¹⁰⁵ Ibid.

¹⁰⁶ Ibid.

He continues by proposing application of the Genocide Convention, and prosecution under such, in regard of instances of pre-natal testing for autism, as discussed earlier.¹⁰⁷

It is this conflation which creates the present legal conundrum. Invoking genocide as a legal concept might create additional obstacles when ‘stretching the law’ to bring acts or omissions within its purview, far further than those that would be encountered when so ‘stretching’ it to cover equality/ non-discrimination issues and other rights breaches.

In this regard, a number of issues would need to be examined. One would need to look into whether or not the Genocide Convention could actually apply to autism, should a least restrictive interpretation of it be used. One must also examine whether a broad interpretation and rigorous enforcement of relevant legal provisions could simply be achieved through re-interpretation when applying the law, and by competent courts and tribunals.

It must be ascertained whether the latter would be a solution, or whether the implementation of ‘hard’ provisions would also be required to allow for such re-interpretation. Such would include, for example, extending the Genocide Convention’s criteria or the terms of reference of relevant courts or tribunals, or extending the legal protection afforded to autism through hard dicta. The latter could be done, for example, by its re-categorisation into ‘qualifying’ categories, or by extending existing protection mechanisms also specifically to autism.

Walker’s only proposal in this regard is to extend to autistic persons the same rights afforded to ethnic minorities.¹⁰⁸ This concept has led self-advocates such as Erich Kofmel and Martin Schöngarth to consider whether to attempt to qualify autistic persons as an ethnic minority, in order to then seek relevant relief from the German courts.¹⁰⁹ This ties in with the argument of the existence of a distinct autistic culture, also put forward in, for example, Michelle Dawson’s submissions to the Supreme Court of Canada in *Auton*.¹¹⁰ Here, this was a notion which the petitioners sought to counter by arguing instead the

¹⁰⁷ Ibid.

¹⁰⁸ Walker, op. cit.

¹⁰⁹ Meeting with Erich Kofmel, op. cit.

¹¹⁰ Intervener’s Factum by Michelle Dawson, in *Auton et al. v. Attorney General of British Columbia*, Supreme Court of Canada, op. cit.

medical basis of the divergence in question, and the claimed therapeutic link of ABA/ IBI therapy in rectifying such.¹¹¹

However, Walker's approach was proposing to recognise autistic persons as a social minority group.¹¹² This, in itself, would go further than his original proposal to interpret legal protections as broadly as possible, since it would require a categorisation, even if minor, involving the enactment of hard dicta.

Thus, it is imperative to dissect Walker's concepts and proposals further. One must examine the applicability of current protections to autism – especially in the case of genocide, as well as studying the possibility of extension of applicable provisions to autism, and also whether a re-interpretation of current protection mechanisms would be sufficient, or whether the enactment of further 'hard' provisions would be required for such.

This matter has become even more pressing, especially since the recent discovery of a genetic signature for autism in newborns,¹¹³ as well as the state of Western Australia's decision shortly after this to authorise pre-natal genetic checks for autism.¹¹⁴

1.1.4.1 Defining Genocide

In the period between the two world wars of the 20th century, Rafał Lemkin initiated a lobby to recognise a crime he termed *genocide* – a combination of the Greek *genos* (nation) and the Latin *cide* (killing), in response to reports he had heard about atrocities against the Armenian populace being committed towards the end of the First World War in the Ottoman Empire.¹¹⁵ While these calls fell mostly on deaf ears when made to League of Nations member states, the horrors of the Holocaust during the Second World War led the

¹¹¹ Interview with Norrah Whitney, op. cit., Larsson, op. cit.

¹¹² Walker, op. cit.

¹¹³ Glatt SJ, Tsuang MT, Winn M, Chandler SD, Collins M, Lopez L, Weinfeld M, Carter C, Schork N, Pierce K and Courchesne E, 'Blood-based gene expression signatures of infants and toddlers with autism.', *Journal of the American Academy of Child and Adolescent Psychiatry*, Vol. 51, Issue 9, September 2012, at 934.

¹¹⁴ *Annual Report 1*, July 2012 to 30 June 2013, Western Australian Reproductive Technology Council, Perth (Western Australia), September 2013.

¹¹⁵ John Cooper, *Raphael Lemkin and the Struggle for the Genocide Convention*, Palgrave Macmillan, Hampshire, 2008.

United Nations General Assembly to heed Lemkin's call in 1948 and adopt the Genocide Convention.

The most basic definition one can give to genocide is, nowadays, the Convention definition. It is quoted by most scholars,¹¹⁶ and its model is also reproduced in similar international documents, such as in the Rome Statute establishing the International Criminal Court.¹¹⁷ While the Convention offers protection to an exhaustive list of categories of persons specified as national, ethnic, racial or religious groups¹¹⁸, the description of the acts constituting genocide set out in Article 2 of the Convention could easily be applied to a broader spectrum of persons.

The Convention in its current form is already seen by many as being held hostage to political intransigence within the United Nations, especially its Security Council, rooted in calculated national interest and geopolitical moves.¹¹⁹ Such political considerations can be seen as potentially standing in the way of any further widening of the scope of the Convention in future.

One can still, nonetheless, engage in a discussion about other acts or series of acts that fulfil the criteria of Article 2 *in toto*, but are excluded from the wording of the Convention definition.

In this regard, other scholars have argued for an extension of the definition of genocide. Although such definitions have largely not yet made it into any courtroom, they are useful in discussing the nature of certain acts that have all the makings of genocide, but fail to fall within the Convention criteria.

For the purposes of this thesis, the concept of Genocide as able to be performed by a State or Supranational body shall be reviewed. This will cover both cases of direct action or

¹¹⁶ See, for example, Leo Kuper, *Genocide: its Political Use in the Twentieth Century*, Yale University Press, New Haven, 1983.

¹¹⁷ Rome Statute of the International Criminal Court, UN Doc. A/CONF. 183/9; 37 ILM 1002 (1998); 2187 UNTS 90.

¹¹⁸ Genocide Convention, op. cit., at art. 2.

¹¹⁹ Peter W. Galbraith, commenting on US Foreign Policy towards Iraq during Kurdish gassing crisis and subsequently First Gulf War in *The End of Iraq: How American Incompetence Created a War Without End*, Simon & Schuster Paperbacks, New York, 2006.

omission by such actors, as well as direct action or omission by non-state actors, for which the State or Supranational body in question would be liable, through the concept of third-party liability.¹²⁰

1.1.4.2 Adapting the Concept – Interpretation and Widening

As mentioned, the Convention lists an exhaustive number of categories of persons falling within its scope. This was the result of much political machinations and bickering, for example, political groups were left out at the request of Stalin, who was concerned about possible prosecution of his actions back in the Soviet Union.¹²¹

Lemkin's original concept for genocide was a statute foreseeing prosecution of the destruction of ethnic groups,¹²² a process he termed 'cultural genocide'. He then added racial and national groups,¹²³ following their inclusion in the Nuremberg trials, as well as adding religious groups.

However, the United Nations General Assembly, in 1946, passed Resolution 96 (I),¹²⁴ which was much more far-reaching. It defined genocide as the “denial of the right of existence of entire human groups, [...] such denial of the right of existence shocks the conscience of mankind, [...] and is contrary to moral law and to the spirit and aims of the United Nations.” This was the first time such a far-reaching definition of genocide had been promulgated, albeit in the form of a General Assembly Resolution, which has no legal

¹²⁰ Andrew Clapham, in The ‘Drittwirkung’ of the Convention, in: R.St. J. Macdonald, F. Matscher, H. Petzold (eds.), *The European System for the Protection of Human Rights*, 1993, at 165, states that this concept, also referred to by the German term *Drittwirkung*, originates from a doctrinal debate in Germany and means ‘third-party effect’. It refers to the possible application of the German Basic Law where both parties are private parties. The ‘third party’ refers to the party outside the classic individual/State relationship who is affected by the constitutional norms. Examples within the genocide debate would be Serb paramilitaries, third-party liability for whom was deemed to be of the Serbian state by the ICTY, see, for example, Serbian state responsibility for ‘Arkan Tigers’ militia in *Prosecutor v. Stanišić & Simatović* ICTY-03-69 (9 December 2015), and; Dutch UN Peacekeepers present in Srebrenica around the time of the 1995 massacres, whom the Netherlands Court of Appeal declared the Dutch state to have third party liability for, in the *Srebrenica Appeals Decision*, Court of Appeal, The Hague, LJN: BR0132 (July 5, 2011).

¹²¹ Robert Gellately & Ben Kiernan, *The Spectre of Genocide: Mass Murder in Historical Perspective*, Cambridge University Press, Cambridge, 2005, at 267.

¹²² Raphael Lemkin, *Axis Rule in Occupied Europe*, Lawbook Exchange, New Jersey, 2005, Ch. IX, at 79.

¹²³ Raphael Lemkin, ‘Genocide’, *American Scholar*, Vol. 15, No. 2, April 1946, at 227.

¹²⁴ United Nations General Assembly Resolution 96 (I), of 13 December 1948.

force and limited legal value.

The interesting element, though, is that the Resolution went on to say that “genocide is a crime under international law [...] whether the crime is committed on religious, racial, political or any other grounds.” The wording contained a reference to political groups, which had been deliberately left out of the final wording of the Convention, as well as referring to ‘any other groups’. This phrase, although not part of a binding resolution, could have great strength in altering the interpretation of the concept of genocide under international law, as well as in different jurisdictions, if reference is also made to the wider context surrounding the Genocide Convention.

This view is also cited by a number of scholars. Pieter Drost, writing 10 years after the birth of the Genocide Convention, stated that “[g]enocide is the deliberate destruction of physical life of individual human beings by reason of their membership of any human collectivity as such.”¹²⁵

1.1.4.3 Israel Charny's Definition

Israel Charny widens the concept further, stating that [a] generic definition of genocide does not exclude or commit to indifference any case of mass murder of any human beings, of whatever, racial, national, ethnic, biological, sexual, cultural, religious or political definition, or any other definitions, or totally mixed groupings of any and all of the above, [...].¹²⁶

As to the definition itself, here Charny states that genocide in the generic sense is the mass killing of substantial numbers of human beings, when not in the course of military action against the military forces of an avowed enemy, under conditions of the essential defencelessness and helplessness of the victims.

He further states that as to the degree of severity of the act of genocide in question, one must look at the factors of Premeditation, Totality of Single-Mindedness of Purpose,

¹²⁵ Pieter N. Drost, *The Crime of State*, Sythoff, Leiden, 1959, at 125.

¹²⁶ Israel W. Charny, ‘Definitions of Genocide and the Study of Genocide’, in Israel W. Charny (Ed.), *op. cit.*, Volume I, Part I, at 3.

Resoluteness to execute policy, Efforts to overcome resistance, Devotion to bar escape of victims and Persecutory cruelty. He also specifies the categories of Actual Mass Murder, Attempted Genocide, Accomplices to Genocide, and “Cultural Genocide” or Ethnocide.¹²⁷

All these different views show the possibility of extending the definition of genocide way beyond the boundaries of the Genocide Convention.

1.1.4.4 Beyond Mass Murder

Henry Huttenback, in 1988, went further and stated that “[g]enocide is any act that puts the very existence of a group in jeopardy.”¹²⁸

In the same year, Helen Fein wrote that “[g]enocide is a series of purposeful actions by a perpetrator(s) to destroy a collectivity through [...] suppressing the biological and social reproduction of the collectivity. This can be accomplished through the imposed proscription or restriction of reproduction of group members [...]. The perpetrator may represent the state of the victim, another state, or another collectivity.”¹²⁹ Finally, John Thompson and Gail Quets, in 1990, said that “[i]n short, given the problems which arise from restrictions, we define genocide as the destruction of a group by purposive action.”¹³⁰

1.2 Thesis Overview and Research Questions

1.2.1 Thesis Overview

The aim of this work is, therefore, to examine the relevant concepts of the applicability of the concept of genocide to autistic persons as a category, through re-interpretation or widening of existing supranational and national legal provisions.

¹²⁷ Ibid.

¹²⁸ Henry Huttenback, ‘Holocaust and Genocide Studies’, Vol. 3 Ch. 3, in Adam, Jones, *Genocide: A Comprehensive Introduction*, Routledge/Taylor & Francis Publishers, London, 2006, at 17.

¹²⁹ Helen Fein, ‘Genocide: A Sociological Perspective’ in Adam Jones, op.cit., at 18.

¹³⁰ John L. Thompson & Gail A. Quets, ‘Genocide and Social Conflict: A Partial Theory and Comparison’, in L. Kriesberg (Ed.), *Research in Social Movements, Conflicts and change* (Vol. 12), JAI Press, Greenwood, 1990, at 248.

This will be done by further examining the concept of autism, as already outlined in Sections 1.1.1 and 1.1.2, as well as the issue of perceptions surrounding it, as covered in these sections, as well as in Section 1.1.3. The genesis of these perceptions, as well as their links to knowledge and awareness about autism on the one hand, and the position of societal status quo on the matter, will be discussed, particularly in Chapter 2.

This will also be covered in terms of a power-related dichotomy, reflecting the position of a dominant social group vis-à-vis a social group in a minority position. The issue of perception will also be couched in terms of social perceptions as to what is 'good and bad' and 'right and wrong'. To this end, the dominant-minority dichotomy will be analysed in terms of linguistic and ethnic groups in Chapter 3, and of LGBTQI persons in Chapter 4, outlining how societal attitudes to both groups were couched in terms of perceived good and bad linguistic identities in Chapter 3, and in terms of right and wrong moral and sexual identity and conduct in Chapter 4.

This will be then compared, in the discussions in these Chapters, against the argument that autism is similarly maligned due to social perceptions, held by the 'neurotypical', non-autistic majority of the population. There will also be analysis of the argument, in virtue of this phenomenon, that it is the issues of different behaviour and communication exhibited by autistic persons that are seen as 'bad' ways of being, or 'wrong' ways of communicating or behaving, by the 'neurotypical' majority, vis-à-vis the autistic minority.

Arguments of capacity and presumption of competence in this regard will also be addressed in Chapter 5, by making comparisons with evolutions in the field of children's rights, in order to separate the element of perception from the element of reality as to these arguments. Comparisons are made with the protection-based approach defining the medical model of disability, as opposed to the empowerment-based approach in which the social model is rooted in, in arguing for presumptions of capacity and competence, and for middle ground such as supported decision-making procedures when necessary, instead of draconian measures such as legal incapacitation.

The shift from the medical to the social model of disability is then further discussed, in light of the notions covered in the previous Chapters, also in terms of case law indicating a gradual shift in perceptions, towards proper awareness, acceptance and inclusion. The

aim of this is to demonstrate that once knowledge and perceptions on a topic are addressed, although societal resistance might persist, the possibility of a journey towards empowerment exists, through a rights-based approach rooted in empowerment.

Hence, the notions of ‘good and bad’ and ‘right and wrong’ were nothing more than social perceptions and prejudices emanating from a societal power dichotomy. And consequently, that the treatment received by a societal group in virtue of such, was in fact mistreatment due to a breach of rights, resulting from actions or omissions by the dominant group.

The parallel journey in the autism rights field is then discussed within the framework of these previous discussions, and related notions, in Chapter 6, discussing the ‘pro-cure’ and ‘anti-cure’ camps, their ethos and efforts. An analysis is conducted as to how these fit into the notions discussed in the previous Chapters, and the state of awareness on the way to acceptance and inclusion, also identifying major stumbling blocks and issues of regression, as well as positive initiatives and attempts to break the deadlock.

Having covered the issue of societal perceptions, and the possibility of mistreatment in case of a lack of moving forward towards empowerment through a rights-based approach, the topic of genocide is then discussed further in Chapter 7, in order to examine the possibility of applying it to scenarios of such possible mistreatment. This would be in cases of a lack of moving forward, not moving forward sufficiently, or else regressing. The thesis looks at the concept of qualifying groups, under national and international statutes, as well as concepts put forward by authors and in case law, in order to extend the applicability and remit of conventional restrictive statutes covering genocide.

The issues of *actus reus* and *mens rea* are also discussed, with similar arguments as to extension of applicability and remit being similarly made here. Chapter 8 further looks at why certain genocide claims in the past have failed, also looking at the genesis of the notion of genocide, and how different developments have rendered it a flexible and malleable concept.

The possibility of mistreatment in virtue of societal perceptions is then discussed in Chapters 9, 10 and 11, covering a number of areas of concern in the field of autism, and of the rights of autistic persons. Chapter 9 covers the pre-natal field, discussing pre-natal

genetic testing and pre-implantation genetic diagnosis (PGD), and disability-specific abortion legislation.

Chapter 10 covers areas in the post-natal field, in particular the issue of cures and research into such, also covering the field of euthanasia, as well as specific therapies, both behavioural, as well those purporting to be science-based, or otherwise curative.

Chapter 11 then discusses specifically the topic of awareness and knowledge, and how omissions or wrong approaches in this field could also result in rights breaches, as well as the effectiveness of efforts in this field, particularly in moving forward along the journey to acceptance, inclusion and empowerment.

The applicability and remit of the concept of genocide is then extended, in line with notions discussed by authors and through case-law, to situations of possible mistreatment outlined in the previous three Chapters, as well as also identified within the wider body of the thesis. This is done in Chapter 12, in order to analyse whether possible genocidal crimes could be said to be resulting from such instances of mistreatment. Following such analysis, the possibility of moving forward towards acceptance, inclusion and empowerment through a rights-based approach, and ways of breaking the deadlock towards such, by reference to authors and real-life examples, is discussed.

1.2.2 Research Questions

Through the analyses and discussions outlined in the previous sub-section, this thesis aims to answer the following research questions:

- Why is autism under attack?
- What are the main issues behind such attack?
- Is such attack leading to mistreatment and breach of rights?
- If so, what would such mistreatment and breach of rights be?

- Would the concept of genocide be applicable or extendable to autistic persons?
- If so, would some/ all instances of mistreatment and breach of rights identified qualify as genocidal crimes?
- If such mistreatment and/ or genocide is happening, is there a way to break the deadlock, and how?

PART II: THE WAR ON AUTISM – A WAR ON PERCEPTIONS

Chapter 2: Autism – Perceptions and Reality

2.1 Introduction

This Chapter will seek to give an overview of autism itself, through an overarching look at the different perspectives used to describe it. It arrives at a conclusion that a more holistic view of autism would point to the main issues in this regard as being variations in behaviour & communication from the current socially-accepted norms.

This is evident, especially after looking at the nature and rationale of the application of certain behavioural therapies, aimed at conditioning behavioural responses rather than accessing the root cause of such behaviours. This outlines the fact that the key concern of those who seek out such therapies, usually parents or guardians of autistic children, is rectifying the ‘problematic’ behaviour itself, rather than tackling deeper underlying issues, and actually addressing the issue of autistic communication. The latter is fundamental to both an autistic person’s daily living, as well as to their rights.

Therefore, it is then being posited that the root cause of the ‘problem’, or of the current ‘autism epidemic’, is based in perception, as well as in lack of, or wrong awareness of autism. This calls for a need to grasp the right facts and to change perceptions, in order to be able to embark on a possible journey towards awareness, acceptance and inclusion. This in line with a shift from the medical model to the social model, in the context of the wider disability rights discussion, as outlined further in Sections 1.1.2, 5.3 and 5.4 of this thesis.

2.2 Illness or Aberrance from the Norm

2.2.1 Identifying Aberrance from the Medical Norm

The autistic community started off life as a pretty much maligned group, as test subjects under the microscope, rather than as a unified vocal front with a collective sense of identity.

Swiss psychiatrist Eugene Bleuer, the first medical professional to attempt a definition of what is nowadays termed autism, described autistic persons in the late 1800s as mentally

ill, detached from reality, suffering from a specific form of schizophrenia.¹ The same line was reinforced by Hans Asperger, mentioned earlier. During his research focusing on children, especially boys, in Vienna in the 1930s, he coined the term ‘autistic psychopathy’ to refer to more ‘high-functioning’ cases of autism.²

These were the cases in which the detached behaviours were still present. They were coupled, however, with an apparently strong enough ability by the ‘sufferers’ to still partake in and function regularly in daily life alongside their non-autistic peers, leading to the assumption that their odd behaviour was, then, some form of ‘psychopathy’. An enlightened psychopathy, nonetheless, since Asperger, as mentioned, also referred to these test subjects as ‘little professors’, due to their overabundant vocabularies and elevated IQ, especially in particular specific areas of interest.

Michael Fitzgerald also insists that Asperger was responsible not only for outlining the basic diagnostic criteria for the autism subtype later standardised as Asperger Syndrome, but also those for the subtype usually referred to as ‘classical’ childhood autism, or ‘low-functioning autism’ at times. This is especially the case when the children in question do not exhibit the verbal communication skills expected to be age-appropriate among their non-autistic peers.

This subtype is usually referred to as ‘Kanner’s Autism’, due to its generally having been attributed to Ukrainian-Jewish doctor Leo Kanner. However, not only have certain discoveries been traced back to Asperger by researchers such as Fitzgerald,³ but a direct link showing that Kanner worked as an assistant to Asperger was also unearthed, through documentation cited by Steve Silberman⁴ in his latest tome ‘*NeuroTribes: The History of Autism and the Future of Neurodiversity*.’

Coincidentally, Asperger was also instrumental at preventing or limiting possibly the first documented purge of persons on the autism spectrum, having identified a basic sort of

¹ Adam Feinstein, *A History of Autism: Conversations with the Pioneers*, Wiley Blackwell, Chichester, 2010, at 5, 6.

² Ibid., at 10.

³ Ibid, at 11; Interview with Michael Fitzgerald, Psychiatrist, Researcher and Author with a specific focus on Autism, Dublin, October 2011.

⁴ Steve Silberman, *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*, Avery, New York, 2015, at 136, 137.

diagnosis just some time earlier. Working at the Vienna University Children's Hospital in 1938, then under the jurisdiction of Nazi Germany following the Anschluss, Asperger, like other doctors, was obliged to follow protocols drawn up the Reich Ministry of Health concerning the treatment of 'mental defectives'. These also included the obligations of turning over such persons in his care to the authorities, for the purpose of such being euthanised, unless such persons were otherwise useful, such as in the case of medical experimentation.

Under the ruse of carrying out such further experiments, Silberman asserts that Asperger was aware, and subsequently saved the lives of hundreds of such autistic boys from the Nazi extermination programme.⁵ Although doubts remain as to whether Asperger was a member of the Nazi party or not, such not having been confirmed till this very day, it was argued that this could have well been to protect the boys under his care. And whatever his affiliation and political beliefs, as Silberman points out, Asperger definitely did save a good number of persons from a certain death during his tenure at the Hospital, for whatever reason.

2.2.2 *Seeking a Cure for this Aberrance*

However, the fact that autism, in the ways portrayed by Bleuer, Kanner and Asperger, was a medical illness, remained the key factor outlining this phenomenon. This was, intentionally or unintentionally, reinforced by the fact that all these three persons were medical doctors by profession, and their research and description of traits was done in their capacity as medical professionals.

In this light, post-war society looked towards the medical community for a solution to the problems this malady afflicted children with – autism still being seen as something linked to the childhood sphere as at then – essentially, looking for a cure.

While the three doctors above spoke of autism as a medical condition then classified in the 'mental' field, by tackling it from a psychiatric point of view, mental conditions could very well be a cause to be taken up by the psychotherapeutic community. In particular, this

⁵ Ibid.

became a cause for the psychoanalytical community at the time, which still held sway in the tradition started by Sigmund Freud, and especially in countries like France, Freud's homeland.

And it was American psychoanalyst Bruno Bettelheim who devised a psychoanalytical explanation and solution to the 'problem',⁶ opening up the problematic channel of using psychoanalysis or any kind of psychotherapeutic intervention as an exclusive self-contained method for curing autism.

Bettelheim put forward the theory of 'refrigerator mothers,' stating that social and emotional deficits in children were the result of mothers having been too cold and distant from their otherwise normally-born children in their early years, thus triggering the social and emotional regression constituting an autism diagnosis. The solution to children already so afflicted was even scarier – the technique of 'packing'.

Used in France and elsewhere up till this very day, autistic children are wrapped in wet blankets, and made to force their way out, in an effort to be 'reborn'. This in order that the mothering process could then start all over again, in the right way. Needless to say, the success rates of this method are far from encouraging, while the subsequent death rate of children so treated is similarly alarming.⁷

Elsewhere in the psychiatric community, however, autism was increasingly seen as an organic brain disorder, with no known genesis as to its aetiology, and no known cure. Narcotic and psychotropic medications were prescribed in order to control symptoms of autism⁸ such as 'challenging behaviours' and anxiety.

⁶ Feinstein, op. cit., at 54, 55.

⁷ Autism-Europe, *Position Paper on 'Packing'*, adopted at the IX Autism-Europe International Congress, Catania, 8-10 October 2010, accessed online at <http://www.autismeurope.org/publications/newsletter-subscribe/newsletter-43-winter-2010-2011/against-le-packing-a-consensus-statement-2.html>.

⁸ See, for example, J Sigafoos, VA Green, C Edrisinha C and GE Lancioni, 'Flashback to the 1960s: LSD in the treatment of autism', *Developmental Neurorehabilitation*, Volume 10, Issue 1, Jan-Mar 2007, at 75-81, shows the way in which new, experimental treatments were being attempted, in a bid to cure the medical condition autism was perceived to be. While medication does help, as part of a holistic care plan, in mitigating conditions co-morbid to autism, such as anxiety, see, for example, Jessica A. Hellings, 'Treatment of Comorbid Disorders in Autism: Which Regimens Are Effective and for Whom?', *Medscape General Medicine*, Volume 2, Issue 1, 2000, some mainstream medical treatments are still being applied to autism from a purely medical point of view.

This is both in the case of medications such as risperidone, the first medication specifically approved

However, other research in the field focused on two areas: finding methods to control the symptoms of autism, in those already around and diagnosed, and; research into the causes of autism, as well as the specifics of causation, and devising methods to prevent or counter such specifics in light of these findings.

As to methodology, it was still the psychotherapeutic field that won the day, however, focus shifted away from the increasingly-discredited field of psychoanalysis, to the emerging field of behavioural therapy.

Therapies such as Cognitive Behavioural Therapy (CBT) were being standardised for a number of more general psychological and emotional conditions at the time, such as neuroses. However, these were also attempted, with limited efficacy, as a central therapy in case of autism, through a more aggressive behavioural intervention customised for the field of autism by Ole Ivar Lovaas,⁹ a Norwegian-American psychotherapist specialised in behavioural therapy.

2.2.3 *Autism – What is it?*

The discussion carried out so far in this thesis has pointed to the main ‘complaints’ concerning autism relating to the outward communication and behavioural manifestations linked with it.

As to communication, this manifests in the absence of communication modes and techniques considered to fall within the standard societal ‘norm’, or else a significant reduction of such as compared to such ‘norm’. A main element of communication in this

for treating "irritability associated with autistic disorder," by the US Food and Drug Administration (FDA), as per Prescribing Information for Risperdal (tm), FDA Reference ID: 3495570, issued by Janssen Pharmaceuticals, Inc, which, however, is used in some circles in the same way as behavioural therapy is used to 'correct' aberrant behaviour, as discussed further in Section 2.4.1 of this thesis, and; in the case of new medical preparations that are still being marketed, such as an oxytocin-based nasal spray recently trialled in Australia in 2015, which state broadcaster ABC said "improves social skills in some children with autism" in an article by Nicole Chettle on 27 October 2015, accessed online at <http://www.abc.net.au/news/2015-10-27/oxytocin-benefits-for-children-with-autism/6889850>, this topic being discussed in more depth in Section 10.1.3.2.6 of this thesis. However, medical perceptions of parents are still clear from this article, one mother quoted as saying "Oxytocin won't make your child normal [...]. There's no cure for autism."

⁹ For a fuller discussion of the work of Lovaas, how his method further developed, as well as arguments for his work, criticisms of it, and rebuttals in this regard, see Sections 2.4 and 3.3 of this thesis.

regard is considered to be the presence or otherwise of communication through spoken language, or verbal communication.

As to behaviour, this manifests in behaviours also considered to be in variance with established standard social 'norms'. This can be due to perceived inappropriateness, or else due to expected behaviours or body language not being manifested at the socially-mandated appropriate time, or expected in response to certain scenarios. Lack of spontaneity in coming forward with or expressing such behaviours is also seen to contribute towards such variance, as are instances of behaviours considered to be 'restrictive, repetitive or stereotyped. Most importantly, the issue of 'challenging' or 'extreme' behaviours is also pinpointed as a major area of concern in autism.

These are the reasons behind the fact that, even in the medical field, autism is classified as a neurodevelopmental condition, due to the way in which neurological development in these two spheres is different from the course of development of persons conforming to the pattern of typically developing norms in these areas. Hence, the labelling of autism also as a neurobehavioural phenomenon¹⁰ by some.

However, the orthodoxy behind such a rigid adherence to this pattern and to these norms has been challenged by some. Researchers such as Martine Delfos have argued that in autistic persons, the development phases as to logical and social/ emotional processing are reversed, but both clusters happen nonetheless.¹¹

Dorit Ben Shalom explains 'deficits' in autism by pointing to a multi-level processing structure rooted in logic,¹² while Carmel O' Sullivan points to expression and communication being amplified through a structured drama-based approach,¹³ this

¹⁰ See, for example, Robert Melillo and Gerry Leisman, *Neurobehavioural Disorders of Childhood: An Evolutionary Perspective*, Springer, New York, 2009, for the framing of autism, albeit from a medical angle, within a neurobehavioural context.

¹¹ See, for example, Martine F. Delfos, *Children and Behavioural Problems: Anxiety, Aggression, Depression and ADHD - A Biopsychological Model with Guidelines for Diagnostics and Treatment*, Jessica Kingsley Publishers, London, 2004.

¹² See, for example, Dorit Ben Shalom, 'The Medial Prefrontal Cortex and Integration in Autism', *Neuroscientist*, Vol. 15, 17 July 2009, at 589.

¹³ As presented by Carmel O' Sullivan and others, during the 'Challenging DSM-5' international conference attended by the author at Trinity College Dublin, and reported in 'Major Changes in the Diagnosis of Autism Debated at Conference', Press Release by the Communications Office, Trinity College Dublin, 7 November 2012, accessed online at

essentially serving as a vehicle to learn and express communication that can be understood by and used in the 'neurotypical' world, as discussed later in this thesis.

Therefore, it is important to look into the question of how and why society views certain behaviours as wrong, whether we should change such behaviours, and if so, how. The questions of where such behaviours are coming from, and the reasons why they are happening, should equally be answered.

The thesis will tackle these questions over the next Chapters. Before entering into the specifics of the questions above, the next section will view autism from an opposing angle to the one viewing it as an aberrance, the theme running through the previous sections. It will address the issue of perception, and how issues of good or bad and right or wrong behaviour and communication styles, can be said to be rooted within this main issue. This will be bolstered by descriptions of autism through the eyes of autistic exponents and self-advocates, before proceeding to discussing the issues of autistic communication and behaviour in more depth.

2.3 The Issue of Perception: Why is Autism Wrong?

2.3.1 Autism – 'The Enemy' Within

The shift from neurobehavioural criteria that society currently considers 'normal' is what makes persons seek treatment for autism, for changing the way such persons are. However, other opinions also exist. Donna Williams says that "[a]lthough many parents share this view, there are also those who don't. Among people with 'autism', too, there are those who identify with their condition and do not seek to change it."¹⁴ She says that professions constantly view autism as "the 'enemy'".¹⁵

She gives the following reasons as to why this happens:

<http://www.tcd.ie/Communications/news/pressreleases/pressRelease.php?headerID=3336&pressReleaseArchive=2014>.

¹⁴ Donna Williams, 'Autism, an Inside-Out Approach', Jessica Kingsley Publishers, London, 1996, at 18.

¹⁵ Ibid.

“

- because it is not what they see as 'normal'
- because they feel that a disability is unquestionably a burden that they should assist in the unburdening of (the issue of disability is also a hotly debated topic in autism)
- because they just don't have the energy, personal resources or social support to cope with someone's 'autism' as it is
- because they imagine that, like peeling a banana, beyond the 'autism' there is some sort of 'normal' child
- because they think they have seen a trappedness in the eyes of someone with 'autism' that tells them that, whoever the person with 'autism' is, that person is more than just a bag of 'autism' with no personality independent of the effects of their condition.”¹⁶

The fact that autism is perceived as wrong, abnormal or simply undesirable by large swathes of society nowadays, is also reflected through the fact that autistic persons are, till this very day, being counselled by some against having children,¹⁷ no matter what the status of their legal rights, as well as their general capabilities may be.

Prejudices exist that the diagnosis of a mental health condition, or of a mental disability as traditionally defined, automatically equates bad parenting skills, and that any child of such persons will be more prone to developing a mental health condition or a mental disability¹⁸ – the same line of thought offered as the rationale for the majority decision in *Buck v. Bell*.¹⁹

¹⁶ Ibid.

¹⁷ Bijal Trivedi, 'Autistic and proud of it', *New Scientist*, volume 2504, 18 June 2005, at 36.

¹⁸ Peter Bartlett, Oliver Lewis and Oliver Thorold, *Mental Disability and the European Convention on Human Rights*, Martinus Nijhoff Publishers, Leiden/ Boston, 2007, at 193.

¹⁹ On the heels of the eugenics movement that also took root in the United States of America, as well as legislation in line with the ideas it put forward, rationales in justifying sterilisation were presented in the landmark case of *Carrie Buck v. John Hendren Bell, Superintendent of State Colony for Epileptics and Feeble Minded*, Supreme Court of the United States of America, per Holmes CJ joined by Taft, Van Devanter, McReynolds, Brandeis, Sutherland, Sanford and Stone JJ, Butler J dissenting, 2 May 1927, 274 U.S. 200 (1927) (*Buck v. Bell*). This involved an allegedly 'feeble-minded' girl, Carrie Buck, whose legal guardian brought a case before the US Circuit Court for Amherst County, Virginia, to prevent her sterilisation, using the ground of the Fourteenth Amendment to the US

The issue with autism is, therefore, first and foremost a question of definition. In deciding how to tackle autism, one needs to understand what autism really is. One must go beyond the guidelines set out in the ICD and DSM, and look at these persons, look into them and, very importantly, listen to them.

A number of books have been written by autistic persons who have made great strides in life, and looking at these works shows another side of the coin, a side which is very often forgotten by the medical community.

2.3.2 *Other Side of the Coin*

In 'How Can I Talk If My Lips Don't Move',²⁰ Tito Rajarshi Mukhopadhyay recounts his childhood memories of how he experienced the world around him. He describes how he saw everything in terms of colours, and how he was following what was going on in the world around him, picking up all the words and meanings that persons on the outside felt he could not grasp. He highlights the fact that he simply processes the world in a different

Constitution, providing for Due Process and Equal Protection for all US citizens under the law.

This court mentioned the fact that Ms. Buck's mother had also been 'feeble-minded', and taken advantage of more than once, this also being the way in which the young Carrie had been conceived, and sterilisation would be able to prevent the same happening to Carrie. The fact that Carrie had been, like her mother, born a 'feeble-minded' person, was also mentioned, at para. 2 of the judgement.

Though Carrie's guardians lost the case, they fought all the way to the US Supreme Court, which in an almost unanimous decision, legalised such a practice through a judgement from which the words of Chief Justice Oliver Wendell Holmes stand out particularly. In this regard, Holmes had stated that sterilisation was a way of being humane with such individuals, by ensuring that their offspring will not go to the gallows, and concluding with the now-notorious words that "three generations of imbeciles are enough", at para 4 of the judgement.

Such terminology is, however, still used in the legislation of some European countries till this very day. Prior to the legal amendments that have occurred from 2013 onwards, a number of provisions, also highlighted by the author at a workshop he gave, hosted by the Richmond Foundation for Mental Health in 2010, were of grave concern. The Maltese Code of Organisation and Civil Procedure (Cap. 12 of the Laws of Malta) stated in Article 520 (1), previously amended as recently as 2004, under Title IV covering Interdiction and Incapacitation, that "[a] demand for the interdiction or incapacitation of persons who are habitual idiots, insane, frenzied or prodigal, is made by an application to the Court of voluntary jurisdiction", further stating in Article 521 (d) that interdiction or incapacitation may be demanded "in case of idiocy or other mental infirmity, by the Attorney General; unless the demand shall have been made by any other person." Article 747 (2) of the Code then covered actions always to be deemed of an indeterminable value, among them, in paragraph (b), "actions as to filiation, adoption, interdiction or incapacitation of lunatics, imbeciles or persons insane or prodigal", while Article 781 covered persons who may not sue or be sued, among them, in paragraph (b), "a lunatic or an insane person". The Income Tax Act (Cap. 123 of the Laws of Malta) also still defines an "incapacitated person" in Art. 2, specifying that the term "means any minor, lunatic, idiot, insane person or person under tutorship or curatorship".

²⁰ Tito Rajarshi Mukhopadhyay, *How Can I Talk If My Lips Don't Move?: Inside My Autistic Mind*, Arcade Publishing, New York, 2011.

way, and in his words, this just necessitated a creative approach to learning, understanding how he 'worked', and addressing learning accordingly, something which his mother did with so much care and dedication.

Tito is a poster-boy for the neurodiversity community, for the simple reason that it proves that a person who is 'non-verbal', which is one of the main concerns of therapies such as ABA being advocated by pro-cure activists, can still grasp what is going on around him, and communicate in his own way.

It highlights the fact of how Tito was not a person locked in himself, the typical stereotype emerging from the generally-prevalent notion of autism. It can be argued that, if the dedication and care of a mother in the slums of Bangalore, India, with no expert knowledge, could bring out the best in her autistic child, then there are some serious questions to be asked about the motives and priorities of the current pro-cure strain in autism.

In 'Unstrange Minds',²¹ Richard Roy Grinker outlines the challenges faced by his daughter Isabel. Not because of her condition, but mainly because of the desire of society around her to make her fit in and label her as 'mentally retarded', giving her a state education on these lines. Isabel turns out to be a very intelligent girl who is passionate about art, and this is brought out in her when she is enrolled at the Smithsonian school, where "concrete, sensory-based and interactive" education is the order of the day.

The classroom is not restricted to autistic children or children with special needs, but covers a wide spectrum of children, both 'neurotypical' as well as 'neurodivergent'. The methodology used brings out Isabel's communication abilities, by exposing her to subjects she can relate to, and allowing her to express herself, in her own way. Grinker says that this was a benefit to the other students in their class, because they could see someone different who, however, in her own way, got along with the rest and shared her talents and passions with everyone, ultimately enriching the lives of the other children in her class.²²

²¹ Roy Richard Grinker, *Unstrange Minds: Remapping the World of Autism*, Basic Books, New York, 2006.

²² In 'The cultural origins and futures of Autism Spectrum Disorders', delivered at the XI Autism-Europe International Congress, in Edinburgh, on 18 September 2016, Grinker spoke further about Isabel's sense of belonging connected to her autistic identity, which although not a concept he shared, was a concept that, according to him, she uses to define herself, leading her to be happy with who she is. He further stated that, for him, this is the most important aspect, discussing the roots of culture,

British author Daniel Tammet is another shining example of how autistics can be different, but ultimately successful individuals, as long as they are allowed to 'do things their own way'. Through his book 'Born on a Blue Day',²³ one can see through the 'veil' of Daniel's 'severe communication issues' as from a young age. Although possessing these characteristics, if one had to use the language generally used to compare children like him to other 'neurotypical' children, he lives in a world ruled by synaesthesia, and possesses the gift of savantism. Due to these gifts, Daniel is able to process numbers rapidly in his brain, through his method of associating these with colours.

He has a compulsive need for order and routine; however, the description of his self-awareness in his book challenges considerably the view that autistics are stunted, and need to be 'put in line'. He describes his way of experiencing the world very vividly, and how he has managed to adapt to a fully independent lifestyle. His story shows that it is all about being able to fit into an environment, about accepting and cherishing difference, rather than trying to align everything to the social constructs, 'social norms'. He makes the touching point that what makes us all human, in the end, is our minds.

Finally, one cannot speak about autism and the autism rights movement without mentioning Dr. Temple Grandin. In her book 'Thinking in Pictures',²⁴ which recently also made it to the silver screen,²⁵ she talks about how her mother used to worry about the fact that she still would not talk at three years of age. However, other things were going on in her mind.²⁶

She was taking in the world, seeing everything in pictures, like one large movie. She eventually managed to make her way through life, using her strengths in order to be able to enter the field of livestock management, going on to read for a PhD in the subject. Her

identity and belonging from an anthropological point of view, as to the way society can both create 'negative' identities and seek to stifle them, while at the same time social groups can decide to own these identities, giving them a sense of belonging and empowerment. In doing this, he focused specifically on the concepts of autism and mental disabilities from an anthropological point of view.

²³ Daniel Tammet, *Born On A Blue Day: Inside the Extraordinary Mind of an Autistic Savant*, Free Press, New York, 2007.

²⁴ Temple Grandin, *Thinking in Pictures, Expanded Edition: My Life with Autism*, Vintage Books, New York, 2006.

²⁵ Mick Jackson, *Thinking in Pictures*, HBO Films, New York, 2010.

²⁶ Refer back to comments about Martine Delfos' work in Section 2.2.3 of this thesis, for further insight into this point.

way of visualising things was what made her go forward in life, and nowadays, apart from being a prominent autism rights activist, she also is one of the leading figures in her field of expertise.

Temple Grandin just needed to do things her way, and society was not yet ready for that when she was still young. Now, it is all about making people understand differences and accommodate them, rather than sticking to one mindset, and trying to mould everyone into it.

2.3.3 *All about choices*

It is true that communication is an important aspect of life, and being able to communicate with peers is an important factor in building and maintaining healthy social relations. However, as was discussed by Deborah Pugh of ACT Canada with the author during an interview,²⁷ it is all about giving autistic children an interface, an outlet in communicating with the outside world. Therapies such as ABA should not be used in an attempt to 'normalise' these children, but simply to enable them to communicate with their 'neurotypical' peers – just like learning another language.

However, for most people, it is still sadly more expedient to try and mould their children into normality, because they cannot handle their tantrums, rather than taking on their responsibility as parents and trying to understand and communicate with their children in a 'language' that they understand.

If a mother in the slums of Bangalore could do it, why are so many persons in much more affluent societies, with many more educational credentials on paper, not trying to do the same? And why are professionals more happy to give in to the whims of these parents, rather than considering the best interests of the child, something which they are bound to do at law in many jurisdictions?

Learning to live with autism as part of one's personality seems, therefore, to be an option too. This in line with the concept of 'neurodiversity', discussed earlier in this thesis. So in

²⁷ Interview with Deborah Pugh, Director of ACT (Autism Community Training) Canada, Burnaby (BC), May 2011.

order to understand the gist of this work, one has to be able to understand both positions – for and against curing autism. It is only when one understands the other side of autism, can one make a more profound legal analysis of the statutes and practices surrounding autism in certain jurisdictions, and be able to decide whether the criteria for genocide are being satisfied or not.

2.4 Autistic Behaviour and the Communication Link

In the previous section, the topic of specific communication methods used or favoured by autistic persons, particularly those classified by the mainstream as ‘non-verbal,’ has already been touched upon. In light of this section, it is useful to draw a parallel between two factors. On the one hand, the need for communication and subsequent link to identity of ethnic and linguistic groups. On the other hand, the subsequent mirroring of this to non-ethnic and non-linguistic groups, where communication and identity are nonetheless both still present, and still central factors.

In this regard, one could speak of the deaf community, with different forms of sign language being recognised as languages at a par with spoken languages, and even accorded the status of official languages in countries such as Malta.²⁸ Together with this, the deaf community has used sign language as one of the central pillars of the building and propagating of what is nowadays known as the ‘deaf culture’ movement.

Similarly, the advent of the autistic rights movement brought with it increased awareness, and eventually empowerment of autistic persons, with acceptance and emphasis on the need and right to communicate in ways that were both appropriate and comfortable to them. Conversely, this right brings with it the right to not be negated these opportunities, and to also not be forced to use communication methods alien to these principles, or to have to make use of such methods exclusively. This especially not under threat of punitive sanctions, or having one’s needs ignored.

²⁸ The Maltese Sign Language Recognition Act (Cap. 556 of the Laws of Malta) provides for Maltese Sign Language (LSM) to be recognised as an official language of Malta, alongside Maltese and British English.

It was recently reaffirmed at the 9th Conference of States Parties to the UN CRPD that language is not just spoken language, but any means by which a human being can communicate.²⁹

Therefore, it is of utmost relevance to understand the needs and preference of certain autistic persons in this regard, as well as relevant methods such as AAC (Adaptive and Alternative Communication),³⁰ and in particular to read the following sections against the backdrop of the previous sections on language and identity.

2.4.1 *Behavioural Therapies – Communication vs Conditioned Responses*

2.4.1.1 Background

The forms of behavioural therapy raising most controversy in the sphere of autism nowadays are those variants built around Lovaas Method,³¹ as the therapy came to be known, before taking on its modern-day moniker of ABA (Applied Behavioural Analysis)/ IBI (Intensive Behavioural Intervention).³²

²⁹ Plenary Proceedings of the United Nations Ninth Conference of States Parties to the UN Convention on the Rights of Persons with Disabilities (COSP 9), UN Headquarters, New York, 14-16 June 2016.

³⁰ See, for example, 'Not being able to speak is not the same as not having anything to say', *Unstrange Minds* blog, 4 September 2014, accessed online at <https://unstrangemind.wordpress.com/2014/09/04/not-being-able-to-speak-is-not-the-same-as-not-having-anything-to-say/>; Footnote 60 in Chapter 1 of this thesis.

³¹ One of the first instances of public coverage of the initial research and experiments in this field, incidentally also applied to autistic children, was the article 'Screams, Slaps and Love: A surprising, shocking treatment helps far-gone mental cripples', in *Life Magazine*, 1965, digital version accession online at [neurodiversity.com](http://neurodiversity.com/library_of_the_history_of_autism_research_behaviorism_and_psychiatry_at_http://neurodiversity.com/library_screams_1965.html), Library of the History of Autism Research, Behaviorism and Psychiatry, at http://neurodiversity.com/library_screams_1965.html.

The method as at then, as well as its application and its goals, were described as follows:

"Enraged bellows at the boy, then a sharp slap in the face. This deliberate, calculated harshness is part of an extraordinary new treatment for mentally crippled children. It is based on the old-fashioned idea that the way to bring up children is to reward them when they're good, punish them when they're bad. At the University of California in Los Angeles, a team of researchers is applying this precept to extreme cases. They have taken on three boys and a girl with a special form of schizophrenia called autism — utterly withdrawn children whose minds are sealed against all human contact and whose uncontrolled madness had turned their homes into hells. And, by alternating methods of shocking roughness with persistent and loving attention, the researchers have broken through the first barriers."

³² The application of the Lovaas method to autism, eventually taking on the ABA/ IBI moniker, was initially described in Ole Ivar Lovaas, 'Behavioral treatment and normal educational and intellectual functioning in young autistic children', *Journal of Consulting and Clinical Psychology*, Volume 55, Issue 1, 1987, at 3.

This method had been developed specifically to rid patients of dysfunctional behaviours they were trying to deal with. More specifically, these were what was then considered to be dysfunctional behaviours, as considered by prevailing social norms in the 1970s, as well as by the psychiatric community at the time, particularly in the United States, where this was crystallised through the norms espoused in the APA's first³³ and second³⁴ editions of the DSM.

In particular, the treatments targeted sufferers of OCD (Obsessive-Compulsive Disorder),³⁵ in order to rid patients of compulsions and rituals performed, generally automatically, in order to extinguish the triggering obsessions, as well as deviant behaviours. These were listed as behaviours that were causing distress to the sufferers, although, in later DSM edits, distress was stated to have to come from within, not from outside of the patient's environment.³⁶

The list of such conditions included paraphilias,³⁷ more generally described as deviant sexual fetishes, this area also being extended to transvestism, the urge to cross-dress – as well as also 'full-blown' deviant behaviours, such as transsexualism,³⁸ the urge to identify as a woman or a man in the body of the other, usually the latter case. It also contained homosexuality,³⁹ the urge to have unnatural sexual relations with a person of the same sex, the subsequent therapies coming to be known as 'conversion therapies',⁴⁰ also referred to elsewhere in this thesis.

These 'therapies' were also applied to children diagnosed as exhibiting 'deviant sexual behaviours' and 'gender disturbances,'⁴⁰ and the way these methods subsequently

³³ American Psychiatric Association, *Diagnostic and statistical manual of mental disorders* (1st ed.), Washington, DC, 1952 (hereinafter 'DSM').

³⁴ American Psychiatric Association, *Diagnostic and statistical manual of mental disorders* (2nd ed.), Washington, DC, 1968 (hereinafter 'DSM-II').

³⁵ DSM, op. cit., at 313; DSM-II, op. cit., at 300.3.

³⁶ DSM, op. cit., at 320.6; DSM-II, op. cit., at 302.

³⁷ DSM, op. cit., at 320.6, 320.6 (062) (sexual perversion); DSM-II, op. cit., included within 302.

³⁸ DSM, op. cit., at 320.6, 320.6 (062) (sexual perversion); DSM-II, op. cit., at 302.3.

³⁹ DSM, op. cit., at 320.6 (036) (homosexuality), 320.6 (082) (panic, acute homosexual); DSM-II, op. cit., at 302.0.

⁴⁰ See, for example, George A. Rekers, Ole Ivar Lovaas, Behavioral Treatment of Deviant Sex-Role Behaviors in a Male Child, *Journal of Applied Behavior Analysis*, Volume 7, Issue 2, 1974, at 173; George A. Rekers, Ole Ivar Lovaas, Benson Low, 'The behavioral treatment of a "transsexual" preadolescent boy', *Journal of Abnormal Child Psychology*, Volume 2, Issue 2, June 1974, at 99; George A. Rekers, Peter M Bentler, Alexander C. Rosen, Ole Ivar Lovaas, 'Child gender disturbances:

developed laid the ground for such model to be eventually ported into the field of autism. In particular, the method as further formulated by that point was aimed at application to autistic children, the field the Lovaas method is best known for nowadays.

2.4.1.2 Using Aversion... To Improve Communication

The basis of such therapies was the concept of aversion, leading to them being known as ‘aversion therapies’.⁴¹ As described in the previous paragraph, the main problem in each case was seen as the presence of an ‘urge’ causing the patient to engage in certain unwanted dysfunctional behaviours. The aim of such therapies was to ‘extinguish’⁴² the urge altogether, and in certain cases, ‘recondition’⁴³ the patient to engage in functional responses to a situation in order to replace the previous dysfunctional ones.

The problem with such behaviours was rooted in the then, and up to a certain extent, still nowadays present importance attached to compliance over social norms over everything else. This is discussed further when tackling the Hart-Devlin redux concerning the decriminalisation of the common law crime of sodomy in the UK in Chapter 4 of this thesis. It was the behaviour itself, within a Victorian-inspired mould, that was seen as dysfunctional, just in the very same way that a parent would tell a child not to pick their noses in public.

However, in all of these conditions, the behaviours in question, apart from being socially unacceptable, then or now, or in virtue of the societal setup such behaviours were

A clinical rationale for intervention’ *Psychotherapy: Theory, Research & Practice*, Volume 14, Issue 1, Spring 1977, at 2; George A. Rekers, Alexander C. Rosen, Ole Ivor Lovaas, Peter M. Bentler, ‘Sex-role stereotypy and professional intervention for childhood gender disturbance’, *Professional Psychology*, Volume 9, Issue 1, February 1978, at 127.

⁴¹ See, for example, J. Shaw, ‘Practice Parameters for the Assessment and Treatment of Children and Adolescents Who Are Sexually Abusive of Others’, *Journal of the American Academy of Child and Adolescent Psychiatry*, Volume 38, Supplement to Issue 12, 1999, at 32S.

⁴² Ibid.; A layman’s version of the concept of ‘extinction,’ also contrasted with the opposite concept of ‘conditioning’ in behavioural therapy, is available on the Changing Minds website, accessed online at <http://changingminds.org/explanations/behaviors/conditioning/extinction.htm>.

⁴³ For a list of possible methods of such reconditioning – also known as ‘arousal reconditioning,’ due to sexual or non-sexual arousal by the ‘offending’ stimulus – including orgasmic reconditioning, minimal arousal conditioning, masturbatory training, modified aversive behavioural rehearsal, sexual arousal card sort, fantasy work, vicarious sensitisation, and behavioural modification, see, for example, D. Burton and J. Smith-Darden, *North American Survey of Sexual Abuser Treatment and Models*, 2000, Safer Society Foundation, Brandon (VT), 2001.

performed in, were also, due to their being attached to a diagnosis, the result of a cause-and-effect mechanism.⁴⁴ This was a factor which Lovaas had neglected when initially developing his therapeutic strategy, much in the same way as the focus of many of his psychotherapeutic contemporaries.⁴⁵

This is the main fallacy of the strict Lovaas method – focusing on ‘extinguishing’ behaviours, with this being an end in itself, rather than roping in this cause-and-effect mechanism. This was true both for behaviours considered repugnant to social norms and described earlier – if and when the subject consents to changing such behaviours, unless they are also detrimental to third parties – or to genuine dysfunctional behaviours or coping mechanisms, that will be tackled a few paragraphs from now.

Further advances in research have confirmed that there is a causative factor or trigger for such behaviours.⁴⁶ Such behaviours, socially seen as dysfunctional behaviours in a particular scenario, have been described as being resulting behaviours expressing a person’s unconscious attempt to communicate a need. Such need, conscious or unconscious, is so communicated when all conscious functional behaviours or coping

⁴⁴ See, for example, Martine F. Delfos, *Children and Behavioural Problems: Anxiety, Aggression, Depression and ADHD - A Biopsychological Model with Guidelines for Diagnostics and Treatment*, Jessica Kingsley Publishers, London, 2004.

⁴⁵ Dennis R. Dixon, Talya Vogel and Jonathan Tarbox, in ‘A Brief History of Functional Analysis and Applied Behavior Analysis’ (Chapter 2), at 3, in Johnny L. Matson (ed.), *Functional Assessment for Challenging Behaviors*, Springer, New York, 2012, outline the history of ABA, and the attempt to shift the intervention from a behavioural modification technique, to an applied behavioural analysis technique, specifically through acknowledging the need for understanding the root causes of the behaviours in question, that the relevant therapy was seeking to amend:

"It is sometimes said that the development of experimental functional analysis methodology by Iwata, among others, led to a major shift in focus in the field of ABA toward an acknowledgment of the need for understanding the root causes of behavior before simply applying potent consequences.

Some call this a transition from “behavior modification” to “applied behavior analysis” (citing F.C. Mace (1994). The significance and future of functional analysis methodologies. *Journal of Applied Behavior Analysis*, 27, 385–392.).

Appreciating the function of behavior when planning treatment is now widely regarded as best practice (as evidenced by the publication of this volume), but it was not always so. Early applications of behavioral principles to problematic behaviors in humans often failed to acknowledge the underlying function of behavior (citing Mace, op. cit.).

In this model, the application of potent reinforcers and punishers were effective when they simply overcame the ongoing contingencies with which they were juxtaposed, not because they addressed the core underlying cause or function of the behavior."

⁴⁶ See, for example, Henry S. Roane, Joel E. Ringdahl, Timothy R. Vollmer, Ernest L. Whitmarsh, Bethany A. Marcus, ‘A Preliminary Description of the Occurrence of Proto-injurious Behavior in Typically Developing Children’, *Journal of Early and Intensive Behavioral Intervention*, Volume 3, Issue 4, 2007, at 334, which describes how challenging behaviours can be used as a means of communication.

mechanisms in that person's repertoire have either failed, or are impossible to perform in a particular situation, due to fear of retribution, embarrassment or other factors.

Therefore, simply 'extinguishing' a behaviour is not as simple as telling a child not to keep their hands in their pockets. 'Extinguishing' a behaviour will not lead to resolving its causative root, and the same need the person in question would have been trying to communicate through that behaviour, will still be present. This with the possibility of such need being communicated through different, possibly more destructive behaviours, since 'extinguishing' is tantamount to nothing more than forcing a person to bottle up their need to express themselves and communicate their anguish.⁴⁷

2.4.1.3 Reconditioning – Behaviourist for Assimilation

As to genuinely dysfunctional behaviours or coping mechanisms described earlier, these might include self-harming behaviours in response to overwhelming pain and stress, when no other outlet or means of communicating this pain seems possible to the person in question.

In this case, however, 'extinguishing' mechanisms are just as effective, if they address the behaviour without addressing the cause. While it is true that, especially in these scenarios,

⁴⁷ In versions of ABA or other therapies where 'effectiveness' is placed before any other consideration, such as in the case of 'extinguishing' behaviours in this case, consequences may be deleterious. In such cases, one must consider an 'effectiveness vs ethics' debate, as explained below, since even if a therapy is deemed effective by way of results achieved, this is by no means an automatic validation of its ethical nature; See also, for example, Michelle Dawson, 'The Misbehavior of Behaviorists', available online at http://www.sentex.net/~nexus23/naa_aba.html, and ASD Today Blog: Autism in Education, 'The ABA Lecture Debacle: A Response to Edward Morris' Response to Morton Ann Gernsbacher's Response to ABA Practice', 17 January 2016, commenting on Edward K. Morris, 'A Case Study in the Misrepresentation of Applied Behavior Analysis in Autism: The Gernsbacher Lectures', *Behavioral Analysis*, Volume 32, Issue 1, Spring 2009, at 205, in response to Morton Ann Gernsbacher, 'The Science of Autism: Beyond the Myths and Misconceptions', Fern Forman Lecture 2007, University of Kansas Department of Psychology, 27 September 2007.

In the latter piece, the author uses the following example in illustrating the 'effectiveness vs ethics' debate:

"In 2005, I interviewed author and linguist Tanya Reinhart about current developments in the Israeli-Palestinian conflict. I mentioned that the recently built wall had drastically reduced Palestinian suicide attacks. She responded by saying that an even better way to reduce suicide attacks would be to put all Palestinians in camps, or just kill them. Reinhart was saying that effectiveness does not justify action, and that the more cruelty we are willing to inflict, the easier things will often become for us. The Israelis have their occupation and their wall, and ABA has its instructional methods and theoretical history. It may seem crass to compare the two, but the key components of both are the same: fear, misunderstanding and victimization."

it is imperative to 'recondition' the person in question to use different, functional behaviours and coping mechanisms, the original Lovaas method is not the appropriate way to do this, also because it raises issues of basic human rights violations in its purest form.

The main concern in this regard is the aggressive method used to 'extinguish' the previous behaviour, in order to be able to 'teach' the patient a new behaviour in its place.⁴⁸ Methodology involves having the patient engage in behaviours or observe imagery related to the dysfunctional behaviour, and receive a sanction whenever such happens.

Otherwise, chemical⁴⁹ or electrical⁵⁰ aversives can be used, examples of the first being emetics such as ipecac, widely used in 'gay conversion therapies',⁵¹ with electric shocks being examples of the second. The latter were initially administered using cattle prods,⁵² having been used in the original version of Lovaas' method.

The delivery method for such electric shocks was eventually replaced by FDA-approved electro-shock administration equipment, still licensed and used at institutions such as the

⁴⁸ See, for example, J. Shaw, op. cit.

⁴⁹ Chemical aversion therapy can range from less 'extreme' forms, such as the application of ammonia under fingernails to reduce nail-biting, see, for example, Vargas, John M., and Vincent J. Adesso. 'A Comparison Of Aversion Therapies For Nailbiting Behavior', *Behavior Therapy*, Volume 7, Issue 3, 1976, at 322; to the use of emetics such as ipecac, that were used mainly in attempts to treat conditions categorised as 'sexual deviance,' see, for example, Sarah Carr, 'The Sickness Label Infected Everything we Said': Lesbian and Gay Perspectives on Mental Distress', in Jerry Tew (ed.), *Social Perspectives in Mental Health: Developing Social Models to Understand and Work with Mental Distress*, Jessica Kingsley Publishers, London/ Philadelphia, 2005, at 172, who reports the personal testimony of a gay man who was subjected to 'slide and emetic' aversion therapy, used by the UK NHS at its hospitals during the 1960s, involving the use of appropriate 'control' together with 'deviant' sexual imagery, coupled with administration of an emetic.

⁵⁰ See, for example, the following protocol for administering electrical aversion therapy, reported in R.J. Maguire and M. Vallance, 'Aversion therapy by electric shock: a simple technique', *British Medical Journal*, Volume 1, 1964, at 151.

⁵¹ This method was demonstrated by gay medical doctor Dr. Christian Jessen, in *Undercover Doctor: Cure Me, I'm Gay*, a documentary that aired on Channel 4 in the UK on 18 March 2014 at 20:00 GMT in which Jessen, at times undercover, explored 'gay cures' past and present in the UK and the US, as also reported in Scarlett Russell, 'You're gay because there are demons in you': Dr. Christian Jessen breaks down in tears as he goes undercover to investigate bogus 'gay cures', *Mail Online*, 18 March 2014, accessed online at <http://www.dailymail.co.uk/femail/article-2583459/Youre-homosexual-demons-Dr-Christian-Jessen-goes-undercover-investigate-bogus-gay-cures.html>.

⁵² See, for example, George S. Baroff and Bobby G. Tale, 'The Use of Aversive Stimulation in the Treatment of Chronic Self-Injurious Behavior', *Journal of the American Academy of Child Psychiatry*, Volume 7, Issue 3, July 1968, at 454, which describes in detail the protocol for administering electric shock aversive therapy to such children, with the prescribed 'shock apparatus' being a specific make and model of cattle prod.

Judge Rotenberg Center in Massachusetts.⁵³ The patient was then exposed to or taught new, different behaviours, with no corresponding sanction administered when these new procedures were observed, or when the patient engaged in these behaviours instead.⁵⁴

The aim of the therapy was to make the new behaviours the default behaviours in the patient, by ‘shocking’ or otherwise expelling the negative behaviours out of their systems, and making them automatically resort to the new behaviours instead, hence the system of ‘punishment’ and ‘reward.’⁵⁵

Here, ‘punishment’ refers to the sanctions described, while ‘reward’ refers to the non-application of said sanctions, with the patient learning that different courses of action led to different outcomes, being either ‘punishment’ or ‘reward.’ Part of the ‘punishment’ process also involved restraints and seclusions being applied to deal with instances of particularly ‘challenging behaviours.’⁵⁶

However, shocking a person or tying them down, in order for them to be too afraid to perform a certain behaviour will still leave the root cause untouched, and lead to the possibility of the latent need in question being communicated through different, possibly more destructive methods instead, as outlined earlier.

Also, as to alternative behaviours, the fact that the subject exhibits functional responsive behaviours seemingly by default in a therapeutic setting, is not testimony to the success of the therapy. Rather, it might be simply a behavioural modification in the patient triggered

⁵³ See Section 2.4.1 of this thesis for a further discussion of this topic.

⁵⁴ See, for example, J. Shaw, *op. cit.*

⁵⁵ See, for example, H.J. Eysenck, ‘Behaviour therapy, extinction and relapse in neurosis’, in H.J. Eysenck (ed.), *Experiments in Behaviour Therapy*, Pergamon Press, Oxford, 1964, at 176; ‘The Difference between Positive/Negative Reinforcement and Positive/Negative Punishment’, published online at bcotb.com on 5 February 2013, and accessed at <http://bcotb.com/blog/2013/02/05/the-difference-between-positivenegative-reinforcement-and-positivenegative-punishment/>, which outlines the concept of reward and punishment in terms of the language of ‘positive and negative reinforcements’ and ‘positive and negative punishment’ used in behavioural interventions such as ABA, these concepts being discussed further, within the context of a rights discussion, in Sections 10.4.1 and 12.2.2.4 of this thesis.

⁵⁶ See, for example, Timothy R Vollmer, Louis P Hagopian, Jon S Bailey, Michael F Dorsey, Gregory P Hanley, David Lennox, Mary M Riordan and Scott Spreat, The Association for Behavior Analysis International Position Statement on Restraint and Seclusion, *The Behavior Analyst*, Vol. 34, Issue 1, Spring 2011, at 103.

by fear, and performed simply in a therapeutic setting or around persons that might once again re-enforce the therapeutic environment, then or later.

And this in order to avoid going through the physical and/ or emotional pain of associated sanctions, with both the behaviour in question, as well as the root cause, remaining untouched for the patient. In many cases, the former would still be performed in 'safe' settings, with resulting psychological and emotional fallout resulting from this process, that might further exacerbate the patient's negative psychological and/ or emotional states, and possible internal and external processes in virtue of this.⁵⁷

This has been seen in the experiences and testimony given by survivors of aggressive therapy using the Lovaas method. These include LGBTQI persons forced to undergo 'conversion therapies' using this method,⁵⁸ as well as autistic persons forced to undergo aggressive ABA addressing the wrong priorities, as stated by Damian Milton, at times with aggressive physical sanctions such as electric shocks.⁵⁹

2.5 Conclusion

This Chapter has argued for a correct understanding of autism. This is due to problems being rooted in perceptions of the 'problem', and while there is a need for willingness to change such perception, there is mostly a need for the right kind of awareness, in order to bring about shifts in the status quo regarding social perceptions. This is necessary in order

⁵⁷ Maia Szalavitz, 'The 'Sissy Boy' Experiment: Why Gender-Related Cases Call for Scientists' Humility', *Time Magazine Online*, 8 June 2011, accessed at <http://healthland.time.com/2011/06/08/the-sissy-boy-experiment-why-gender-related-cases-call-for-scientists-humility/>, covered the case of the suicide of an effeminate boy, whose 'gender disturbance' was sought to be corrected through a therapeutic intervention conducted by Lovaas and his colleague George Rekers.

Once again, the element of 'indistinguishability' had been emphasised by Lovaas in this specific intervention, claiming in a paper cited in Footnote 40 of this Chapter, that the boy, after completing treatment, was "indistinguishably unfeminine and showed no signs of homosexuality". However, the boy admitted to keeping such 'signs' hidden, due to his father giving him spankings if he were given a different colour poker chip as 'punishment' for feminine-like behaviour during therapy.

⁵⁸ See, for example, Footnotes 49 and 57 of this Chapter.

⁵⁹ Damian Milton, 'So what exactly are autism interventions intervening with?', *Good Autism Practice*, Vol. 15, Issue 2, 2014, at 6; See also, for example, Footnote 47 of this Chapter, regarding aggressive behavioural therapy, as well as Section 3.3.2 and Footnote 86 of Chapter 3 of this thesis, regarding continued use of electro-shock aversive therapy at the Judge Rotenberg Center in Massachusetts, including on autistic children till this very day.

to be able to embark on journey towards awareness, acceptance and inclusion, as discussed later in this thesis.

Similarly important is highlighting the element of the dominant/ minority dichotomy in society, with the dominant majority trying to extirpate difference, and dictating what is good or bad, and what is right or wrong, in tune with what varies from the norm.

This point will be fleshed out through the next Chapter, which will illustrate this point by drawing parallels to the situation concerning linguistic and ethnic minorities in different countries. This will be done through illustrating points concerning perceptions and status quo, within the framework of said dominant/ minority dichotomy, justifying attempts to extirpate difference on the basis of notions, sometimes genuine, of good or bad and right or wrong. This will be followed by charting the journey to realisation that such view was jaded, that these minorities were equally deserving of their rights in the same way as the majority, and the slow but resulting change in virtue of this, also due to outside pressures, even if old habits and resistance die hard.

This will then be twinned with the issue of processing and communication, and its link to autistic behaviour and identity, with the argument being made concerning the status quo regarding autism right now being similarly mirrored. Problems on both sides and complicating factors, for example, the anger of hurt autistic activists, will also be discussed, as will then the need for similar action as with linguistic and ethnic minorities, to follow a similar journey through a similar path, opening up the possibility of a way forward. The need for middle ground to be sought among all sides is also highlighted in the discussion, with the nascent Maltese model being given as a possible example.

Chapter 3: Stifling Communication – Stifling Identities

3.1 Introduction

As mentioned in the previous Chapter, the first part of this Chapter will carry out an analysis of the journey from monolingualism to multilingualism in different countries. This section will tackle what caused such situation to emerge, the ensuing attempts at assimilation and extirpation in the linguistic and cultural fields, and the reasons for such practice continuing as the status quo in different countries. The main reasons and steps on the journey for that to change will also be discussed, as well as how this did, and what problems still remain in this regard.

This will then be compared with situation concerning the rights of autistic persons, tackling the issues of processing and communication, as well as their links to the identity and personhood of such persons. An analysis will be made of those who want to retain the status quo, and of those on the other side. The situation on the ground will be discussed, as well as a possible way forward, with the Maltese model being illustrated as a possible example.

3.2 Monolingualism to Multilingualism – Language and Identity

3.2.1 Introduction

Monolingualism was for long periods considered to be the norm in most societies. Originally, a single language defined a specific ethno-linguistic group, with different groups living in a specified territory, and sharing a common identity and culture, one of the defining features of such being a common language.

However, territorial expansion projects by certain groups, either as a result of political ambition, or else through mechanisms such as the intermarriage of royal houses, resulted in new polities in which different identities and cultures were grouped side by side into a larger polity. This eventually morphed into the modern notion of the nation state, especially in the post-Westphalian scenario, and particularly following the advent of the Industrial Revolution.

One of the key aspects of what was to become the Westphalian model, however, was the concept of unitarianism, and of a centralised 'nation-state.'¹ This placed power in the hands of a dominant faction. And, especially at a time where disputes were settled by the sword, since they meant the surviving and thriving of one clan or group at the expense of the other, it was essential to the survival of a new polity that its identity and culture were stamped as the new norm. Such process almost always resulting in the exclusion of other competing identities and cultures.

3.2.2 *Assimilation and 'Extirpation' of Difference*

Thus, one could observe the situation emerging in France, following the Treaty of the Pyrenees of 1659 with Spain. In 1700, King Louis XIV promulgated an edict² banning the use of the Catalan language, then the native language of the territory, in these lands. In the edict's reasoning were the considerations that continued use of the language, particularly for official business, was 'repugnant', as well as undermining the authority of the French state, and being contrary to the 'honour of the French nation.'³

It was very clearly stating that now the territory was French, and overtly stated the need to deepen and complete a process of assimilation, that was not yet satisfactory 31 years on from the Treaty's adoption. In this regard, it mentioned concerns such as the fact that the natives did not exhibit the same 'zeal and affection' for the state as other subjects did.⁴

The same process was followed in the Kingdom of England, following the bloody defeat of Welsh forces under Llywellyn the Last in 1282, and the subsequent purging of all the resistance leaders and associated intelligentsia progressively over the next centuries. This culminated in the passage of the Welsh Acts of Union, known as the Laws in Wales Acts,⁵ and in particular that of 1536.⁶

¹ See, for example, Derek Croxton, 'The Peace of Westphalia of 1648 and the Origins of Sovereignty', *The International History Review*, Vol. 21, No. 3, September 1999, at 569.

² Interdiction de la langue catalane en Roussillon, Edit du Roy – Louis XIV, 2 April 1700.

³ Ibid., at para. 1. The original text (in period French) reads: "Mais comme outre que cet usage répugne & est en quelque sorte contraire à Notre Autorité, à l'honneur de la Nation Française [...]"

⁴ Ibid.

⁵ An Acte for Laws & Justice to be ministred in Wales in like fourme as it is in this Realme, 27 Henry VIII c. 26 (Laws in Wales Act 1536); An Acte for certaine Ordinaunces in the Kinges Majesties Domynion and Principalitie of Wales, 34 & 35 Henry VIII, c. 26 (Laws in Wales Act 1542).

⁶ Laws in Wales Act 1536.

The latter piece of legislation was not principally aimed at the enfranchisement of new Welsh subjects by according them the right to send representatives to Westminster. This, rather, was a side-issue to the principal issue of Henry VIII of England's stated mission to "extirpate all and singular sinister usages and customs belonging to Wales."⁷

Hence, such legislation sent a clear message laying down who was in control now. Furthermore, it also made clear that, since Wales was now an integral part of the Kingdom of England, not only was the law of the land henceforth English law, but also the language in which legal matters, administration and ultimately daily life would be conducted in, would be the English language, and no longer the Welsh language.

The notion of holding the fort, and fending off an adversary in order to make sure that the adversary would no longer raise an army against the victorious power, can also be seen in the situation that unfolded in the Kingdom of Spain in 1716, following the victory of Philip V in the Spanish War of Succession.

The Catalan nobility, long having been afforded their own institutions and autonomy, even following the Union of the Crowns in 1479, had been instrumental in supporting Holy Roman Emperor Charles VI, rival contender to the throne of the Kingdom of Spain, against Philip. They had thus used the resources and stature of their autonomy in order to raise armies and drum up public support in backing a different polity that would have emerged had Charles been victorious, rather than the polity resulting from the victory of Philip.

Thus, in order to clip the wings of the Catalans, and ensure that they would no longer be a threat, in preserving his victory and the stability of the unified Kingdom of Spain, Philip promulgated the Nueva Planta decrees between 1707 and 1716.⁸ The specific decree applicable to Catalonia was promulgated on 16 January 1716,⁹ abolishing Catalan autonomy and institutions, and bringing Catalonia directly under the central control of Madrid.

⁷ Acts of Union, op. cit., as cited in Heiko Wigge, 'Reevaluating Diglossia: Data from Low German', ProQuest, Ann Arbor (MI), 2006, at 203.

⁸ Stanley G. Payne. Chapter 16, 'The Eighteenth-Century Bourbon Regime in Spain', in *A History of Spain and Portugal*, Vol. 2, The Library of Iberian Resources Online, accessed at <http://libro.uca.edu/payne2/payne16.htm>.

⁹ Ibid.

In the process of so doing, such legislation also affirmed Castillian Spanish as the sole language of administration and of the Courts all throughout the Kingdom of Spain, suppressing in the process the use of the Catalan language, long a defining feature of the Catalan national identity and of the existence of Catalonia. This process was enforced with varying degrees of brutality for centuries thereafter, with a view to retaining the dominance of the Castillian hegemony over the rebellious Catalan elements within the unified Spanish Kingdom.

Although these polities, and eventually post-Westphalian nation states, were so created due to nothing more than historical circumstance, the reality ensued that nation states existed with a multitude of nationalities, ethnicities and languages pertaining to such, within their sovereign internationally-recognised borders. While still the cause of skirmishes for such states, both internally, as well as with foreign powers, usually displaying some ethnic or cultural affinity with certain of these groups, there was no effort or, indeed, interest, to integrate these national, ethnic and linguistic groups into the fibre of these nation-states.

There were no steps taken towards weaving their ethnic, cultural and linguistic identities within the common fabric of the national tapestry. In the process of so doing, this would have both accorded rights to these groups, not least linguistic rights, as well as also fostering awareness and acceptance of this difference among other national, ethnic and linguistic groups in the country, particularly among the dominant such groups in these different polities.

Rather, the Kingdom of France, and later the French Republic, even though the latter state was committed to the principles of liberty, equality and fraternity, were very adamant on stamping out a common national identity in the name of equality and fraternity – albeit one based on a common French identity.

Such measures imposed in the process the cultural and linguistic identity built around one group, on all other groups within that nation state's jurisdiction. The identity that evolved from the *langues d'oïl* originally adopted by the Franks, living in the modern-day region of Île-de-France and surrounding areas, was imposed upon the rest of the state's sovereign territory, through a process of aggressive assimilation.

This happened through a succession of laws extending mainstream French language and culture to different historically linguistically and culturally diverse areas in France. Notable instances are those occurring in Bretagne starting in 1836,¹⁰ in Alsace notably after 1918¹¹ and Occitania in the later 1800s,¹² the resulting process in the latter case still known as ‘La Vergonha’ (The Shame).

All such measures followed on from the *Ordonnance de Villers-Cotterêts* promulgated in 1539, which established standard French as the language of record and business throughout the Kingdom of France, in place of Latin.¹³

Such a model was eventually also copied by the nascent Turkish Republic from 1922 onwards, where a nominally socialist ideology in the form of Kemalism advocated the creation and progress of a people, unified by a common Turkish nationality and language, as exemplified through the Turkish Constitution.¹⁴

This was reinforced through the passage of laws such as the Law Concerning Publications and Broadcasts in Languages Other Than Turkish,¹⁵ which stated that “[t]he mother tongue of all Turkish citizens is Turkish,”¹⁶ and which forbade the use of any language but Turkish “as a mother tongue”, defying basic principles of anthropology.¹⁷ These processes were seen as trampling on the ethnic and linguistic rights of centuries-old groups within the Turkish state, such as the Kurds and the Armenians, and remain a source of friction and division within Turkey till this very day.

¹⁰ Kerstin Mendel, 'Regional Languages in France: The Case of Breton', *LSO Working Papers in Linguistics*, Vol. 4, 2004, at 65, 69.

¹¹ Christopher J. Fischer, *Alsace to the Alsations?: Visions and Divisions of Alsatian Regionalism, 1870-1939*, Studies in Contemporary European History, Berghahn Books, New York/ Oxford, 2010.

¹² Gavin Radford, French language law: The attempted ruination of France's linguistic diversity, Trinity College Law Review website, 4 March 2015, accessed online at <http://trinitycollegelawreview.org/french-language-law-the-attempted-ruination-of-frances-linguistic-diversity/>.

¹³ Ordonnance no 188 de 1539 (ou «ordonnance de Villers-Cotterêts») prise par le roi François Ier imposant l'usage du français dans les actes officiels et de justice, Enregistrée au Parlement de Paris le 6 septembre 1539.

¹⁴ Article 3 of the Turkish Constitution declares Turkish to be the official language, while Article 42.9 goes further by stating that, “Aside from Turkish, no other language shall be studied by or taught to Turkish citizens as a mother tongue in any language, teaching, or learning institution.”

¹⁵ Law No. 2932 of October 1983.

¹⁶ *Ibid.*, at art. 3.

¹⁷ ‘Prohibitions Against the Use of Kurdish and Languages Other than Turkish’ in Chapter IX, ‘Restrictions on the Use of the Kurdish Language’, in *Violations of Free Expression in Turkey*, Human Rights Watch, 1999, accessed online at <https://www.hrw.org/reports/1999/turkey>.

3.2.3 *Changing Perceptions and Initial Reforms*

The advent of ideas such as multiculturalism and inclusion, especially strong over the second half of the twentieth century, brought with it more elaborate human rights legislation, particularly emanating from international and regional collective agreements.

However, even though signatories to the European Convention on Human Rights, states such as France, Spain, the United Kingdom and Turkey refused to become party to more specific treaties, such as the European Charter on Regional and Minority Languages.¹⁸ Such states feared that implementing provisions of this framework Convention would lead to unrest and dissent within their borders, and only inflame tensions that were also behind increased activity, many times violent, by separatist tendencies within particular diverse communities.

3.2.3.1 United Kingdom

The United Kingdom only repealed the 1535 Laws in Wales Act in 1993,¹⁹ and eventually signed and ratified this Convention, also introducing awareness and acceptance of linguistic rights in the public and private spheres, especially following the passage of devolution bills for Scotland²⁰ and Wales²¹ in 1998. However, the United Kingdom's situation could be considered to be mild compared to that prevailing in the other three countries in question.

While nationalist sentiments were more pronounced in Scotland, such sentiments were never strong enough to threaten the existence of the United Kingdom, as the result in the 2015 referendum on Scottish independence also demonstrated.

Particularly, the issue of linguistic rights and multilingualism was not a concrete matter, due to the fact that, aside from in small pockets in the different home nations of the United Kingdom, languages other than English had been wiped out through an aggressive process

¹⁸ European Charter for Regional or Minority Languages, 4 November 1992, ETS 148.

¹⁹ Welsh Language Act 1993, c. 38. The long title of the Act also made provision for the "repeal [of] certain spent enactments relating to Wales, and for connected purposes".

²⁰ Scotland Act 1998, c. 46.

²¹ Government of Wales Act 1998, c. 38.

of assimilation over the centuries. Also, where such languages were still in use, they were still subservient to an administrative, legal and everyday system in which English was both necessary and still the dominant language.

On the other hand, the issue of language was still much more closely tied to the issue of national identity in Spain and Turkey, and to a lesser degree in France.

3.2.3.2 Spain

In Spain, the Catalan language and identity had been constantly suppressed under the Franco regime,²² however, use of the language was still as alive as ever throughout, as was the notion of a Catalan nation and identity.

The passage of the new Spanish Constitution of 1978²³ during the post-Franco democratisation process, as well as the adoption of Statutes of Autonomy for the various regions of Spain, including for Catalonia,²⁴ were seen as a positive gesture. However, the continued centralisation of main decisions, and the continued hegemony of the central government in Madrid over the regions, was still a source of tension within the Spanish state.

Spain's ratification of the Charter on Regional and Minority languages in 2001 was a positive step, although Catalan aspirations were still subservient to the central government, particularly in the linguistic field. The Council of Europe, in its 2015 Committee of Experts Report, criticised the Spanish Government for the recurring problem of lack of bilingual staff in certain areas of public administration,²⁵ as well as in providing state services such as healthcare.²⁶

²² See, for example, Conxita Mir, 'The Francoist Repression in the Catalan Countries', *Catalan Historical Review*, Volume 1, 3008, at 133.

²³ Spanish Constitution of 1978, at art. 144.

²⁴ The latest Statute of Autonomy for Catalonia was approved on 19 July 2006.

²⁵ Council of Europe, European Charter of Regional and Minority Languages, *Application of the Charter in Spain, 4th monitoring cycle, Report of the Committee of Experts on the Charter*, adopted on 20 March 2015, and Recommendation of the Committee of Ministers of the Council of Europe on the application of the Charter by Spain, adopted on 20 January 2016, Strasbourg, 20 January 2016, ECRML (2016) 1, at 13.

²⁶ *Ibid*, at 32.

It noted that such ‘significant problems’ were still recurrent,²⁷ even though they had been raised in the Committee’s previous report in 2012.²⁸ The same concerns were more recently reiterated in 2016, in Recommendations made to the Spanish government by the Council of Europe’s Committee of Ministers.²⁹

These realities, together with a number of continuing incidents, such as inter-community racist behaviour,³⁰ have perpetuated the existing situation. Specifically, Catalonia and the rest of Spain, dominated by a culturally and linguistically different central government, are daily becoming increasingly strange bedfellows.

And short of a compromise that can normalise what is currently an artificial relationship, Catalan aspirations for independence, achieved in whatever manner, are simply a question of time.

While commentators argued that ‘devo-max’ proposals by leaders of the three main unionist parties in the United Kingdom contributed to the ‘No’ voted prevailing in the Scottish independence referendum, the breach in between Catalan citizens of Spain, and the rest of the Spanish state, is much wider. Consequently, such situation must be addressed in a much deeper manner than it was in the United Kingdom, if a ‘devo-max’ proposal is to save the unity of the Spanish state.

3.2.3.3 Turkey

Turkey, on the other hand, refused to sign or ratify the Charter on Regional and Minority Languages, and technically still refuses to even admit to the existence of separate ethnic or national identities within its borders. Turkish statute books still containing dicta “[p]reventing the creation of national minorities,”³¹ in line with the constitutional provision

²⁷ Ibid., at 4.

²⁸ Council of Europe, European Charter of Regional and Minority Languages, *Application of the Charter in Spain, 3rd monitoring cycle, Report of the Committee of Experts on the Charter*, and Recommendation of the Committee of Ministers of the Council of Europe on the application of the Charter by Spain, Strasbourg, 24 October 2012, ECRML (2012) 5.

²⁹ Recommendation of the Committee of Ministers of the Council of Europe on the application of the Charter by Spain, adopted on 20 January 2016, op. cit.

³⁰ See, for example, ‘Attack in Barcelona on two Spanish supporters’, AStv, 6 June 2016, accessed online at http://en.as.com/en/2016/06/06/football/1465216438_949782.html.

³¹ 1981 Law on Political Parties, at art. 81.

that [e]veryone bound to the Turkish State through the bond of citizenship is a Turk.³² This scenario is of relevance particularly with regard to the ever-more volatile situation concerning Kurdish citizens of Turkey.

For a long time, Turkey continued to enforce a concurrent policy of sole use of the Turkish language in all spheres of life, even in areas of the Turkish Republic which were all but Kurdish-speaking. Here, most such residents have limited or no knowledge of the Turkish language, being mainly monolingual Kurdish speakers.³³

Under international pressure from institutions it is party to, such as the Council of Europe³⁴ and NATO, Turkey finally started to relax its position on the matter, through legislation promulgated from 1991 onwards, falling short of recognising the existence of separate ethnicities and nationalities within its borders, but allowing limited use of minority languages, such as in regional and later national broadcasting,³⁵ as well as in school instruction.³⁶

A major contributing factor to these steps was also Turkey's bid to bolster its business and other international relations with major partners. In particular, it hoped such measures would curry favour in its ever-growing efforts with its European Union membership bid, which had been in limbo since originally lodged in 1987.

However, Turkey still did not proceed to either sign or ratify the Convention, and has mostly prevented the situation from mirroring that in Spain through the use of force, and through the military might of the Turkish Armed Forces. It is clear that, though changes have been made, Turkish policy in the area is merely window-dressing, especially with the recent shifts in Turkish government policy to the right.

³² Turkish Constitution of 1982, at art. 66.

³³ Human Rights Watch, op. cit.

³⁴ See, for example, *Opinion on the Constitutional and Legal Provisions Relevant to the Prohibition of Political Parties in Turkey*, opinion No. 489/2008, CDL-AD (2009) 006 Venice Commission Council of Europe, 13 March 2009. This Opinion also dealt with bans on regional minority parties, such as Kurdish parties.

³⁵ Human Rights Watch, op. cit.

³⁶ Ibid.

This particularly with regard to these minorities, as demonstrated, for example, through the Turkish response to the Diyarbakir-Kobane bombings in 2015. This included indiscriminate arrests of Kurdish political opponents by way of preventive internment, since there was no link of such persons to the events in question.³⁷ These arrests were coupled with a subsequent campaign of Turkish airstrikes in Syria, that seemed more intent on destroying unfriendly Kurdish positions, rather than on Turkey's stated aim of targeting Daesh militants.³⁸

3.2.4 *Conclusions*

One could, by way of conclusion, observe that all of the above states analysed practised monolingual policies for a reason – that of attaining and maintaining a dominant hegemony of the group holding principal power within that state.

All these states proceeded to brutally enforce the status quo and root out dissenters. They rejected overtures towards inclusion, acceptance and empowerment of other diverse groups within such polities, seeing such moves as a threat to the status quo and to stability.

Many of these states still continue internal persecution, to varying degrees. At times, the situation seems placid to outside observers, so such states' actions are ignored, or simply let off with a slap on the wrist, particularly when political alliances or interests are at play. However, at other times, the situation is much worse, so matters boil over and come to the surface.

In all such situations, whatever the magnitude of the issue at hand, there is a need to matters for what they are, and a responsibility for both nation states, and particularly the regional and international bodies they form part of, and 'watchdog' institutions within, to recognise such matters, and take appropriate action before it is too late.

³⁷ See, for example, Ehubekir Isik, 'Arresting Kurdish Politicians; Impacts on Turkey's Domestic and Foreign Policy', Rudaw Media Network, 7 April 2016, accessed online at <http://rudaw.net/english/opinion/07042016>.

³⁸ See, for example, Uzay Bulut, 'Turkey Uses ISIS as Excuse to Attack Kurds', Gatestone Institute - International Policy Council, 26 July 2015, accessed online at <https://www.gatestoneinstitute.org/6223/turkey-isis-kurds>.

Matters would work much better through, for example, admitting to a problem, and attempting a 'devo-max' solution in the linguistic field, rather than resorting to measures such as bloodily suppressing dissent, which could lead to ethnic strife and eventual fracturing of the polity in question in the longer term, as was, for example, the case in the Balkans in the 1990s.

By way of possible solutions, the goal of the European Charter of Minority Languages was the affirmation of diversity and inclusion, and the promotion of harmony, in multilingual and multi-ethnic states. The aim was to shift from the mentality of old terming certain vernaculars 'patois' or 'kitchen languages,' and moving instead towards the stated goals of the Charter, through the vehicle of multilingualism.

As overtly stated in some of the documents discussed above, 'extirpating' the language of a people was an essential step in similarly extirpating the identity of a people, and attempt to integrate them instead into the mainstream. In this regard, the majority in different countries still guards its status fearfully, leading to the need of instruments such as the Charter, and mechanisms such as the Committee of Experts, and the system of periodic reviews. This, however, only for those states who willingly agree to become party to such instruments and mechanisms, with more radical believers in unitarianism remaining outside of the fold.

The link between such processes and variants of genocide has been raised in the past, especially in the context of ethnocide, discussed earlier, as well as of cultural and social genocide,³⁹ this specific notion having in particular been applied to La Vergonha,⁴⁰ the

³⁹ This term is used, without a specific definition, in the Draft United Nations declaration on the rights of indigenous peoples (drafted by The Sub-Commission on Prevention of Discrimination and Protection of Minorities Recalling resolutions 1985/22 of 29 August 1985, 1991/30 of 29 August 1991, 1992/33 of 27 August 1992, 1993/46 of 26 August 1993, presented to the Commission on Human Rights and the Economic and Social Council at 36th meeting 26 August 1994 and adopted without a vote) in Article 7, in which it states that they "have the collective and individual right not to be subjected to ethnocide and cultural genocide". This wording did not, however, make it into the final Declaration (United Nations Declaration on the Rights of Indigenous Peoples, GA Res 61/295, UN GAOR, 61st sess, 107th plen mtg, UN Doc A/RES/61/295 (13 September 2007)).

⁴⁰ Jaume Corbera Pou, in 'Le patois des vieux', *Llengua Nacional: Catalan Linguistic Review*, Spring 2002, English translation accessed at <https://en.wiki2.org/wiki/Vergonha>. In this article, Pou sums up the situation with regard to La Vergonha as follows:

"France, that under Franco's reign was seen here [in Catalonia] as the safe haven of freedom, has the miserable honour of being the [only] State of Europe—and probably the world — that succeeded best in the diabolical task of destroying its own ethnic and linguistic patrimony and moreover, of

attempted eradication of Occitan language and culture by the French authorities, mentioned above.

One could simply end by saying that the status quo speaks for itself. The struggle will remain, from both sides. The nationalist movement that emerged with the advent of Romanticism in the 19th century, did eventually allow for the emancipation of certain ethnicities, especially following the Treaty of Versailles in 1919, with linguistic emancipation being part of their reacquisition of identity.

However, a number of groups still did not manage to attain this emancipation, both within pre-Versailles polities, as well as in new polities emerging after Versailles. The issue was particularly of concern in the latter case, since newly re-emerging states such as Poland⁴¹ were adamant to fiercely guard and not lose once again that which was so painfully torn away from them, at times for hundreds of years.

Different groups will fight hard for asserting and preserving their identity, however, this might come at the expense of other groups – out of pride, out of fear, or out of both. The next Chapters will also analyse other groups fighting for emancipation by invoking different characteristics in asserting their rights. However, the analysis in this chapter shows that, the more a characteristic is intrinsically linked to a group's existence, the more it will fight, even at the expense of other groups, to retain that. Even resorting to extreme measures at times.

In the case of autism, this is nothing more than a scenario of the dominant against the oppressed, of society imposing its version of normal, whatever the intent, and fighting to extirpate difference. It boils down to arguments of 'good and bad' and of 'right and wrong'. With time, there might be a similar shift, as observed in the case of the shift from the

destroying human family bonds: many parents and children, or grandparents and grandchildren, have different languages, and the latter feel ashamed of the first because they speak a despicable patois, and no element of the grandparents' culture has been transmitted to the younger generation, as if they were born out of a completely new world. This is the French State that has just entered the 21st century, a country where stone monuments and natural landscapes are preserved and respected, but where many centuries of popular creation expressed in different tongues are on the brink of extinction. The "gloire" and the "grandeur" built on a genocide. No liberty, no equality, no fraternity: just cultural extermination, this is the real motto of the French Republic."

⁴¹ See, for example, Winson Chu, *The German Minority in Interwar Poland*, The German Historical Institute, Washington, DC, and Cambridge University Press, Cambridge, 2012.

medical to the social model of disability, in line with the ethos of the radical disability rights and autistic rights movements.

Two things are important here – to ensure the continued emancipation of the identity of certain groups, while also making sure that, in the struggle for such, none of the sides involved resorts to extreme measures, either in retaining their status quo, or in achieving their goals.

3.3 Different Processing and Communication Styles

While the previous section dealt with the issue of the dominant/ minority dichotomy, in terms of dictating ‘good and bad’ and ‘right and wrong’ in the field of linguistic and ethnic groups, this section will examine a parallel dichotomy, however within an autism scenario.

Within this context, it is being argued that there are different processing and communication styles, rather than good or bad such styles, and that the key to being able to see such phenomenon lies in understanding the nature of autism, and understanding the communication and processing elements linked with such.

These are also a major component in understanding the autistic identity as a variation of the dominant majority’s norms, as opposed to sanctioning maligned behaviours as right or wrong, for simply being an infraction of such norms. This rather than being open to different modes of expression, as well as looking further towards such behaviours’ root cause in cases of concern, rather than sanctioning them simply for the sake of their outward manifestation.

By understanding this mechanism also within the context of autism, one would then be able to undertake a journey, rooted in proper awareness, towards acceptance and inclusion, as also further described over the next Chapters. This in place of assimilation and extirpation, on the basis of diffusion of correct information, and of understanding, initiating a similar shift as in the case of linguistic and ethnic groups, along a same path, also mirroring shifts in other areas, such as that from the medical to the social model of disability already introduced in Section 1.1.2 of this thesis.

This Chapter will first look at further novel ways used by elements of the dominant majority to put across their argument as to what constitutes right and wrong, after which examples shedding light on the 'other side of the coin' will be put forward. The issue of activist anger around the issues of good and bad, and right and wrong, will then be discussed, also taking stock of the situation on the ground, as well as looking into what needs to be done to turn the tables and change the situation at hand, arriving instead at a middle ground. The nascent and evolving Maltese scenario will also be described as a possible model as to how to achieve this.

3.3.1 *Behavioural Therapies and the Right to Education*

The issue of perceptions and genuine beliefs as to what is right and wrong, going by mainstream information available within and current norms enforced by society in respect of autism, and autistic behaviour and communication, has led to further novel approaches beyond that in *Auton*.

3.3.1.1 O' Cuanachain v. Minister for Education

As discussed earlier, the issue of autistic behaviour and communication had made it all the way to the Canadian Supreme Court in *Auton*, where the use of Applied Behavioural Analysis (ABA) therapy in respect of autistic children was challenged.

Here, the court upheld the arguments of activists such as Michelle Dawson in not ruling that the state was to fund such therapy found questionable by some in respect of autism,⁴² although the main reason behind the decision was due to technicalities concerning the financing of Canada's public healthcare system. The main argument about improper forms of such therapy, as outlined in Section 2.4 of this thesis is that, rather than help bring out the best in autistic children, it just aims to make them 'subservient' to neurotypical norms.

While the ethos behind *Auton* could be argued to be 'a right to be normal', in *O' Cuanachain v. Minister for Education*,⁴³ petitioners argued a similar subject matter, all the

⁴² Michelle Dawson, 'The Misbehavior of Behaviorists', available online at http://www.sentex.net/~nexus23/naa_aba.html.

⁴³ *Sean O' Cuanachain (a minor suing by his father and next friend, Cian O' Cuanachain) v. The*

way up to the High Court of Ireland. However, their approach focused not on the behavioural therapy element of ABA as the main argument through which funding was claimed. Rather, it went further and classified such therapies as part of a ‘special education’ curriculum, as a necessary add-on in every autistic child’s education in Ireland.⁴⁴

Petitioners argued that such add-ons were required, in order for the basic level of education received by such children to be at a par with the constitutionally and legally-mandated norms applicable to their non-autistic peers. Thus, not funding the necessary special education ‘add-on’ was argued to be a violation of the petitioner children’s, represented by their parents and guardians, right to education, and to equal treatment and non-discrimination, in terms of the Irish Constitution and relevant legislation.⁴⁵

The High Court ultimately rejected the claim that ‘ABA education’, as per the terminology used by petitioners, qualified as a necessary equalising add-on.⁴⁶ This in terms of bringing these children’s education package, in both the special and mainstream spheres, at a par with standard mainstream education where ‘special education’ was not warranted. Hence, there was no obligation on the State to fund such ‘add-ons’.⁴⁷

However, the main concern emerging from *O’ Cuanachain* is about the use of terminology, and what it really signifies. Arguing for a child’s right to educational equality appeals to one of the very fundamental notions a society must uphold, especially in terms of the constitutional protection of this right under Irish law. However, although this might be seen as a noble cause raising indignation to a person not versed in the subject, the underlying rationale behind it might be more debatable.

Classifying ABA therapy as a central, equalising part of an autistic child’s education, results in a situation in which part of the child’s education is being ‘taught’ to be normal. This, together with the other ‘add-ons’ provided by special education to the child, would

Minister for Education and Science, the Minister for Health and Children, The Health Service Executive, Ireland and the Attorney General, High Court of Ireland, per Pearl J, 16 May 2007, [2007] IEHC 170 (hereinafter ‘*O’ Cuanachain v. Minister for Education*’). The case was subsequently appealed by plaintiff to the Supreme Court of Ireland, but eventually settled in 2010.

⁴⁴ Ibid., at 5.

⁴⁵ Ibid., at 2.

⁴⁶ Ibid., at 123-124.

⁴⁷ Ibid.

be seen as one of the basic skills allowing that child to be able to take in a mainstream education, and subsequently be better prepared to face life, on a par with his or her non-autistic peers.

The issue of the form of ABA therapy used might arise here, as well as whether the aim of such therapy would be indistinguishability/ normalisation, or rather behavioural analysis taking stock of cause and effect, as further discussed in Section 2.4 of this thesis. Such a scenario might be considered to fall within a child's right to education, since it would be comparable to a language class allowing the child to bridge the gap between their own world and the 'rest of the world', in terms of the discussion in Section 3.2 of this thesis. However, the facts in *O' Cuanachain* do not seem to point to this.

The petitioners spoke of 'ABA education' the primary aim of which was normalisation/ indistinguishability,⁴⁸ and as a component offered within the school setting,⁴⁹ neglecting the important element of making therapy a two-way bridging process, also bringing in the child's family and peers into the exercise. Such kind of therapy, rather than being a component or a driver in a child's education, will actually have deleterious effects on a child's communication and subsequent behavioural manifestations. These can rather be a block, instead of a bridge, to a child being able to progress to receiving educational equality at a par with their non-autistic peers.

O' Cuanachain made exactly the same claim, and for the same reasons as in *Auton*, but instead couched the right to ABA therapy in terms of a right to education. While *Auton* could be seen as pushing for a 'right to be normal', *O' Cuanachain* can be seen as saying that 'if a child is not educated in how to be normal, then he or she is not normal'.

An autistic child's right to education may definitely be breached, in terms of equality and non-discrimination provisions. However, the criteria for this are much broader than what was claimed in *O' Cuanachain*, as two cases brought before the Council of Europe's Committee on Social Rights, through its Collective Complaints Mechanism, amply demonstrate.

⁴⁸ Ibid., at 50.

⁴⁹ Ibid., at 3.

3.3.1.2 Autism-Europe v. France

The first such case was a collective complaint against France, filed on behalf of the families of a number of autistic children by the European umbrella advocacy network Autism-Europe.⁵⁰ The complaint concerned the claim that the French state was not living up to its obligations in terms of the European Social Charter, requiring that States guarantee the right to education to people with disabilities.⁵¹ The Charter mentions that such right applies to all such persons, regardless of the natures and origins of their disabilities and of their age.⁵²

In this regard, the Committee of Social Rights upheld Autism-Europe's claim that, in this regard, the Charter "clearly covers both children and adults with autism."⁵³

Although the French state had promulgated an autism strategy in 2003, the Committee observed that, at the time of the complaint,

"in the case of autistic children and adults, notwithstanding a national debate going back more than twenty years about the number of persons concerned and the relevant strategies required. [...] France has failed to achieve sufficient progress in advancing the provision of education for persons with autism".⁵⁴

⁵⁰ *International Association Autism-Europe v. France*, Complaint No. 13/2002, decision on the merits of 4 November 2003 (hereinafter '*Autism-Europe v. France*').

⁵¹ As stated in *ibid.*, at 7, Autism-Europe asked the Committee:

-to rule that France is failing to satisfactorily apply its obligations under Articles 15§1 and 17§1 of Part II of the Revised European Social Charter, 3 May 1996, ETS 16, because children and adults with autism do not and are not likely to effectively exercise, in sufficient numbers and to an adequate standard, their right to education in mainstream schooling or through adequately supported placements in specialised institutions that offer education and related services;
and

-to rule that France is in violation of the non-discrimination principle embodied in Article E of Part V of the Revised European Social Charter since persons with autism do not benefit from the right to education recognized to persons with disabilities by Article 15§1 and generally set out in Article 17§1 of Part II of the Charter.

⁵² These qualifications apply to the rights enunciated in Footnote 51 above.

⁵³ *Autism-Europe v. France*, at 48.

⁵⁴ *Ibid.*, at 54.

The issue of perceptions played a part, since the complaint had outlined the fact that, at the time of its being lodged, most French official documents dealing with autism still used a more restrictive definition of autism than that adopted by the WHO.⁵⁵

The Committee further stated the following, in addressing the issues of exclusion and double discrimination:

“the proportion of children with autism being educated in either general or specialist schools is much lower than in the case of other children, whether or not disabled. In this regard, the decision finds that autistic people are an excluded group within the excluded. The decision also observes that there is a chronic shortage of care and support facilities for autistic adults”.⁵⁶

The link to long-term damage to the children was also accepted by the Committee, which recognised the importance of providing an appropriate educational environment, in order to prevent the development of “circumstances where the effects of ineffective or untimely intervention are ever likely to be undone [sic].”⁵⁷

As can be seen, the importance of equalisation of opportunities for autistic children, thus preventing discrimination, was not pinpointed to stem from one or more specific causes, but instead the Committee mandated a holistic approach to the system, arguing that equalisation would result from an overhaul of the underlying mechanisms, rather than from the inclusion of one or more specific ‘add-ons’.

In this regard, one could draw parallels with the longest-ever judgement to date of the European Court of Human Rights, in the Grand Chamber's decision on the merits of *D.H. and others v. the Czech Republic*.⁵⁸ The Grand Chamber dealt a severe blow to institutionalised discrimination against Roma in the Czech Republic, forcing Roma children into 'special schools' where they would receive little by way of a useful education, leading them on to a life with many less opportunities than their Czech peers, and leading

⁵⁵ Ibid.

⁵⁶ Ibid.

⁵⁷ Ibid., at 49.

⁵⁸ *D.H. and Others v the Czech Republic*, Application No. 57325/00, Grand Chamber judgement 13 November 2007, (2008) 47 EHRR 59.

to the vicious circle of antisocial behaviour which has earned many persons in this category their reviled status in the Czech Republic.

In so doing, the ECtHR sent a message to all its member countries that such practices were unacceptable, and the Czech government was obliged to update its legislation. In the Autism-Europe collective complaint, the Committee on Social Rights similarly concluded its decision in a comparable vein.

It restated France's obligation under the Charter to ensure the education and training of persons with disabilities and children and young people alike. In virtue of this, it decided that France had to, "in particular by providing for the establishment or maintenance of institutions and services sufficient and adequate for this purpose",⁵⁹ henceforward take "not merely legal action but also practical action to give full effect" to the right to education of autistic persons within its jurisdiction.⁶⁰

3.3.1.3 AEH v. France

Equalisation does not only extend to shoring up the field of special education in line with a holistic strategy based on a proper understanding of autism. While 'special needs' might still need to be addressed independently or concurrently, access to education is only fully achieved when, wherever possible, integration and inclusion of autistic children is provided for.

As with other disabled children, this is to be sought by working to integrate them as best as possible into the mainstream educational system, also in line with relevant enunciations in the UN CRPD.⁶¹ Especially in this light, this is viewed as an area of major concern particularly in jurisdictions where special schools and mainstream schools are still two separate and mutually exclusive phenomena, such as in Israel,⁶² where the Office of the

⁵⁹ Ibid., at 49.

⁶⁰ Ibid., at 53.

⁶¹ UN CRPD, especially at Preamble and at art. 24.

⁶² This concern was mentioned by the staff at Beit Issie Shapiro, Israel's largest disability advocacy and service provision NGO, during a tour of its facilities on the last day of the 6th International Conference on Disabilities hosted by the NGO, Ra'anana, Israel, 10 July 2016.

Commissioner for Equal Rights of Persons With Disabilities has taken up this issue as a matter of priority.⁶³

It was in this vein that French disability rights association AEH brought a second collective complaint against France in 2014.⁶⁴ Here, the Commission on Social Rights found violation of the right of autistic children and adolescents to be educated primarily in mainstream schools, in terms of the European Social Charter,⁶⁵ stating that such right was not guaranteed by the French state.⁶⁶ In this regard, it found the information, consisting mainly of statistics, provided by the French government in this regard,⁶⁷ to not have demonstrated that such aim was achieved.⁶⁸

In this regard, it is important to state that different countries have different laws, but implementation and not just enactment, is key. For example, one might mention the fact that Portugal has a law on Inclusive Education, while Greece recognised the right of autistic children to also have specialised teachers assisting them in mainstream educational institutions. However, the latter law is not being enforced according to Autism-Europe.⁶⁹

The Committee found a further violation of the Charter,⁷⁰ also with regard to the fact that the relevant structural framework was not in place for autistic children to have their needs met in mainstream schools, while also availing of a regular mainstream education. The

⁶³ Interview with the Office of the Israeli Commissioner for Equal Rights of People with Disabilities, Ahiya Kamara – Commissioner and Gaby Admon-Rick, Jerusalem, July 2015.

⁶⁴ *European Action of the Disabled (AEH) v. France*, Complaint No. 81/2012, decision on the merits of 11 September 2013.

⁶⁵ European Social Charter, at Article 15§1.

⁶⁶ *AEH v. France*, at 94.

⁶⁷ The French Government stated in the information registered on 17 December 2014 with the Secretariat, in the form of the *14e rapport sur la mise en œuvre de la Charte sociale européenne, soumis par le gouvernement de la France: Suivi donné aux réclamations collectives; Informations complémentaires sur l'article 13§1 (Conclusions 2013)*, RAP/RCha/FRA/14(2015), that several autism plans had been implemented since the Committee's decision. It referred to the following autism plans: 2005-2007; 2008-2010; 2013-2017.

- As to access to education, the information gave several sets of figures relating to pupils with autism being educated in schools: in 2013-2014, 23 545 pupils; 15 670 benefited from the support of a school assistant (AVS);
- 3 681 attended school on a part-time basis (school and teaching unit);
- some 10 900 pupils were educated solely in teaching units.

⁶⁸ *AEH v. France*, at 83, 84.

⁶⁹ These countries were featured in the Issue 52 of Autism-Europe's *Link* magazine, published in December 2009.

⁷⁰ Here, the Committee found a violation of Article E of the European Social Charter, taken in conjunction with Article 15§1.

inadequacy of schooling in general for autistic children and youths in France was also raised.⁷¹ Due to this, their families had no other choice than to leave France in order to educate their autistic children in schools that did have such appropriate structural framework.⁷²

Limited funding for the education of autistic children and adolescents by the French state under its national Autism Plan⁷³ was also found to breach the Charter. Furthermore, the Committee found that the right of young autistic persons to vocational training was also not guaranteed by the French state,⁷⁴ this similarly being in violation of the Charter.⁷⁵

In this regard, the Committee asked the French state to, when submitting follow-up information in October 2017, state whether work done in so-called ‘specialised institutions’ identified as caring for autistic children and adolescents, was predominantly educational in nature,⁷⁶ rather than amounting to nothing more than sheltered workshops. It similarly asked the French government to state what reforms had been made by then to the relevant structures in the formal education system.⁷⁷

Thus, rather than focusing on what specific elements or ‘add-ons’ completed an autistic child or young person’s effective access to education, the Committee looked at more general frameworks, in the formal and non-formal fields. And as to the latter case, it insisted that educational content be delivered, by ensuring a relevant structure and approach tailored to the autistic young persons attending such structure.

3.3.2 *Activist Anger*

The life experiences of many autistic advocates, as also described earlier in this thesis,⁷⁸ have led many of them to actively campaign against the use of any form of ABA therapy

⁷¹ *AEH v. France*, at 86, 88, 90. Here, the Committee found a violation of Article E of the European Social Charter, taken in conjunction with Article 15§1.

⁷² *Ibid.*, at 136.

⁷³ *Ibid.*, at 139, 142.

⁷⁴ *Ibid.*, at 93, 94, 141.

⁷⁵ Here, the Committee found a violation of Article 15§1 of the European Social Charter.

⁷⁶ In *AEH v. France*, at 119, 121, this had been shown to not be the case.

⁷⁷ *AEH v. France*, at Conclusions.

⁷⁸ See Footnote 59 in Chapter 2 of this thesis.

on autistic children,⁷⁹ also stating that such methods would be found to be unacceptable if applied to non-autistic children.⁸⁰

This especially with such persons having gone through life, observing a bigger picture where society tries to impose its norms on persons, and shuns 'deviant' persons, sanctioning them mercilessly for any infraction of social norms. This process starts from the home, through the school system, through to the wider social system, the world of work, and every nook and cranny of a person's existence.⁸¹

Many of these persons have been forced to adapt in order to be able to access or survive in situations which far from meet the needs of universal design from the sensorial aspect. This, many times, is linked simply to the way other persons approach these persons in essential social situations, be it asking a teacher for clarifications, or applying for a driver's licence. Such persons expect or compel these autistic persons to act way outside of their basic comfort zone, in order for them to be afforded the same response as non-autistic persons.⁸²

While activists such as Michelle Dawson, referred to in the previous section, stated that a wrong approach to therapy simply aims to make autistic persons 'subservient' to neurotypical norms, rather than helping bring out the best in them, other activists have gone even further, positing that genocide is also being carried out by trying to silence and assimilate the millions of autistic persons in our midst.⁸³

⁷⁹ See Sections 10.4-10.6 and 12.2.2.4 of this thesis for a further discussion of this topic within a rights-based context and, for example, 'ABA', *Unstrange Minds blog*, October 7 2014, accessed online at <https://unstrangemind.wordpress.com/2014/10/07/aba/>, which was cited as one of the reasons prompting a therapist to discontinue practising ABA methods, as reported in the therapist's blog post, 'Why I Left ABA', *Socially Anxious Advocate blog*, 22 May 2015, accessed online at <https://sociallyanxiousadvocate.wordpress.com/2015/05/22/why-i-left-aba/>.

⁸⁰ See, for example, Heidi LoStracco, 'Would You Accept This Behavior Towards a Non-Autistic Child?', 'Speak for Yourself' AAC website, 22 February 2014, accessed online at <http://www.speakforyourself.org/uncategorized/accept-behavior-towards-non-autistic-child/>.

⁸¹ See, for example, Donna Williams, *Nobody Nowhere: The Extraordinary Autobiography of an Autistic*, Jessica Kingsley Publishers, London, 1999; Estee Klar-Wolfond, 'The Mismeasure of Autism: The Basis for Current Autism 'Advocacy'', Keynote address at AutCom conference in Edmonton, Canada October 13, 2007, reported in 'Exploring The Social Model: Accessibility', *Shift Journal of Alternatives: Neurodiversity and social change*, 2 August 2010, accessed online at <http://www.shiftjournal.com/2010/08/02/exploring-the-social-model-accessibility/>.

⁸² Ibid.

⁸³ See Footnotes 93-95 and 102 of Chapter 1 of this thesis.

Certain activists have commented that “obedient autistic people get condescending praise like beloved pets, while the same autistics standing up for ourselves get treated like rabid wild animals masquerading as housecats.”⁸⁴ British autistic rights activist Larry Arnold is quoted as saying “I am not a tame, house trained autistic, I am the feral kind. I am a wolf, not a sheep dog.”⁸⁵ However, such conditioning therapy continues till this very day, as is the case with the widely-publicised use of electric shock therapy for autism at the Judge Rotenberg Educational Center in Massachusetts.⁸⁶

Dawson further insists that while most researchers are trying to determine how autistic brains are broken, it would be more useful to try and determine instead how autistic brains worked.⁸⁷ The main problem of parents relying on such therapies is, according to such activists, that they blame their children's difference for the cruelty that other people show to people who are different, thereby shifting the responsibility for their actions off intolerant people and onto autism.⁸⁸ This point was made in response to an open letter sent to the New York Times by Kit Weintraub,⁸⁹ a 'pro-cure' mother of an autistic child, in response to an article by Dawson criticising ABA for autism, reference to which was made earlier.⁹⁰

The main argument at stake can be seen to be that such persons are a minority who are admittedly quite different from what is considered to be contemporary social norms. However, without particular hindrances, and given the right environment to flourish in, these persons could also function with a high degree of independence, and regale society with a very valuable contribution derived from their very particular gifts. Here, one could mention the ability of markedly increased perceptual functioning found in individuals having Asperger Syndrome, when compared to their 'neurotypical' peers.⁹¹

⁸⁴ Said activists, names not listed specifically, authored ‘In Support of Michelle Dawson and Her Work’, published in the Autism Information Library at autistics.org, available online at <http://www.autistics.org/library/dawson.html>.

⁸⁵ Ibid.

⁸⁶ Emily Friedman, ‘Electric Shocks Can Continue at Mass. School After Hoax’, abc News online portal, Health section, 24 December 2007, accessed online at <http://abcnews.go.com/Health/story?id=4022502&page=1>.

⁸⁷ Roger Collier, ‘Autism Reconsidered’, *The Ottawa Citizen*, 1 December 2007, accessed online at <http://www.rogercollier.net/clipping.feature.28.autism.reconsidered.html>.

⁸⁸ ‘In Support of Michelle Dawson and Her Work’, op. cit.

⁸⁹ Letter to the New York Times from Kit Weintraub, Date Not Available, quoted in *The Schafer Autism Report*, accessed online at <http://www.sarnet.org/ltr/weintraub1-05.htm>.

⁹⁰ Michelle Dawson, ‘The Misbehavior of Behaviorists’, op. cit.

⁹¹ Virginia Bovell, ‘We don't need to wipe out autism... we need to care more’, published in *Daily Mail*

Many persons have the impression of a person labelled as 'mentally disabled', as conforming to the stereotype illustrated by the example of the character of Charlie Babbitt in the film 'Rain Man', mentioned in Section 1.1.2.1 of this thesis. While such persons are viewed by these sections of society as falling either within the category of madness, or else that of retardation (while at times not even knowing the exact meaning of terms such as these), few persons know that some of the most prominent persons in contemporary society, such as Steven Spielberg, actually have what society still at times terms a 'mental disability'.⁹²

However, many such persons do not speak about it due to the taboo connected with it. And many have overcome and adapted to 'normal' life on their own steam and with much suffering, not having the luxury of finding more inclusive institutions to also serve their needs in the societies they lived in.

3.3.3 *Reality Nowadays and Need for Middle Ground*

The reality is that the situation with these therapies has changed substantially nowadays, with many countries banning aggressive, especially physical, elements to therapies, such as restraints, seclusion and electric shocks. This is the case particularly in those states bound by the provisions in the CRPD, having ratified such document.

And where such practices are still legal, there are usually reviews in place in order to curtail or ban such practices altogether, such as with the 2016 FDA review into electro-shock practices in the United States. The stated purpose of such therapies is also being challenged, as with the situation of President Obama calling for an end to the use of such therapies for the purposes of 'gay conversion' within the United States.⁹³ His words emphasised the

online edition at <http://www.dailymail.co.uk/news/article-391318/We-dont-need-wipe-autism--need-care-more.html>, last updated on 19 June 2006.

⁹² 'AUTISM and other geniuses', from *blog by Hilde K*, 23 July 2006, available online at http://blog.360.yahoo.com/blog-TNE7dZ82fqjkcXBpSWNFIR0s_m5j1YRK?p=1315.

⁹³ Michael D. Shear, 'Obama Calls for End to 'Conversion' Therapies for Gay and Transgender', *The New York Times Online Edition*, 8 April 2015, accessed online at http://www.nytimes.com/2015/04/09/us/politics/obama-to-call-for-end-to-conversion-therapies-for-gay-and-transgender-youth.html?_r=0.

conclusions of a relevant government report,⁹⁴ and have already started to be heeded at state level.⁹⁵

Still, the system of aversion, reward and punishment, and extinguishment and reconditioning, is unfortunately still the ethos of the way certain autism interventions and therapies are applied. The only difference in such cases, nowadays, is the substitution of physical elements for more psychologically-based ones.

There is minimisation of the extent of restraint and seclusions, restriction of punishment to time-outs, and implementation of the reward component through actual rewards such as a child being able to play with their favourite toy, for example.⁹⁶ However, as long as the mindset behind what the therapy is attempting to tackle, and the desired outcomes of said therapy, remain the same, then the therapy itself remains just as harmful.

Autistic activists campaign against therapies being abusive. But they also campaign about autistic identity, and about the fact that such therapies strip a person of their identity, and ignore a person's communication needs. Instead, they try to replace them with a different system alien to the person's innate system.

This can be seen to similarly mirror the way in which France or the United Kingdom harshly enforced a system of linguistic assimilation, imposing physical punishments and pecuniary sanctions on persons speaking their native vernaculars rather than French and English. The relevant comparison can be drawn as to the reinforcing a system in both cases, in which persons were only safe, or even rewarded, if they spoke and used the right languages in their everyday lives.

⁹⁴ *Ending Conversion Therapy: Supporting and Affirming LGBTQ Youth*, Substance Abuse and Mental Health Services Administration (SAMHSA), Washington, DC, October 2015, accessed online at <http://store.samhsa.gov/shin/content//SMA15-4928/SMA15-4928.pdf>.

⁹⁵ As reported in Aditya Agrawal, 'Illinois Bans Gay Conversion Therapy for Minors', *Time Magazine Online*, 21 August 2015, accessed online at <http://time.com/4006675/illinois-bans-gay-conversion-therapy-on-minors/>.

⁹⁶ See, for example, Fereshteh Mohammadzaheri, Lynn Kern Koegel, Mohammad Rezaee and Seyed Majid Rafiee, A Randomized Clinical Trial Comparison Between Pivotal Response Treatment (PRT) and Structured Applied Behavior Analysis (ABA) Intervention for Children with Autism, *Journal of Autism and Developmental Disorders*, Vol. 44, Issue 11, November 2014, at 2769; Chloe Lambert, 'Is it right to try to 'normalise' autism?', *Special Education Needs, The Guardian*, 29 October 2013, accessed online at <https://www.theguardian.com/education/2013/oct/29/specialeducationneeds-autism>.

The problem remains, in such cases, that there are also a number of coping skills and life skills which could be learnt through properly-administered therapies.⁹⁷ Rejecting any form of therapy or intervention in its totality, due to the abusive record, in every sense, of past therapies and practitioners, going by well-founded fears, is simply going to allow certain challenges a person might feel in life to go unaddressed.

This too can lead to frustration in not being able to communicate a person's needs, and increase in a person's anxiety and damage to their emotional and/ or psychological state of well-being, the same root cause mentioned earlier when discussing behaviours.⁹⁸

A person, while retaining their identity and primary communication style, might also need to learn alternative communication styles to be used with different persons in different situations. This while affirming that it would be equally ideal for other persons to also be aware and accepting of the other person's communication style and identity, whichever style or mixture of styles is used in the actual interactions.⁹⁹

This would take shape much in the same way as a Frenchman and an Englishman would have a French or an English identity, and use French or English as their mother tongues. However, knowledge of the other tongue and culture would be invaluable for any kind of interactions with persons from the other country, or in the other country, whether such interactions are conducted in French, English, a mixture of both, or a mixture of various elements.

As described earlier in this thesis at Section 2.4, any form of intervention or therapy, be it early or otherwise, rather than being an exercise in Pavlovian conditioning, should have the main focus of treating the therapy subject as a person.

⁹⁷ See, for example, James Gallagher, 'Super-parenting' improves children's autism', *BBC News Online*, 26 October 2016, accessed online at <http://www.bbc.com/news/health-37729095?SThisFB>; Conversations with Monique Blakemore, autistic self-advocate and mother of 3 autistic children, as further detailed later at Footnote 116.

⁹⁸ Conversations with Monique Blakemore, Founder of Autism Women Matters, Brussels, March 2016.

⁹⁹ See Footnote 116 of this Chapter for further clarification in this regard. This point was equally emphasised by Deborah Pugh, Director of ACT (Autism Community Training) Canada, Burnaby (BC), during an Interview conducted on May 2011.

A person, with their own individuality, and building around the person's personality, strengths and weaknesses, devising a method in order to bring out the best in that person, while addressing the challenges that particular person faces. This while also teaching the person 'different languages' in order to be able to bridge the gap in social situations that require this.

While it is important for social change to occur as a parallel process to this, such as through the exhortation in Maltese law to diffuse both autism awareness and acceptance in society,¹⁰⁰ any individual therapies must be person-centred. Additionally, they should also bring in the person's family, educators and closest peers to be part of the process if possible.¹⁰¹

The therapy should not be about society's or other persons' needs exclusively, as with the strict Lovaas method. Rather, it should be about the other person's needs, twinned with the realities and needs of the person's inner circle, but with such needs being addressed simply as part of the social interlinking the person would have to live in every day. This should be the main goal of therapy, rather than society's or other persons' needs taking priority or precedence over the person's fundamental needs in said therapy.

Such methods would include occupational therapy, any properly-applied form of behavioural therapy, such as Cognitive Behavioural Therapy (CBT) or Applied Behavioural Analysis (ABA), as well as therapies such as Me2You which involve both the person and the person's inner circle.¹⁰² They would be methods in which the therapy's operating protocols are ideally rigorously scrutinised, and subject to approval for one or more specific areas, as well as follow-up review, by a state regulatory body, against fixed regulatory guidelines.

¹⁰⁰ See Section 11.5.3 of this thesis for a further discussion of this topic and relevant *travaux préparatoires* with respect to legislation.

¹⁰¹ Interview with Monique Blakemore, op. cit.

¹⁰² Ibid.

3.3.4 *Legislating for Change: The Current Maltese Scenario*

3.3.4.1 Early Intervention and Therapies – Legislation and Policy

The Maltese Persons within the Autism Spectrum (Empowerment) Act seeks to address the issue of early intervention and therapies, as a key factor within the local and overarching autism debates.¹⁰³ In this regard, the Act as adopted directs the Autism Advisory Council, constituted in terms of said Act,¹⁰⁴ to address the issue of "effective and sustainable intervention programmes".¹⁰⁵

While the language used by the Act in this regard could raise concern, it seemed impossible for the law to be made more specific, especially after interventions during the Second Reading debate of the Bill in Parliament, that exposed a more medicalised view of the topic among certain Parliamentarians.

Having followed the debates in Parliament, one could rightly say that some matters mentioned in this regard were downright horrible,¹⁰⁶ even if coming from a good place, and this simply signals the existing state of play concerning knowledge of the autism sector and the way forward in society.

Hence, there is a heavy responsibility of the Council to address this matter clearly and thoroughly in the Autism State Support Plan that it is tasked by law to draft.¹⁰⁷ However, an amendment was introduced and unanimously approved at Committee Stage,¹⁰⁸ at the behest of the author, as to specifying that the Council address "appropriate" early intervention services.¹⁰⁹

¹⁰³ Author's meeting with Hon. Justyne Caruana, Maltese Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing, within the Ministry for the Family and Social Solidarity, to discuss feedback to the Persons within the Autism Spectrum (Empowerment) Bill, Valletta, April 2016.

¹⁰⁴ Persons within the Autism Spectrum (Empowerment) Act, Cap. 557 of the Laws of Malta, at art. 10(1)(f)(v).

¹⁰⁵ Ibid.

¹⁰⁶ See Minutes of Parliamentary Debates, Second Reading Debates, Persons within the Autism Spectrum (Empowerment) Bill, Bill No. 136 of 2015, 4 April 2016, 19 April 2016, 26 April 2016.

¹⁰⁷ Persons within the Autism Spectrum (Empowerment) Act, op. cit., at art. 10(1)(a).

¹⁰⁸ See Minutes of Debates in the Committee for Consideration of Bills, Persons within the Autism Spectrum (Empowerment) Bill, Bill No. 136 of 2015, House of Representatives, Malta, 3 May 2016

¹⁰⁹ Ibid., at art. 10(2)(d).

The use of the term "evidence-based support"¹¹⁰ was also queried by self-advocates, since many times, in present-day literature, this means ABA, with applications of such able to include unsavoury forms discussed elsewhere in this thesis.¹¹¹ The concern was that, if this were the case, such would betray the concept by putting forward a very wrong understanding of "support", again based in the medical model of autism.

In this regard, the response of the Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing, the Hon. Justyne Caruana, in respect of Article 10(1)(f)(v), discussed further in this Section, is being referred to. Furthermore, both the Parliamentary Secretary and her Chief of Staff also stated and guaranteed that they personally did not support any aggressive therapies that did not fall within these criteria, and that regulation of such therapies would also be considered,¹¹² as discussed further in the Section 3.3.4.

It was also proposed to the Parliamentary Secretary, through feedback obtained from self-advocates, that "early identification and intervention"¹¹³ should further include engagement and involvement of autistic persons, while including support and funding for self-advocacy organisations run by and for autistic persons.

The Parliamentary Secretary's response was that such efforts were covered by the inclusion of "adult support and services" in the Bill, while they were also to be elaborated further in the Autism State Support Plan.¹¹⁴

3.3.4.2 Subsidiary Legislation

It was further discussed with the Parliamentary Secretary, that references to early intervention and intervention programmes, while neutral in wording, should be eventually interpreted as excluding all invasive and abusive therapies.¹¹⁵ Examples of such excluded

¹¹⁰ Ibid., at art. 10 (2)(e).

¹¹¹ See Section 2.4.1 of this thesis.

¹¹² Discussion with Hon. Justyne Caruana, Maltese Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing, within the Ministry for the Family and Social Solidarity, and John Zerafa, Chief of Staff, Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing, Valletta, April 2016.

¹¹³ Persons within the Autism Spectrum (Empowerment) Act, op. cit., at art. 11.

¹¹⁴ Author's meeting with Hon. Justyne Caruana, April 2016, op. cit.

¹¹⁵ Ibid.

practices would be using a particularly therapy such as ABA 'out of the box,' in the same manner for all persons it is offered to.

Concurrently, such subsidiary legislation would also insist that a focus be made on such interventions being person-centred (ie. centred around the child/ adult involved), holistic, and tailored specifically to the situation of the particular needs of the child and the family in question, with necessary changes being applied according to how the situation evolves.¹¹⁶

The author's suggestion to Government, in this regard, was that a specific guidance note about Early Intervention and Intervention Programmes be drawn up, adopted by the Social Affairs Committee of Parliament, and handed down officially as terms of reference to the Advisory Council in terms of the Act, to guide it in its work.

It was later further suggested that such concepts be also codified within a Legal Notice (subsidiary legislation) promulgated under the Act, regulating the matters outlined above.

Whatever the situation, however, no one specific therapy and, in particular, no abusive therapies, would have the exclusive direct support or endorsement from the State, such support or endorsement being given neither at law, nor in policy matters.

Any intervention would have to comply with the requirements of the law and National Disability Policy (and eventual Autism State Plan). Legal requirements would eventually also include the Subsidiary Legislation specifically regulating interventions and practitioners, with final approval for every specific programme having to be signed off for by the Minister, should such subsidiary legislation be promulgated.

¹¹⁶ Ibid., citing Conversations with Monique Blakemore, op. cit., who has three children on the autism spectrum, and was also recently diagnosed herself. Blakemore describing how such a method worked with respect to her children, using elements of the 'More than Words' method, to also teach the parents communication skills in understanding their children. This made the process a two-way one, however, Blakemore's family did not stick to one blueprint, but customised as they went along, and changed elements of the therapy along the way to fit in with the evolution in the children's and the parents' communication styles. This ties in with the arguments laid out in Section 3.3.3 of this thesis.

3.3.4.3 Enabling Participation vs Mandating Normalisation

The author also conveyed feedback from self-advocates to Government,¹¹⁷ as to the point that the term ‘Autism State Support Plan’ in the Bill¹¹⁸ could be conceived as too narrow, further querying as to indications of what kind of support the Bill had in mind.

In this regard, the answer from the Parliamentary Secretary was an unequivocal statement to the effect that the Support in question was support in reaching Empowerment, as per the title of the Act.¹¹⁹

A further clarification in this regard was made concerning the use of the term ‘enable’,¹²⁰ when faced with concern that such could allude to early diagnosis, early intervention, ABA, making children more ‘functional’, and ‘normalisation’. Emphasis was also made, in stating this, that education (and the community) should accept autistic children and adults as they are, not force them to adapt to non-autistic expectations.

The clarification was to the effect that said provision was an open provision. It spoke in terms of the word ‘enable,’ not in terms of the word ‘mandate’. Specific details in this regard were to be laid out in the State Plan, and any therapies around which concerns revolved would anyway be regulated¹²¹ as described in Section 3.3.4 of this thesis.

This comment was also meant to address more specific comments as to ‘enabling participation’ of autistic children in their home, school and locality,¹²² where concerns were raised as to seemingly obvious intentions inferred from the text of the Act, to the effect of encouraging early identification through diagnosis, that would lead to early intervention, in order to make children more ‘functional’ and ‘normalise’ them. Such a situation would result in a completely wrong understanding of "participation," that is based

¹¹⁷ The author drafted and also passed on, after requesting such from a number of self-advocates active in different jurisdictions, a number of proposals concerning such Bill, to the Hon. Justyne Caruana, Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing, within the Ministry for the Family and Social Solidarity, after having secured a meeting with her in April 2016.

¹¹⁸ Persons within the Autism Spectrum (Empowerment) Act, op. cit., at art. 10(1)(a).

¹¹⁹ Author’s meeting with Hon. Justyne Caruana, April 2016, op. cit.

¹²⁰ Persons within the Autism Spectrum (Empowerment) Act, op. cit., at art. 10(1)(f)(ii).

¹²¹ Author’s meeting with Hon. Justyne Caruana, April 2016, op. cit.

¹²² Persons within the Autism Spectrum (Empowerment) Act, op. cit., at art. 10(2)(d).

in a medical understanding of autism, rather than in the social model that underlies the CRPD.

Chapter 4: Wrong Behaviour or Undesirable Behaviour?

4.1 Introduction

The previous Chapters have discussed perceptions concerning autism, in terms of good or bad and right or wrong, emanating from a dominant stance as to what is 'normal' in a dominant/ minority dichotomy. This in line with preserving the status quo and extirpate difference. It has been illustrated that such holds water also in the autism debate, and that if one understands what autism is, such would similarly lead to an understanding of why one would be undertaking certain efforts, such as in the field of 'correctional' behavioural therapy.

Parallels were drawn in the case study on linguistic and ethnic minorities, and having gleaned a similar understanding of the situation, as the countries that moved forward in this field, one could move towards similar parallel paradigm shifts towards awareness, acceptance and inclusion for autism, also mirroring elements of the journey from the medical to social models of disability, discussed in Section 1.1.2 of this thesis, and further at Sections 5.3 and 5.4.

When discussing the situation of LGBTQI persons, a similar framework can be observed, as to a similar presence of a dominant/ minority dichotomy of social groups, a strong featuring of the status quo element, and the 'right or wrong' issue at the heart of the debate. There was also, similarly, a need for understanding core concepts, in order for necessary rapprochement to start happening, and for change to eventually start to be implemented. There is also a specific similarity to the situation with autism, in that the same 'correctional' therapies, in terms of misguided rationale and methodologies, were in the past and are still, in certain cases, being used on LGBTQI persons, and in particular strains of such therapies so applied based on the Lovaas method.

The situation and journey of LGBTQI persons bears many similarities to that of autistic persons, and while a transformation in this field is currently 'on the up', still, major issues concerning rights are nonetheless present. Furthermore, although here the issue was more one of 'right or wrong' rather than of 'good or bad', the 'take home' point is about giving in to society's collective prejudices, rather than looking at the actual facts on the ground.

This can be seen through a shift from public morality to constitutional morality that occurred in certain jurisdictions in this field, illustrated through a number of transformative cases in such jurisdictions.

4.2 Social Views: From Gender Deviance to Gender Diversity

Perhaps the strongest 'anti-cure' movement ever to make headlines was the LGBTQI rights, or 'gay rights' movement.

While in Europe and North America, such rights are afforded protection by the statute book, as well as by the courts to varying extents, in certain other parts of the world, homosexual acts are still classified as crimes, sometimes also punishable with the death penalty. Even the terminology used reflects the position in these countries, with their statute books using terms such as 'the abominable act of buggery'.¹

This rights movement started off against a backdrop of laws prohibiting 'unnatural carnal connection', and a mental health community pushing methods such as 'conversion therapies', described earlier in this thesis,² and aimed at delving into the minds of homosexual persons and making them realize what was wrong with their actions and perceptions. The main drive behind the gay rights movement, however, was the belief among LGBTQI persons that they were 'normal' too.

They had different sexual preferences, made the choice of a different lifestyle, and this was the only thing separating them from mainstream society. These persons insisted, though, that this was not a mere matter of choice, but rather, a reflection of their identity and of their personhood.

LGBTQI persons were capable of replicating the capabilities of a similarly-trained or skilled heterosexual counterpart in the workforce, were just as willing and able to serve in the military, could lead independent lives without the need of further assistance, and as an

¹ See, for example, the Jamaican Offences Against the Person Act (Cap. 269), at s.76: "**Unnatural Offences.** Whosoever shall be convicted of the abominable crime of buggery, committed either with mankind or with any animal, shall be liable to be imprisoned and kept to hard labour for a term not exceeding ten years."

² See, for example, Footnotes 49 and 57 of Chapter 3 of this thesis.

end result did not prove to be a burden on society at large.

In the European Union, for example, one nowadays finds provisions in the Treaties prohibiting discrimination on such grounds,³ as well as similar provisions in secondary legislation.⁴ At the same time a multitude of judgements of the European Court of Human Rights have widened the scope of rights under the European Convention on Human Rights, addressing issues such as unfair dismissal, including from the military⁵ tenancy rights,⁶ and more recently, possibly, also the right to a family life.⁷

The whole aim of the laws mentioned, as well as the 'conversion therapies' in question, all stemmed from the issue of public morality, a very vague and flexible concept. This is the concept with which the main comparison shall be carried out in this section, vis-à-vis the autism rights movement.

Public morality defined homosexual persons as sick, and their resulting way of life as wrong, with a resulting need of these persons to be cured, and their lifestyle abandoned and sanctioned accordingly.

³ Article 10 of the Treaty on the Functioning of the European Union foresees that the Commission shall aim to combat discrimination when defining and implementing any of its policies and activities – further to this, the Commission has defined a List of Actions to Advance LGBTI Equality, accessed online at http://ec.europa.eu/justice/discrimination/files/lgbti_actionlist_en.pdf. Furthermore, the Charter of Fundamental Rights, applicable to all Member States in virtue of the adoption of the Treaty of Lisbon (saving opt-outs granted to Poland and the United Kingdom), explicitly prohibits discrimination based on sexual orientation in Article 21.

⁴ Protection in this regard is through the implementation of Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation, L303 02.12.2000 pp. 16-22 (hereinafter the 'Framework Equality Directive'), by the different Member States, the ground of 'sexual orientation' being mentioned as one of the grounds covering the Directive's purpose in Article 1.

⁵ In *Jeanette Smith and Graeme Grady v. the United Kingdom*, Application No. 33985/96, judgement 27 September 1999, (1999) 29 EHRR 493, applicants succeeded in their case against the British government, having their dismissal from the RAF on the grounds of their homosexual orientation declared as being in violation of Article 8 ECHR.

⁶ In *Siegmund Karner v Austria*, Application No. 40016/98, judgement 24 July 2003, (2004) 38 EHRR 24, the ECtHR confirmed the right of applicant to succeed to the statutory tenancy of his deceased gay partner, finding that the Austrian state had violated Article 14 in conjunction with Article 8 of the ECHR in not allowing this.

⁷ In *E.B. v. France*, Application No. 43546/02, judgement 22 January 2008, (2008) 47 EHRR 21., the ECtHR confirmed that the French state discriminated against applicant on the ground of her sexual orientation, in refusing to allow her to become an adoptive parent, finding a violation of Article 14 in conjunction with Article 8 ECHR, and overturning an earlier ruling to the contrary in *Philippe Fretté v France*, Application No. 36515/97, judgement 26 February 2002, (2002) 38 EHRR 21.

In the same way, present-day society still largely views autism, classified as a disability, and also a source of identity for many, in pathological terms, and the behavioural expression of autism as wrong – failing, many times, to separate autism from its comorbidities – and pursuing a resulting need find a cure for autism, with the way autistic persons interact with the world needing to be rendered ‘indistinguishable’ from the norm, and infractions of such being sanctioned accordingly.

Views as regards the concept of public morality, with regard to LGBTQI persons have, however, changed over time. While in the past the government was supposed to reflect the will of society in that its members refrained from 'acts abhorrent to God and man',⁸ a concept reinforced by the fact that many states were officially not secular, the consensus has now shifted.

By way of comparison, one could talk of the advent of autism rights in Israel, that could seem to have been the product of social compromise on the surface with, however, many uncomfortable undertones lying beneath it. Disability policy in the jurisdiction has come a long way, with relevant institutions such as the Office of the Commissioner of Disabled Persons having been set up by statute during the last few years.⁹

Nevertheless, a recent article in an Israeli daily newspaper of record still refers to disability rights today as being in the place that LGBTQI rights were at 20 years prior.¹⁰ Going by the still-rampant homophobia present in Israeli society till this very day, such comments provide much food for thought at the very least.¹¹

Shifting back to a more global view, the denial of rights, and with it the denial of identity and personhood that LGBTQI persons faced, was not due to something intrinsically wrong with them, or to something intrinsically wrong that they were doing. It was due to society

⁸ Russian Supreme Mufti Talgat Tajuddin, calling for the banning of Moscow Gay Pride 2006, as quoted in 'Russian Muslim Leader Calls for Gays to be "Thrashed"', *ukgaynews.org.uk*, 15 February 2005, accessed online at <http://www.ukgaynews.org.uk/archive/2006feb/1503.htm>

⁹ By virtue of the Equal Rights for Persons with Disabilities Law, 1998, as subsequently amended.

¹⁰ Ron Kampeas, 'Disabilities rights are where gays were 20 years ago, says activist', *Times of Israel*, 7 February 2015, accessed online at <http://www.timesofisrael.com/disabilities-rights-are-where-gays-were-20-years-ago-says-activist/>.

¹¹ See, for example, Marissa Newman, 'Day after marking LGBT rights, Knesset nixes 5 gender equality bills', *Times of Israel*, 24 February 2016, accessed online at <http://www.timesofisrael.com/day-after-marking-lgbt-rights-knesset-nixes-5-gender-equality-bills/>.

deciding to see them as not being 'normal,' and to take issue with their gender identity, gender expression and related choices. Thus, it was committing to target such persons in order to 'cure' or 'normalise' them, linking this with a hate-filled campaign tinged with prejudice in the meanwhile.

As regards the element of cure, society was trying to cure something that just 'stood out', but that did not impair its everyday functioning and, most importantly, was not an issue to the people it affected, the LGBTQI community. Rather, it was only an issue to the rest of mainstream society. So as long as the LGBTQI community felt fine with being gay, and as long as society was not being affected in any negative way, then campaigning against a 'cure' was indeed the most logical thing to do.

It was only with changing social mores, that social attitudes towards LGBTQI persons shifted, and consequently the access to rights of these persons shifted. One could see this as being simply an issue that whatever one does in their own private life, or one could even say in their own bedroom, is one's own business, and should not be subject to public scrutiny.

This position was enunciated by the European Court of Human Rights in the *Dudgeon v. the United Kingdom* judgement.¹² However, although privacy and individual choices are a first layer in such processes, as will be seen in the case of *Lawrence v. Texas* and its aftermath, it is only a first layer, leading to a wider recognition of a person's rights in connection with identity and personhood.

The journey and relevant debate around this shift will be analysed in this chapter, in order that parallels could also be drawn with the journey being undertaken by the disabled and autistic communities, both at present and in future.

¹² *Jeffrey Dudgeon v. the United Kingdom*, Application No. 7525/76, judgement 22 October 1981, (1982) 4 EHRR 149. In this case, the European Court of Human Rights declared s.11 of the Criminal Law Amendment Act 1885 as applicable to Northern Ireland, criminalising male homosexual acts, to be in violation of Article 8 of the European Convention on Human Rights, protecting the right to one's private and family life.

4.3 *The Decriminalisation of Sodomy – Hart-Devlin Redux*

Awareness in the field of LGBTQI rights started primarily in the United States, through the Stonewall movement, forming part of the broader civil rights movement of the period.¹³

This also led to debate in other countries regarding the revision of legal treatment of LGBTQI persons and homosexual acts, one of the most notable being the Wolfenden Commission set up by the UK Parliament in the 1950s, tasked with considering the decriminalisation of the common law crime of sodomy.

The contributions by Patrick Lord Devlin and H.L.A. Hart in this regard are often referred to as the ‘Hart-Devlin Redux’, and have influenced both legislators and courts in their decisions on the matter, as will be outlined.

The Commission chaired by Lord Wolfenden aimed at considering the decriminalisation of the common law crime of sodomy. The Committee authored the Wolfenden Report, release in 1957, recommending the decriminalisation of “homosexual behaviour between consenting adults in private.”¹⁴

4.3.1 *The Actual Debate*

Devlin argued against the decriminalisation of sodomy in the United Kingdom, this being an expression of his view that criminal punishments that reflected the public temperament were essential as a cohesive force in society.¹⁵ Discussing the topic of homosexuality at the time, he further stated that, if society found such a behaviour to be extremely offensive, then it should have the right to treat the matter as a crime, with the ultimate goal of seeking its eradication – or else, he opined, risk the very survival of that society.¹⁶

Ronald Dworkin states that it was such criminal punishment enforcing public attitudes that, Devlin argued, was an essential coherent force, such coherence being linked to preventing

¹³ Ibid.

¹⁴ *Report of the Departmental Committee on Homosexual Offences and Prostitution*, London, 4 September 1967.

¹⁵ Ronald M. Dworkin, ‘Lord Devlin and the Enforcement of Morals’, *Yale Law Journal*, Vol. 75, 1965-1966, at 986, 986-987.

¹⁶ Ibid.

the disintegration of a society.¹⁷ Commenting on the topic, Meyerson insists that Devlin, as can be clearly seen, is not an objectivist about morality. He wishes to translate not *reasoned judgements* about morality into law, but rather *gut feelings* of indignation, intolerance and disgust.¹⁸

The argument Devlin makes, therefore, is not that a certain behaviour or mode of action is wrong *per se* but, rather, that society *thinks* that specific behaviour or mode of action is wrong. This would be the litmus test based on which that behaviour or mode of action, as with the common law crime of sodomy at the time of Devlin's observations, could be criminalised.

Turning then to same-sex relations, he continues: "I do not think there is anyone who asserts vocally that homosexuality is a good way of life."¹⁹ Although Burt states that such a proposition would be utterly implausible today, it would not have been back in 1965, when these words were written by Devlin.²⁰

This would be the same basis to, for example, criminalise any related acts, such as advocacy by the LGBTQI community, an argument which could be made in a more current context, in light of the Parliament of the Russian Federation passing a law criminalising the 'propagation of non-traditional relationships' to minors in 2014.²¹

Hart, on the other hand, took the viewpoint that Devlin was saying that the rightfulness or wrongfulness of societal morality was irrelevant, and that the critical point was rather that society enforce its prevailing morality, failing which that specific society would disintegrate.²²

¹⁷ Ibid.

¹⁸ Denise Meyerson, *Understanding Jurisprudence*, Routledge-Cavendish, Oxford/ New York, 2007, at 140.

¹⁹ Devlin, *op. cit.*, at 116.

²⁰ Robert A. Burt, 'Moral Offenses and Same Sex Relations: Revisiting The Hart-Devlin Debate', Faculty Scholarship Series, Paper 711, 2004, at 9.

²¹ Federal Law No. 135-FZ of 2013, on Amendments to Article 5 of the Federal Law "On the Protection of Children from Information Harmful to their Health and Development", and Miscellaneous Legislative Acts of the Russian Federation for the Purpose of Protecting Children from Information that Promotes the Rejection of Traditional Family Values, accessed at: <http://www.refworld.org/docid/5492c81c4.html>.

²² HLA Hart, 'Social Solidarity and the Enforcement of Morality', *University of Chicago Law Review*, Vol. 35, Issue 1, Article 2, 1967, at 1, 1.

Furthermore, he questioned the disintegration thesis put forward by Devlin.²³ Hart rather opted for the classical thesis rooted in the works of Plato and Aristotle, to the effect that, in terms of morals, law should be used to promote an idealised morality, rather than enforce an existing perceived one.²⁴

More specifically, Hart squarely questioned whether what would essentially be nothing more than a failure to convert popular prejudices into criminal law would jeopardise the fabric of society²⁵ – the element of prejudice in this argument being treated as paramount in certain jurisdictions, when piloting a shift from public morality to constitutional morality in evaluating social behaviour, as discussed further in Section 4.7 of this thesis.

For Hart, the central question was as follows: “Can anything or nothing be said to support the claim that ... the maintenance of the moral status quo in a society’s morality are values sufficient to offset the cost in human misery which legal enforcement entails?”²⁶

In line with Meyerson’s comment about Devlin’s reliance on society’s ‘gut feelings’ in drawing his conclusions, Hart further argues that when we bear in mind ‘all the misery which criminal punishment entails,’²⁷ there is no justification for turning feelings of this kind into criminal law without subjecting them to critical scrutiny.²⁸

4.3.2 *Redux – Then and Now*

The views espoused by these two men could be said to lead to an almost contradictory situation. One might argue that, if Devlin’s theories were to be applied to British society today, Devlin, seen as one of the proponents of retaining the common law crime of sodomy, would be the first to argue to have it abolished. This could be said to be in line with his reasoning, whatever views he might have held about the nature of the impugned offence itself.

²³ HLA Hart, ‘Immorality and Treason’, in Ronald Dworkin (ed.), *The Philosophy of Law*, Oxford University Press, Oxford, 1977, at 83-85.

²⁴ Hart, ‘Social Solidarity and the Enforcement of Morality’, op. cit., at 1.

²⁵ Ibid.

²⁶ HLA Hart, *Law, Liberty and Morality*, Stanford Univ. Press, Stanford, 1963, at 45.

²⁷ Hart, ‘The Immorality of Treason’, in Dworkin (ed.), op. cit., at 84.

²⁸ Ibid., at 87.

Hart, as opposed to Devlin, argued that society might indeed think that a certain behaviour or mode of action is wrong. However, this would be no basis for enacting such social views into law, even if an overwhelming majority of the society in question felt in this manner about the behaviour or mode of action in question. In explaining Hart's views, Plauché gives the example of vice which, while to be avoided, would not in Hart's views warrant the violation of an individual's rights.²⁹

Rather, if one were truly concerned about the deleterious effects of vice on someone and on the rest of society, then one ought to start by setting a good example in this regard. Then one would perhaps seek peacefully to persuade the other of the error of his ways; this being, in line with Hart's thinking, the only moral way to lead another to virtue.³⁰

4.3.3 *Analogous Scenarios*

A similar situation could be outlined as to the older crime of high treason, not to mention that of treason itself, as enunciated by both common law and statute in the United Kingdom up till the post-Second World War period. This reflected the values that were considered acceptable at a different age, but which were subsequently varied by both Parliament and the Courts, reflecting the shifts in social mores of British society.³¹

The traitor or the LGBTQI activist was nothing more, in Devlin's world view, than a dissenter harming the body politic. However, Devlin's reliance on social mores as the

²⁹ Geoffrey Alan Plauché, 'Moral Legislation and Democracy: The Devlin-Hart-Dworkin Debate Revisited', paper delivered at the 2006 Annual Meeting of the American Political Science Association, August 31-September 3, 2006, at 21.

³⁰ Ibid.

³¹ The UK Treason Act of 1351, 25 Edw 3 St 5 c 2, at s. II, declared it treasonous to engage in sexual intercourse with "the King's companion, or the King's eldest daughter unmarried, or the wife of the King's eldest son and heir." Such a provision has since been repealed, and would be considered unthinkable in this day and age.

William Blackstone, in *Commentaries on the Laws of England*, Sweet, Pheney, Maxwell & Stevens, London, 1829, at 80, stated that "the plain intention of this law is to guard the Blood Royal from any suspicion of bastardy, whereby the succession to the Crown might be rendered dubious."

However, such was still an offence on the statute books up till the 1990s, with British tabloid *The Mirror* attempting to have the statute enforced against James Hewitt, with whom Diana, Princess of Wales, who at the time had been wife of the heir to the throne, had admitted to having an affair, as carried in 'Editor defends Mirror over Diana letters', *BBC News*, 31 August 2000, accessed at http://news.bbc.co.uk/2/hi/uk_news/905239.stm.

litmus test for criminalising or otherwise allowing or tolerating certain modes of action gives rise to a peculiar situation.

Devlin argued for values over emotions, but also that values resulting from a deep antipathy to a particular behaviour or mode of action were sufficient for a particular society to criminalise such, in line with his argument for retaining the common law crime of sodomy back in the 1950s.

However, notwithstanding Devlin's beliefs concerning the intrinsic crime impugned, in line with his theory, Devlin could be the first person expected to come forward in favour of decriminalising the common law crime of sodomy, had it still been part of the legal system of the different jurisdictions within the UK today.

Consequently, he would also be a vociferous proponent of legislating in favour of LGBTQI rights, and controversial topics such as same-sex marriage and adoption, to a certain extent.

4.3.4 *But Do All Roads Lead to Rome?*

In discussing Hart's theories, Burt insists that social mores would have also played a part in interpreting his theories in the present day. Hart had insisted on weighing the 'public nuisance' caused by a particular act, against the 'human misery' its banning would bring about.³² Still, Hart's dicta, in Burt's view, conceal a lack of deeper understanding that the "rejection of [sodomy] laws must necessarily lead to validation of same-sex marriages."³³

The 'human misery' on the part of the spouses would outweigh 'public nuisance,' in terms of the spouses' constitutional guarantees to 'liberty' and 'equality,' thus leading the Massachusetts Supreme Court to rule in favour of same-sex marriage in *Goodridge v. Department of Public Health*.³⁴ This still in a climate where the 'public nuisance' factor

³² Ibid., at 12.

³³ Burt, op. cit., at 7.

³⁴ *Hillary Goodridge, Julie Goodridge, David Wilson, Robert Compton, Michael Horgan, Edward Balmelli, Maureen Brodoff, Ellen Wade, Gary Chalmers, Richard Linnell, Heidi Norton, Gina Smith, Gloria Bailey, and Linda Davies v. Department of Public Health and Commissioner of Public Health*, Massachusetts Supreme Judicial Court, per Marshall CJ joined by Ireland and Cowin JJ, Greaney J concurring, Spina, Sosman and Cordy JJ dissenting, 18 November 2003, 440 Mass. 309, 798 N.E.2d 941 (2003).

was still strong enough to push the Defense of Marriage Act (DOMA) Bill³⁵ through Congress, and all the way to the US Supreme Court, where it was struck down by an extremely slim majority of 5-4.

In conclusion, one could argue, in such a scenario, that Devlin would become the 'subversive standing against liberal society', in light of changed social mores, should he be the one to stand up and oppose such rights in the new changed social context.

On the other hand, the theories of authors such as Hart and Mill³⁶ would see no re-interpretation in this changed social scenario, since rather than being rooted in social mores, and consequent shifts in such, they are rooted instead in the immutable, unwavering principle of individual rights. And as long as Hart's test of 'no harm to other parties'³⁷ is fulfilled, then any behaviour or mode of action would not be criminalised, the only change in such a situation happening should such behaviour or mode of action, or any part of such, evolve in any and such way as to breach the principle so espoused by Hart.

Hart-Devlin redux would also have an impact for jurisdictions outside those contained within the UK. Certain other jurisdictions, particularly African jurisdictions under study later in this chapter, would quote this reasoning, also espoused in the seminal *Bowers v. Hardwick*³⁸ case in the United States, in order to justify retaining the common law crime of sodomy within their jurisdictions. Similarly, they would also use such an approach as a basis for rejecting any discrimination or other human rights violation claims using such ground.

It will then look at how this reasoning was side-lined in favour of an approach more resembling Hart's, in transformative judicial exercises in the United States, South Africa and India.

³⁵ H.R. 3396 (104th).

³⁶ John Stuart Mill, 'On Liberty', Longman, London, 1869.

³⁷ Hart's views echo those of Mill, who much earlier had opined, in his essay 'On Liberty', op. cit., at 72, that a certain behaviour or mode of action cannot be criminalised, unless such hurts another person, with Mill writing that "the only purpose for which power can be rightfully exercised over any members of a civilized community, against his will, is to prevent harm to others."

³⁸ *Michael J. Bowers, Attorney General of Georgia v. Michael Hardwick, et al.*, Supreme Court of the United States of America, per White J joined by Burger CJ, Powell, Rehnquist and O' Connor JJ, Burger CJ and Powell J concurring, Blackmun J joined by Brennan, Marshall and Stevens JJ dissenting, Stevens J joined by Brennan and Marshall JJ, dissenting, 30 June 1986, 478 U.S. 186 (1986) (hereinafter '*Bowers v. Hardwick*').

4.4 Sodomy in Court – *Bowers v. Hardwick*

Although not yet ruling sodomy statutes unconstitutional, this judgement and, especially its dissenting opinions, were enough to make waves within the United States and elsewhere, especially in line of the arguments just tackled in this thesis. Bowers did, however, lay the ground for what was to come later, especially with the Supreme Court's eventual ruling in *Lawrence*.

Allison Jernow states that the decision therein can be seen as Hart-Devlin redux,³⁹ with on the one hand, the notion of law as an extension of morality, and that it may be used to criminalise what is morally condemned, and on the other, the notion of the autonomous self, protected from interference by the State, so long as both the activity and the location are essentially private.

In this regard, Blackmun J stated in a joint dissenting opinion that "[t]he concept of privacy embodies the 'moral fact that a person belongs to himself and not others nor to society as a whole,'" ⁴⁰ This resonated with Hart's reasoning, to the effect that the failure to punish 'some private sexual practice' would not cause society's downfall.⁴¹

This stands in contrast to White J, who did not argue that homosexuality was harmful and could be banned on that basis, arguing rather that a society could choose to criminalise conduct solely on the basis of morality.

In this regard, he stated, in delivering judgement, that:

"Even if the conduct at issue here is not a fundamental right, respondent asserts that there must be a rational basis for the law and that there is none in this case other than the presumed belief of a majority of the electorate in Georgia that homosexual sodomy is immoral and unacceptable. This is said to be an inadequate rationale to support the law. The law, however, is constantly based on notions of morality, and if all laws

³⁹ Allison Jernow, 'Morality Tales in Comparative Jurisprudence: What the Law Says About Sex', *Amsterdam Law Forum*, Vol. 3, No. 2, 2011, at 4, 4.

⁴⁰ *Bowers v. Hardwick*, Joint Dissenting Opinion per Blackmun J et., at 204.

⁴¹ Jernow, op. cit., at 11.

representing essentially moral choices are to be invalidated under the Due Process Clause, the courts will be very busy indeed."⁴²

Discussing the same topic, Burt also states that the Supreme Court's refusal to overturn Georgia's sodomy law in this instance "clearly rested on the same underlying assumptions about the unquestionable moral wrongfulness of same-sex relations that Devlin assumed in his statement that literally no one 'asserts vocally that homosexuality is a good way of life.'"⁴³

4.5 Drawing Parallels: Africa

The same issues were tackled, albeit much later, by the Supreme Court of Zimbabwe and the Court of Appeals of Botswana, both reaching conclusions similar to those in *Bowers* in their analyses of constitutional challenges to the sodomy laws in those countries, both opinions relying heavily on legal moralism.

This was the case even though appellants in both cases asserted claims based on constitutional non-discrimination and equality provisions, rather than privacy. However, in both instances, the issue of traditional morality as a sufficient justification was squarely confronted, according to Jernow.⁴⁴

While countries such as the United States are moving forward and liberalising the state of play for LGBTQI individuals, countries such as Nigeria, within the same timeframe, are moving instead in the totally opposite direction, the Nigerian Parliament having voted in favour of the Same-Sex (Prohibition) Act⁴⁵ as late as 2013, toughening the stance taken by the eponymous Act of 2006.⁴⁶

In the United States, however, charges for crimes against humanity were filed in 2012⁴⁷

⁴² *Bowers v. Hardwick*, op. cit., at 196.

⁴³ Burt, op. cit., at 24.

⁴⁴ Ibid.

⁴⁵ An Act to Prohibit a Marriage Contract or Civil Union entered into Between Persons of Same Sex, Solemnization of Same; and for Related Matters, also known as the Same-Sex (Prohibition) Act 2013.

⁴⁶ Act to Make Provisions for the Prohibition of Relationship Between Persons of the Same Sex, Celebration of Marriage by Them, and for Other Matters Connected Therewith, also known as the Same Sex (Prohibition) Act 2006.

⁴⁷ *Sexual Minorities Uganda v. Scott Lively*, United States District Court, District of Massachusetts, 1st

against a pastor who assisted the Ugandan government in passing its Anti-Homosexuality Act,⁴⁸ colloquially referred to as the ‘Kill the Gays’ law, due to its homophobic content and punitive nature. Having failed over the past few years to successfully have the case dropped on jurisdictional courts, domestic US courts will now proceed to try the charges brought against him.

This scenario serves to highlight the difference in social mores between Africa, more specifically Uganda, where the pastor’s views were not only shared, but openly welcomed and requested – and his home country, the United States, which on the opposite hand, far from took kindly to his efforts abroad, and the views propagated during such.

4.5.1 Zimbabwe

In *Banana v. State*,⁴⁹ a 4-2 majority of the Zimbabwean Supreme Court held that the

Circuit, 12-30051 (matter currently *sub judice*).

⁴⁸ Anti-Homosexuality Act, 2014. The Act was subsequently invalidated by the Constitutional Court of Uganda in *Prof. J Oloka-Onyango, Hon. Fox Odoi-Oywelowo, Andrew M. Mwenda, Prof. Moris Ogenga-Latigo, Dr. Paul Nsubega-Semugoma, Jacqueline Kasha Nabagesera, Julian Pepe Onziema, Frank Mugisha, Human Rights Awareness & Promotion Forum (HRAPF), Centre for Health Human Rights & Development (CEHURD) v. Attorney General*, per Kavuma A.DCJ and Nshimye, Mwangusya, Opio and Bossa JJ.A, Constitutional Petition No. 08 of 2014, accessed online at <http://chapterfouruganda.com/sites/default/files/downloads/Constitutional-Court-Judgement-AHA-case-Uganda.pdf>, due to the Act not having been passed with the required quorum.

Government planned to appeal the decision to the Supreme Court, but later backtracked, possibly due to possible international fallout, as mentioned by Nicholas Bariyo in ‘Uganda’s Attorney General Won’t Appeal Ruling on Antigay Law’, *The Wall Street Journal*, 13 August 2014, accessed online at <http://www.wsj.com/articles/ugandas-attorney-general-wont-appeal-anti-gay-law-ruling-1407946971>.

The law also triggered a judicial challenge before the East African Court of Justice, in *Human Rights Awareness and Promotion Forum (HRAPF) vs. Attorney General of the Republic of Uganda*, filed on April 25 2014, Reference No. 006 of 2014. The challenge, as reported by Adrian Jjuko in the Editorial of *The Human Rights Advocate*, Second Issue - Beyond Quorum: Why the Anti-Homosexuality Act 2014 was Unconstitutional, published by the HRAPF in March 2015, and accessed online at <http://hrapf.org/wp-content/uploads/2016/08/SECOND-ISSUE-OF-THE-HUMAN-RIGHTS-ADVOCATE.pdf>, at 3, contended that Uganda was in violation of the Treaty for the Establishment of the East African Community by enacting the Act, and that certain provisions of Uganda’s Act were in violation of the Treaty for the Establishment of the East African Community at arts. 6(d), 7(2) and 8(1)(c), which provisions enjoin partner states to govern their populace on the principles of good governance, democracy, the rule of law, social justice and maintenance of universally accepted standards of human rights which include *inter alia*, provision of equal opportunities and gender equality as well as the recognition, promotion and protection of human and people’s rights in accordance with the provisions of the African Charter on Human and Peoples’ Rights. The reference was, however, dismissed by the First Instance Division of the Court on 27 September 2016, per Mugenyi PJ and Ntezilyayo and Jundu JJ, on the basis of that the Court would have usurped the powers of the Ugandan Parliament, had it decided on the subject-matter of the reference.

⁴⁹ *Canaan Banana v. State*, Supreme Court of Zimbabwe, per McNally JA joined by Muchechetere and

common law crime of sodomy did not violate the constitutional prohibition on discrimination on the ground of gender. Although the case itself was one of discrimination, and not a direct challenge to Zimbabwe's sodomy statute, it is interesting to analyse how such statute came into play, and the legal reasoning of the Court justifying its retention.

According to Justice McNally, the "social norms and values of Zimbabwe" did not require the court to decriminalise consensual sodomy.

However, as to the main constitutional argument of non-discrimination, McNally also assumed, for the sake of argument, that the criminalisation of consensual sodomy was in fact disparate treatment on the basis of gender in terms of Section 23 of the Zimbabwean Constitution, and discussed whether, in such case, it was also reasonably justifiable in a democratic society:

"I do not believe it is the function or right of this court, undemocratically appointed as it is, to seek to modernise the social mores of the state or of society at large. [...] Zimbabwe is a conservative society on questions of sexual morality and the court should not strain to interpret provisions in the Constitution which were not designed to put Zimbabwe among the front-runners of liberal democracy in sexual matters."⁵⁰

Quansah states, in this regard, that "[t]he real complaint by homosexual men, in the majority's view, was that they were not allowed to give expression to their sexual desires, whereas heterosexual men were."⁵¹ And Jernow argued that, in other words, the only justification for the law and the only justification needed was the public morality of Zimbabweans, in McNally's opinion.⁵²

Dissent to the majority opinion, authored by Chief Justice Gubbay, argued that

"It may well be that the majority of people, who have normal heterosexual

Sandura JJ.A, Gubbay CJ joined by Ebrahim JA dissenting in part, 29 May 2000, [2000] 4 LRC 621 (hereinafter '*Banana v. State*').

⁵⁰ Ibid.

⁵¹ EK Quansah, 'Same-sex relationships in Botswana: Current perspectives and future prospects', *African Human Rights Law Journal*, Volume 2, 2004, at 201, 214.

⁵² Jernow, op. cit., at 13.

relationships, find acts of sodomy morally unacceptable. This does not mean, however, that today in our pluralistic society that moral values alone can justify making an activity criminal. If it could one immediately has to ask, 'By whose moral values is the state guided?'"

He then quoted Ronald Dworkin's dissection of homophobia as a compound of prejudice, rationalisation, and personal aversion, stating that "[i]f so, the principles of democracy we follow do not call for the enforcement of a consensus, for the belief that prejudices, personal aversions and rationalisations do not justify restricting another's freedom, itself occupies a critical and fundamental position in our popular morality."⁵³

Like Dworkin, Gubbay argued that he was "not persuaded that in a democratic society such as ours it is reasonably justifiable to make an activity criminal because a segment, maybe a majority, of the citizenry consider it to be acceptable."⁵⁴ He also stressed on the stated anti-majoritarian function of the Supreme Court, which included protecting the rights of "marginalised members of society." Jernow states that, in doing so, Chief Justice Gubbay squarely rejected the use of the law for the "enforcement of private moral opinions[.]" citing his own words.⁵⁵

His dissent was also cited by the Hong Kong Court of Appeal, in partially striking down a statute criminalising 'homosexual buggery,'⁵⁶ in *Secretary for Justice v. Yau Yuk Lung Zigo et.*⁵⁷

Rather, his views were inspired and aligned with those of an academic elite overseas, in this case the elites sitting on the benches of foreign judiciaries. Aside from quoting authors such as Dworkin, he frequently looked for inspiration to judges from foreign Supreme

⁵³ Ibid.

⁵⁴ Ibid., at 646. This point ties in with the earlier discussion of Hart's views, as to why the conventional morality of a few members of the population should be considered justification for preventing people doing what they want.

⁵⁵ Ibid., at 648, in Jernow, op. cit., at 13.

⁵⁶ S. 118F (1) of the Crimes Ordinance, that read "A man who commits buggery with another man otherwise than in private shall be guilty of an offence and shall be liable on conviction on indictment to imprisonment for 5 years[.]" was deemed to be unconstitutional.

⁵⁷ *Secretary for Justice v. Yau Yuk Lung Zigo and Lee Kam Chuen*, Court of Final Appeal of the Hong Kong Special Administrative Region, per Li CJ joined by Mason NPJ, Bokhary, Chan and Ribeiro PJJ concurring, 17 July 2007, [2006] 4 HKLRD 196 (CFA).

Courts such as in the United States. Just as much can be said of the bench of the Constitutional Court of South Africa, that decided cases such as *State v Makwanyane et*,⁵⁸ where the Court's ruling on the death penalty flew in the face of prevailing public opinion on the topic.⁵⁹

4.5.2 Botswana

The same views were echoed in *Kanane v. The State*⁶⁰ by the Court of Appeal of Lobatse, Botswana, which in a unanimous decision upheld national laws criminalising same-sex sexual conduct. In its decision, the Court asked the question as to "whether in Botswana at the present time the circumstances demanded the decriminalization of homosexual practices",⁶¹ with the Court answering this question in the negative.

To this end, the court stated that there was no evidence that "public opinion in Botswana has so changed and developed that society in this country demands such decriminalisation."⁶²

Tebbutt JP stated in the Court's judgement that:

"I am of the view that while the courts can perhaps not be dictated to by public opinion, the courts would be loath to fly in the face of public opinion, especially if expressed through legislation passed by those elected by the public to represent them in the legislature. [...] The public interest must therefore always be a factor in the court's consideration of legislation, particularly where such legislation reflects a public concern. [...] It was for the legislature, not the Court, to decide what conduct to criminalise. [...] In making such a decision parliament must inevitably take a moral position in tune with what it perceives to be the public mood."⁶³

⁵⁸ *The State v. T Makwanyane and M Mchunu*, Constitutional Court of South Africa, per Chaskalson P, Ackermann, Didcott, Kriegler, Langa, Madala, Mahomed, Mokgoro, O'Regan and Sachs JJ, and Kentridge AJ all concurring, 6 June 1995, [1995] ZACC 3 (hereinafter '*State v. Makwanyane*').

⁵⁹ *State v. Makwanyane*, at 87 et seq.

⁶⁰ *Ujiwa Kanane v. The State*, Court of Appeal, Lobatse, per Tebbutt JP, Nganunu CJ, and Korsah, Zietsman and Kirby JJA, 30 July 2003, 2003 (2) BLR 64 (CA) (hereinafter '*Kanane v. The State*').

⁶¹ *Ibid.*, at 1, in Jernow, op. cit, at 13.

⁶² *Ibid.*, at 7.

⁶³ *Ibid.*

Elaborating on the matter, Quansah also mentions that, in this judgement, “[g]reat reliance was placed on the Wolfenden Report and the response to it by Lord Devlin in a series of lectures.” However, he also points out that “the Court of Appeal was of the view that ‘gay men and women do not represent a group or class which at this stage has been shown to require protection under the Constitution’”.⁶⁴

In this regard, Quansah states that the Court felt that:

“whilst there must be a need for the courts to be alive to the fact that the constitutional rights of citizens of Botswana must, where circumstances demand, keep abreast of similar rights in other kindred democracies, the time had not yet arrived for the adoption of progressive trends taking place elsewhere.”⁶⁵

4.6 Rehabilitating Behaviours – Lawrence v. Texas

It was, however, these same grounds that the Supreme Court then used in 2003, when such notion was embraced by the majority opinion in *Lawrence v. Texas*.⁶⁶

In this regard, the Supreme Court revisited the Due Process Clause of the Fourteenth Amendment, and voted to overrule Bowers, citing the overriding concerns of liberty and privacy.

Robert Post states that *Lawrence* is “best interpret[ed] . . . as the opening bid in a conversation that the Court expects to hold with the American public,”⁶⁷ if one were to bear in mind the earlier discussion concerning Hart-Devlin redux.

⁶⁴ Quansah, op. cit., at 208, commenting on *Kanane*, at 8.

⁶⁵ Quansah, op. cit., at 208.

⁶⁶ *John Geddes Lawrence and Tyron Garner v. Texas*, Supreme Court of the United States of America, per Kennedy J joined by Stevens, Souter, Ginsburg and Breyer JJ, O’Connor J concurring, Scalia J joined by Rehnquist CJ and Thomas J dissenting, 26 June 2003, 539 U.S. 558 (2003) (hereinafter ‘*Lawrence v. Texas*’).

⁶⁷ Robert C. Post, Foreword: ‘Fashioning the Legal Constitution: Culture, Courts and Law: “We must seek a conception of law which realism can accept as true,”’ *Harvard Law Review*, Vol. 117, Issue 4, 2003, at 104.

The case concerned the arrest and subsequent conviction of two men for 'deviate sexual intercourse' under the Texas Penal Code,⁶⁸ having been so intercepted by police officers answering a call concerning an unrelated weapons disturbance at petitioner Lawrence's residence.⁶⁹

The Court started its journey away from the dicta set in *Bowers*, by stating that the *stare decisis* established by the Supreme Court therein 'was not an inexorable command.'⁷⁰ Echoes of *Bowers*, nonetheless, were still evident, both through O' Connor J's concurring opinion, as well as through the joint dissenting opinion authored by Scalia J.

The former, stating that she had joined in the majority opinion in *Bowers*, opined that she still found the relevant Texas legislation in *Lawrence* unconstitutional, but not due to the Fourteenth Amendment's Due Process Clause, but rather because of its Equal Protection Clause.⁷¹

In this regard, she argued that this would be due to the fact that the treatment afforded to the petitioners in virtue of application of such statute went beyond merely the initial criminal scope of said statute:

"And the effect of Texas' sodomy law is not just limited to the threat of prosecution or consequence of conviction. Texas' sodomy law brands all homosexuals as criminals, thereby making it more difficult for homosexuals to be treated in the same manner as everyone else.

Indeed, Texas itself has previously acknowledged the collateral effects of the law, stipulating in a prior challenge to this action that the law "legally sanctions

⁶⁸ The statute, at § 21.06(a), defines "[d]eviate sexual intercourse" as follows:

"(A) any contact between any part of the genitals of one person and the mouth or anus of another person; or

"(B) the penetration of the genitals or the anus of another person with an object." § 21.01(1).

⁶⁹ *Lawrence v. Texas*, op. cit., at 562.

⁷⁰ *Ibid.*, at 577.

⁷¹ O' Connor J, Concurring Opinion, in *Lawrence v. Texas*, op. cit., at 579.

discrimination against [homosexuals] in a variety of ways unrelated to the criminal law," including in the areas of "employment, family issues, and housing."⁷² ⁷³

As to both O' Connor and Scalia's concerns, though, as to the latter, the Court's majority opinion made reference to the danger on relying only or solely on the Equal Protection Clause, outlining a scenario in which the prohibition could still possibly stand in the absence of a wider overarching notion, such as if a new conviction under the impugned statute were to include both homosexual and heterosexual men.⁷⁴

In this regard, one could revisit the earlier discussed notion that decriminalising sodomy would invariably lead to a snowball effect. William Binchy had hinted at this possibility when discussing American jurisprudence in this field.⁷⁵

Mary Ann Case, on the other hand, states that the trajectory in question is of "two steps forward, one step back, but the trajectory is still far from simply onward and upward without serious reversals."⁷⁶ She mentions that the scenario had changed over a period of ten years, when he had written, as regards LGBTQI litigation, that the situation then was

⁷² *The State of Texas v. Linda Morales*, Tom Doyal, Patricia Cramer, Charlotte Taft and John Thomas, Court of Appeals of Texas, Austin, per Carroll CJ joined by Kidd and David JJ, 11 March 1992, 826 S.W.2d 201 (1992) (hereinafter '*State v. Morales*'), in O' Connor J Concurring Opinion, *Lawrence v. Texas*, op. cit., at 582.

⁷³ O' Connor J, Concurring Opinion, in *Lawrence v. Texas*, op. cit., at 581-582.

⁷⁴ O' Connor J, Concurring Opinion, in *Lawrence v. Texas*, op. cit., at 582.

⁷⁵ William Binchy, writing in 1977, in 'New Vistas in Irish Family Law', *Journal of Family Law*, Vol. 15, 1976-1977, at 645, cited J. Edward Thornton, who in *Marriage Vows: Who Cares About Them?*, *The Alabama Lawyer*, Vol. 35, 1974, at 158, 163, who had stated that "[t]hrough the gays and perverted are now being tolerated in some circles, where they had been despised, hated and prohibited, such liaisons can never become nor have they ever been marriages."

Binchy then proceeded to argue that the trend of academic commentary at the time was, rather, 'in the other direction.' In this regard, he pointed to the fact that decisions in which American courts held that same sex union could not be considered to be marriages, such as *Baker v. Nelson*, 191 N.W.2d 185 (1971), appeal dismissed 410 U.S. 810 (1972), *B. v. B.*, 355 N.Y.S. 2d 712 (Sup. Ct. 1974) or *Singer v. Hara*, 11 Wash. App. 247, 522 P.2d 1187 (1974), had been criticised on constitutional grounds (including equal protection, due process and privacy) by different commentators, citing Anon., 'The Legality of Homosexual Marriage', *Yale Law Journal*, Vol. 82, 1973, at 573, and Lentz, 'Marriage Rights: Homosexuals and Transsexuals', *Akron Law Review*, Vol. 8, 1975, at 369.

He also mentioned that, with regard to the legality of transsexual marriages, in *M.T. v. J.T.*, 140 N.J. Super. 77, 355 A.2d 204 (App. Div. 1976), the validity of the marriage of a post-operative transsexual was upheld, the court not following the argumentation laid out by the English High Court in *Corbett v. Corbett*, [1970] 2 All. E. R. 33, per Ormrod J. Here, the Court had held that a man who went through a ceremony of marriage with a person who was psychologically a transsexual, but who was biologically a male, was entitled to a decree of nullity.

⁷⁶ Mary Ann Case, 'Of This and That in *Lawrence v. Texas*', *Supreme Court Review*, Vol. 75, 2003, at 75, 79.

"not ...one of steady progress, more of one step forward, two steps back."⁷⁷

She maps out relevant developments in the field in the United States, noting that:

"[i]n just the last decade, Clinton's attempt to broaden possibilities for gays and lesbians in the military led to adverse Congressional action and more involuntary military discharges than ever; Boulder's antidiscrimination ordinance led to Amendment 2, which in turn led to *Romer*; the Hawaii Supreme Court's same-sex marriage decision⁷⁸ led to the Defense of Marriage Act and a Hawaiian constitutional amendment reversing the decision, but also to partnership rights from the Hawaiian legislature; and *Lawrence* itself seems to have sparked intensified interest in a federal constitutional amendment on same-sex marriage and a sharp decline of support in the polls for gay rights."⁷⁹

The drive forward, termed a 'Kulturkampf' over gay rights by Scalia J, could be seen as the possible pattern being observed here.⁸⁰ What can be observed of this situation, though, is that the fight of the LBGTQI community in asserting identity and personhood, to not be criminalised where others are not, and to be accorded the same positive rights as others, did manage to egg along considerably, with a number of fits and starts.

The latter aspect can be said to be due to the resistance and hegemony of a dominant group over other groups. This as will be pointed out later when discussing Catherine MacKinnon's work,⁸¹ and as was also outlined earlier in the case of linguistic and ethnic groups.⁸² However, this is the natural course every such struggle will have to run, with some societies being at an earlier, and some at a later point on the course.

⁷⁷ Mary Anne Case, 'Couples and Coupling in the Public Sphere: A Comment on the Legal History of Litigating for Lesbian and Gay Rights', *Virginia Law Review*, Volume 79, 1993, at 1680-93, in Case, 'Of This and That in *Lawrence v. Texas*', op. cit., at 79.

⁷⁸ *Ninia Baehr, Genora Dancel, Tammy Rodrigues, Antoinette Pregil, Pat Lagon and Jeseeph Mellilo v. John C. Lewin, in his official capacity as Director of the Department of Health, State of Hawai'i*, per Levinson J joined by Moon CJ, Heen J dissenting, Hawai'i Supreme Court, 5 May 1993, 74 Haw. 645, 852 P.2d 44., in Case, 'Of This and That in *Lawrence v. Texas*', op. cit., at 80.

⁷⁹ Case, 'Of This and That in *Lawrence v. Texas*', op. cit., at 80.

⁸⁰ *Roy Romer, Governor of Colorado, et al. v. Richard G. Evans, et al.*, Supreme Court of the United States of America, per Kennedy J joined by Stevens, O' Connor, Souter, Ginsburg and Breyer JJ, Scalia J joined by Rehnquist CJ and Thomas J dissenting, 20 May 1996, 517 U.S. 620 (1996) (hereinafter *Romer v. Evans*), at 636, in Case, 'Of This and That in *Lawrence v. Texas*', op. cit., at 80.

⁸¹ See section 7.4.2 of this thesis.

⁸² See section 3.2 of this thesis.

Still, the basis in which this rights journey is grounded is also of paramount importance. Sometimes, it is also necessary to look further than classic Hart-Devlin redux in this area, as can be seen through transformative judicial activism in two other jurisdictions.

4.7 From Public Morality to Constitutional Morality

For further transformation to occur, one must delve further into whether social mores, and the fact that a certain society found a practice ‘morally acceptable’⁸³ or otherwise, was enough to justify its continued criminalisation.

Simply tapping into the ‘public mood’,⁸⁴ as observed into *Kanane*, in order to determine whether an issue was ‘acceptable conduct’⁸⁵ as defined in *Banana*, or ‘moral’⁸⁶ as defined in *Bowers*, could be seen as democratic in Devlin’s views, but can also be seen to dangerously be missing a fundamental issue affecting that very society.

While Ronald Dworkin, as cited by Gubbay, relies instead on another philosophical principle – the principle of possible harm to society, drawing on the reasoning of Mill, as cited in Section 4.3.4 of this thesis, and as also reflected in the Wolfenden Report – certain legal realities are not rooted in mere philosophy but rather, further, in hard facts.

The fact that a certain society has made a choice as to what is morally acceptable, can never negative the fact that there are reasoned criteria behind that choice. And when those reasoned criteria include ‘illegitimate bias’ or outright ‘prejudice,’ then one is no longer faced with a philosophical debate as to how social feels, or why it should feel in a certain way, about a topic.

One is now faced with courses of action that are already *prima facie* illegal and discriminatory when assessed against the wider law of the land. Therefore, at this point, neither the judiciary nor the other organs of state would any longer have the luxury of being able to continue to rely on the ‘public mood’.

⁸³ *Kanane v. State*, op. cit., at 7.

⁸⁴ *Ibid.*, at 7.

⁸⁵ *Banana v. State*, op. cit., at 646.

⁸⁶ *Bowers v. Hardwick*, op. cit., at 196.

While populism writ large, to rephrase the previous citation, is definitely a strong factor in maintaining the cohesion of the social order in different jurisdictions, as also outlined in the cases reviewed, states are applied to either apply the law, or else change the law, when certain practices are actually in breach of the law.

This might prove more difficult, even in the face of continued public support for the disputed actions, and particularly when such illegality stems from a state's obligation under international covenants it would have ratified.

The above scenario played out in the ruling handed down by the Constitutional Court of South Africa in *National Coalition for Gay and Lesbian Equality and Another v. Minister of Justice and Others*.⁸⁷ The Court was well aware that the popular morality argument was one that masked animus, in the same way that the US Supreme Court was aware, and always uneasy in tackling the issues of moral justifications and illegitimate bias, both before and after *Lawrence*.⁸⁸

However, the transformative constitutional tradition of this jurisdiction, allowed the Court to sidestep this bias, with Ackermann J evoking the very fresh experience of apartheid in handing down judgement.⁸⁹ The Court determined that the moral justification for criminalising same-sex sexual conduct rested "to a large extent on nothing more than prejudice."⁹⁰

In this regard, Sachs J, concurring, stated that:

⁸⁷ *The National Coalition for Gay and Lesbian Equality and The South African Human Rights Commission v The Minister of Justice, The Minister of Safety and Security, and the Attorney-General of the Witwatersrand*, Constitutional Court of South Africa, per Ackermann J joined by Chaskalson P, Langa DP and Goldstone, Kriegler, Mokgoro, O'Regan and Yacoob JJ, Sachs J concurring, 9 October 1998, (CCT11/98) [1998] ZACC 15; 1999 (1) SA 6; 1998 (12) BCLR 1517 (hereinafter '*National Coalition*').

⁸⁸ Suzanne B. Goldberg, 'Morals-Based Justifications for Lawmaking: Before and After *Lawrence v. Texas*', *Minnesota Law Review*, Vol. 88, 2004, at 1233.

⁸⁹ *National Coalition*, op. cit., at 28.

⁹⁰ *Ibid.*, at 37.

'It is no exaggeration to say that the success of the whole constitutional endeavour in South Africa will depend in large measures on how successfully sameness and difference are reconciled.'⁹¹

The Court's approach in this regard very much tied in with that in its declaring the death penalty unconstitutional in *Makwanyane*, again in the face of prevalent public opinion at the time.

The approach adopted in *National Coalition* was also replicated by the High Court of Delhi in the *Naz Foundation* case,⁹² which in dismissing the public morality argument in deciding that a criminal prohibition on sexual activity 'against the order of nature,'⁹³ stated that

'public animus and disgust toward a particular social group or vulnerable minority is not a valid ground for classification ... Section 377 IPC [Indian Penal Code] targets the homosexual community as a class and is motivated by an animus towards this vulnerable class of people.'⁹⁴

In this regard, the Court noted that enforcing such legislation amounted to nothing more than enforcing the concept of 'prejudice,'⁹⁵ observing that section 377 was reminiscent of colonial-era legislation that had criminalised entire tribes.

Rather public morality, the Court defined instead the notion of constitutional morality, espousing a broader vision of the common good which, in the words of the Court, "must outweigh the argument of public morality, even if it be the majoritarian view."⁹⁶

This notion was similarly echoed by the South African Constitutional Court in *National Coalition*, by evoking the 'deep political morality' of the new South African Bill of Rights,⁹⁷ and norms such as equality and non-discrimination that it stood for. These points

⁹¹ Ibid., at 131.

⁹² *Naz Foundation v. Govt. of NCT of Delhi and Others*, High Court of Delhi, per Shah CJ and Muralidhar J, 2 July 2009 160 Delhi Law Times 277 (hereinafter '*Naz Foundation*').

⁹³ Section 377 of the Indian Penal Code, 1860, Act No 45 of 1860.

⁹⁴ *Naz Foundation*, at 91.

⁹⁵ Ibid., at 53.

⁹⁶ Ibid., at 86.

⁹⁷ *National Coalition*, at 136.

were also touched upon, although not as overtly, in the US Supreme Court's decision in *Romer v. Evans*,⁹⁸ as well as in O' Connor J's concurring opinion in *Lawrence*, discussed earlier.

One could also cite Plauché, who observes legislation couched in terms of public morality is inherently paternalistic,⁹⁹ immoral, and unjust. In parallel with this, he argues that the very nature of the state, and of the modern democratic state in particular, necessarily ensure that granting society the power of moral legislation through the state will be counterproductive in the long run.¹⁰⁰

In this regard, he refers to Devlin's analogy of the jury box as the representative of the moral majority, observing that jurors rarely stray away from decisions based on points of fact, rarely exercising their prerogative to nullify unjust laws, even in countries with long common law traditions such as the United States.¹⁰¹

He states that even moral majorities on individual issues on society - since he contests the notion of majority as to public morality as a whole - would not really care enough about an issue to actually do something about it themselves, if they did not have the state to do something about it for them. Rather, he states that having the power of the state at their disposal lowers the opportunity cost for dealing with things they consider to be immoral, thus giving them an incentive to violently enforce or prohibit behaviour (or lack thereof) that they otherwise would have tolerated.

The consequence of this would be that violence and other anti-social behaviour would be made more likely and prevalent, as individuals and groups vie with each other 'to use the power of the state against or in defence of their favorite peccadillos.'¹⁰²

⁹⁸ *Romer v. Evans*, op. cit.

⁹⁹ This notion echoes the reasoning of Feinberg, who stated that the two instances in which the state was wrong to coerce its subjects as to certain modes of behaviour was if it acted through 'legal paternalism' or through 'legal moralism,' See, for example, Joel Feinberg, *Harm to Others*, Oxford University Press, Oxford, 1984; Joel Feinberg, *Harm to Self*, Oxford University Press, Oxford, 1986.

¹⁰⁰ Plauché, op. cit., at 21-22.

¹⁰¹ Lysander Spooner, 'Trial by Jury', in the Lysander Spooner Reader (1992), available online at http://www.lysanderspooner.org/bib_new.htm, in Plauché, op. cit., at 22.

¹⁰² Plauché, op. cit., at 24-25.

4.8 *Doing Away with Tyranny*

Writing about the effects of *Lawrence* on the limits of criminal law, Haque discusses the US Constitution's Eighth Amendment as an independent source of substantive limitations on the scope of the criminal law.¹⁰³ He sees this as one of the key tenets in which the majority opinion in *Lawrence* was grounded, echoed in the words of Kennedy CJ when delivering the Court's majority opinion, to the effect that “[t]he issue is whether the majority may use the power of the State to enforce [its] views on the whole society through operation of the criminal law.”¹⁰⁴

Although in terms of LGBTQI rights, the main issue chosen as a discussion point was the decriminalisation of consensual sodomy, and society's approach and responses to such, the fact that criminal law was brought into the picture was merely a factor specific to this subject-matter. The main aim of the discussion was to view how a diverse group can be shunned by the side-lines, or accepted into the mainstream, depending on society's mores and prevailing views, and also whether a group would be allowed to survive and thrive, or be forced to 'adapt or die,' on the basis of the same.

Therefore, the above quote from *Lawrence*, as to its possible conceptual applicability to other diverse groups, including that of autistic persons, could be reframed as to consider instances of whether the majority may use the power of the State to enforce their views on the whole of society, through the operation of the law (and related policy), no matter the nature of the legislation in question.

¹⁰³ Adil Ahmad Haque, 'Lawrence v. Texas and the Limits of the Criminal Law', *Harvard Civil Rights-Civil Liberties Law Review*, Vol. 42, at 1, 4.

¹⁰⁴ *Lawrence v. Texas*, op. cit., at 571, in Haque, op. cit., at 4.

Chapter 5: Shifts in Disability Perception: The Situation and the Struggle

5.1 Introduction

The disability rights movement can be said to have also been subjected to the same dynamics of ‘good or bad’, ‘right or wrong’ and the dominant/ minority dichotomy, outlined in the previous Chapters. The thesis so far has looked at the situation surrounding autism, and the need for understanding such situation, in order to move forward towards awareness, acceptance and inclusion. It backed up such blueprint by 2 case studies, covering linguistic and ethnic groups, focusing more on the dominant/ minority dichotomy and its effect on extirpation of difference, in line with ‘good or bad’ practices, and LGBTQI persons, focusing more on ‘right and wrong’ and ‘correction’ or ‘normalisation’.

This thesis will now focus on the blueprint of the way forward undertaken in both these scenarios following realisation of truth. As mentioned earlier, in autism the closest form of such blueprint would be the shift from the medical to the social model in disability rights. Since autism also falls within the realm of disability, the thesis shall now examine this blueprint, as laid out earlier, in terms of disabilities. This will follow on from descriptions of the medical and social model in Section 1.1.2 of this thesis, with the facts, related perceptions and eventual journey to be seen in light of the relevant discussions concerning ‘good and bad’, ‘right and wrong’ and the dominant/ minority dichotomy, as carried out in previous chapters.

In the following Chapters, this will also be done from a further law and rights-based perspective. They will examine legal provisions from instruments such as the Council of Europe’s European Convention on Human Rights and the European Union’s Charter on Fundamental Rights, as well as case law from these institutions’ judicial bodies, but culminating in testing rights against the UN CRPD. The thesis will examine parallel shifts in perspective, what was done, and what still needs to be done, in order to provide a wider background context for autism, and possible rights violations in that scenario. The thesis will also look at where matters are going forward in parallel with progress achieved in the wider disability and other fields, and what might also be done in certain areas in the field of autism.

Particularly in the field of disabilities, one central argument was always the notion of ‘presumed incompetence’, as discussed in Section 5.2.4 of this thesis, and that such persons so presumed incompetent could not speak for themselves. This was due to such persons being viewed with a mixture of derision and pity, with the overarching rationale being that others had to do things for them. While the latter might be the case in certain instances, possible middle ground in these instances is frequently forgotten, for example, in respect of independent living, or of supported-decision making with regard to capacity issues. This notion is also made reference to, in the context of autism, in Section 1.1.2 of this thesis.

Therefore, in such instances, a journey from protection to empowerment, as well as the notions underlying this, are equally important. This topic will also be examined as part of the disability rights debate in this Chapter, before moving on to discussing the medical to social model journey specifically, as well as particular issues in this regard as per the outline above.

5.2 From Protection to Empowerment: Lessons from Children’s Rights

This section will look at the journey undertaken in the field of children’s rights, as a comparator scenario, as to the need of rights-based shifts to also be a journey from protection to empowerment-focused legislation and policy. This will also be useful in understanding notions of competence and capacity, and as to how to factor such in, when drafting, as well as implementing and enforcing legislation. The ‘social interest’ theory of rights will be contrasted against the ‘will’ or ‘choice’ theory in this regard, and the topic of the section shall be viewed through both domestic and supranational examples.

5.2.1 The English Scenario

While other countries within the United Kingdom had been pushing forward with legislation and policy in the field of children’s rights,¹ England was much slower in getting on board. Although it did finally work at catching up in the mid-2000s, in the wake of certain incidents, the tone and import of the legislation was still of concern to some.

¹ For example, through the passage of the Children’s Commissioner for Wales Act of 2001, c. 18, the Commissioner for Children and Young People (Scotland) Order 2003, and the Commissioner for Children and Young People (Northern Ireland) Order 2003.

Even when a Commissioner for Children for England was finally appointed in terms of the new Children's Act in 2004,² as a result of Government accepting the Recommendations of the Report³ following the Laming Inquiry into yet another child's death, said Commissioner's role was limited to "representing the views and interests of children and young people"⁴ instead.

In this regard, then Children Rights' Minister Margaret Hodge also insisted on excluding any references to rights,⁵ to the ire of rights groups such as the National Society for the Prevention of Cruelty to Children (NSPCC)⁶ – although the very name of organisations such as this, even if historical vestiges, still conveyed a message steeped more in concerns over protection, than in empowering children as to their rights.

Such situation was only finally remedied through the passage of the new Children and Families Act in 2014,⁷ with the role description of the Commissioner being upgraded to that of "promoting and protecting children's rights."⁸ This followed the direct applicability of the provisions of the European Convention on Human Rights,⁹ in as far as they applied

² c. 31, at Part 1, ss. 1-9.

³ William Laming, Nellie Adjaye, John Fox, Donna Kinnair and Nigel Richardson, *The Victoria Climbié Inquiry: Report of an Inquiry by Lord Laming*, Presented to Parliament by the Secretary of State for Health and the Secretary of State for the Home Department, CM 5730, HM Stationery Office, January 2003.

⁴ Children's Act 2004, c. 31, at s. 2(1).

⁵ See, for example, *Children Bill, Nineteenth Report of Session 2003-04, Report, Together with Formal Minutes, Appendices and Minutes of Evidence*, House of Lords Papers 2003-04,161/House of Commons Papers 2003-04,537, Great Britain: Parliament: Joint Committee on Human Rights, The Stationery Office, 2004, at 9.

⁶ In a Briefing following the appointment of the first Commissioner for Children for England, issued by its Information Service in March 2015, the NSPCC stated that "the England Children Commissioner office does not meet the European standards set out for all European Commissioners [...]. the NSPCC believes that the Commissioner's remit and responsibilities should be more closely tied to the UNCRC [...] which the Government ratified in 1991, granting all children a comprehensive set of economic, social, civil and political rights."

⁷ c. 6.

⁸ Children and Families Act 2014, at s. 113(3)(a).

⁹ The inadequacy of this development alone was, however, one of the points raised by the Committee on the Rights of the Child in its Second Concluding Observations concerning the United Kingdom, at 4, stated that "[t]he Committee regrets that, notwithstanding the legal obligation inherent in the ratification of the Convention, many of the concerns and recommendations contained in its concluding observations on the State party's initial report have been insufficiently addressed," while further continued, at 8, that "While noting the entry into force of the Human Rights Act 1998 [...], the Committee is concerned that the provisions and principles of the Convention on the Rights of the Child - which are much broader than those contained in the European Convention - have not yet been incorporated into domestic law, nor is there any formal process to ensure that new legislation fully complies with the Convention. The Committee [...] remains concerned that the State party does not ensure that its legislation is compatible with the Convention throughout its territory."

to children's rights, within the UK legal order, by virtue of the Human Rights Act of 1998,¹⁰ and was succeeded by further legislation with a stronger focus on rights in particular areas.¹¹

5.2.2 *From Rights Declaration to Rights Convention*

The development at the international level can be said to be analogous. The UN Declaration on the Rights of the Child,¹² adopted in 1959, emphasised children's entitlement to and enjoyment of rights without discrimination on account of race, colour, sex, language, religion, political or other opinion, national or social origin, property, or birth or other status, whether of the child or of the child's family.¹³

Such criteria could also be seen as bringing this document in line with the UDHR. The criterion of a child's entitlement as from birth to a name and a nationality was also included in this document.¹⁴

This Declaration led to an increased set of substantive rights, though still not internationally enforceable, and focused mainly on protection. This date has also been adopted as Universal Children's Day.¹⁵ Jane Fortin insists that the Declaration of Geneva was brief and only aspirational, since it merely invited the member states to be 'guided by its principles in the work of child welfare'.¹⁶

But while of far greater importance for the promotion of children's rights, the UN Declaration still had the limited status of a declaration, in that it did not attempt to claim that the 'rights' listed constituted legal obligations. Instead, she insists, states were merely required to take note of the principles contained therein, on the basis that they were

¹⁰ c. 42.

¹¹ See, for example, Children and Adoption Act 2006, c. 20; Forced Marriage Act (Civil Protection) 2007, c. 20; Education Act 2011, c. 21, at Part 2, ss. 2-6 (provisions on school discipline).

¹² Declaration of the Rights of the Child, 20 November 1959, A/RES/1386(XIV).

¹³ Ibid., at para. 1.

¹⁴ Ibid., at para. 3.

¹⁵ General Assembly Resolution on Universal Children's Day, 14 December 1954, A/RES/836.

¹⁶ D Hodgson, 'The Historical Development and "Internationalisation" of the Children's Rights Movement', *Australian Journal of Family Law*, Vol. 25, Issue 6, 1992, at 261, in Jane Fortin, *Children's Rights and the Developing Law* (2nd ed.), Cambridge University Press, Cambridge, 2005, at 37.

universally accepted as being applicable to all children.¹⁷

Nevertheless, she argues, some of the ideas it contains are surprisingly modern and reappear in an elaborated form in the UN Convention on the Rights of the Child (UNCRC),¹⁸ introduced 30 years later in 1989. For example, it refers to the child's right to treatment without discrimination, to special protection, to material and spiritual development, to socio-economic rights such as housing, medical care and food, and to rights to education and protection from exploitation, neglect and cruelty. It also includes a reference to the child's right to name and nationality.¹⁹

Perhaps the generality of the 1959 Declaration, and the fact that it carries no legally binding obligations, led to a general tendency by many nations to continue ignoring the appalling conditions being suffered by large numbers of children. In particular, it contains no acknowledgment that children are entitled, like adults, to the first-generation human rights, the freedoms from state oppression. Indeed, barring the reference to name and nationality, there is no mention of children's civil and political rights.²⁰

The UNCRC was born out of calls for a more systematic approach to protecting children's rights. By the 1970s, growing concern over the violations of children's rights throughout the world led finally to a move to establish an international document guaranteeing children's rights through the imposition of legal obligations.²¹

Poland continued in its tradition of promoting children's rights at the international level, by being the main proponent and driver behind this document.²² It was finally adopted by the UN in 1989.²³ Some countries have lodged reservations or declarations, such as

¹⁷ Fortin, op. cit., at 38.

¹⁸ Convention on the Rights of the Child (CRC), G.A. res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), adopted 20 November 1989; entered into force 2 September 1990, 1577 U.N.T.S. 3 (hereinafter 'UNCRC').

¹⁹ Ibid.

²⁰ Ibid.

²¹ Hodgson, op. cit., at 275-276, in Fortin, op. cit., at 38.

²² United Nations – Office of the High Commissioner for Human Rights (OHCHR), *Legislative History of the Convention on the Rights of the Child – Volume I*, New York/ Geneva, 2007, at xxxviii.

²³ Convention on the Rights of the Child (CRC), G.A. res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), adopted 20 November 1989; entered into force 2 September 1990, 1577 U.N.T.S. 3 (hereinafter 'UNCRC').

Oman's controversial reservation to the Convention concerning freedom of religion,²⁴ and Russia's declaration as to age of induction into the military concerning the relevant Optional Protocol.²⁵

The UNCRC is a Convention enforceable at international law, unlike its predecessor texts, and also provides a specific mechanism for its enforcement.²⁶ It one of the most comprehensive of all the human rights treaties containing a complete list of civil and political and social, cultural and economic rights.

The UNCRC, in enunciating the above provisions, also shares a relationship with other major international texts, more specifically the ICCPR, ICESR, Torture Convention, Race Discrimination Convention and CEDAW.

5.2.3 Involvement of Civil Society/ Beneficiaries in UNCRC Drafting

For the first time in such a scenario, the assumption of capacity as regards children was shifting. This was due to the fact that the instrument was not only a document devised to protect children, and written for children by other persons. It was also, for the first time, a document written for children, also with the input of such children, as far as this was possible in view of their capacity to so contribute.

The participation of such international organisations as the International Labour Organisation, the United Nations Educational, Scientific and Cultural Organisation

²⁴ The Omani Reservation on freedom of religion, opposed by many Western states, reads as follows: "The Sultanate of Oman is not committed to the contents of Article (14) of the Convention, which gives the child the right to freedom of religion until he reaches the age of maturity."

²⁵ The relevant Declaration by the Russian Federation reads as follows: "In accordance with the legislation of the Russian Federation, citizens who have reached the age of 16 are entitled to admission to professional military educational institutions. Upon enrolment in these institutions they shall acquire the status of members of the military performing compulsory military service. The legislation of the Russian Federation guarantees that such citizens shall conclude military service contracts on reaching the age of 18, but not before they have completed the first year of education in these educational institutions."

²⁶ In this regard, the Committee on the Rights of the Child (CRC) may consider individual communications alleging violations of the Convention or of the Optional Protocols on the sale of children, child prostitution and child pornography (OPSC), and on the involvement of children in armed conflict (OPAC), by State Parties that have ratified the Third Optional Protocol on a communications procedure (OPIC), website of the Office of the United Nations High Commissioner for Human Rights (OHCHR), Human Rights Bodies – Complaints Procedure, accessed at <http://www.ohchr.org/EN/HRBodies/TBPetitions/Pages/HRTBPetitions.aspx>.

(UNESCO), the World Health Organisation (WHO) and the International Committee of the Red Cross was becoming more and more conspicuous. Non-governmental organisations cooperated effectively under the umbrella of the NGO Group, for which Defence for Children International served as the secretariat.²⁷

However, when submitting proposals on the draft, a UN official publication on the process states that the delegates of a few States referred to opinions held by children and youth organisations active in the countries they represented. Sweden was one such country. When work on the draft was about to be completed, a group of Swedish children entered the hall where the Working Group was holding its meeting and submitted a petition written on a poster one metre wide and several metres long signed by approximately twelve thousand children.

The petition contained support for the Convention and especially for Sweden's proposal that children should not be called up for service in the armed forces or involved in armed conflicts. On a few occasions, schoolchildren from Canada came to listen to the debates in the Working Group. Also, representatives of several French child and youth organisations displayed an active interest in the work on the draft convention.²⁸

However, the effectiveness of such contribution by children is contested by authors such as John Tobin, who states that the process leading to the adoption of the UNCRC did not include children,²⁹ this being a major obstacle to the justification of the rights for children under the UNCRC.³⁰

In this regard, he quotes Michael Freeman to the effect that "[t]he Convention thus encodes a set of rights and takes an image of childhood from the perspective of the adult world looking in almost as an external observer on the world(s) of children."³¹ Tobin states this to be a substantial dilemma under the concept of social interest theory,³² leading to what

²⁷ *Legislative History of the Convention on the Rights of the Child – Volume I*, op. cit., at xxxix.

²⁸ *Ibid.*, at xi.

²⁹ John Tobin, 'Justifying Children's Rights', in Michael Freeman (ed.), *The Future of Children's Rights*, Brill/Nijhoff, Leiden/ Boston, 2014, at 275.

³⁰ *Ibid.*

³¹ Michael Freeman, 'The sociology of childhood and children's rights', *International Journal of Children's Rights*, Vol. 6, 1998, at 439, in John Tobin, op. cit. in Michael Freeman (ed.), *The Future of Children's Rights*, op. cit., at 275.

³² For a broader discussion of the topic, see S. Brennan, 'Children's Choices or children's interests:

he calls an adult construction dilemma in this situation.³³

Such a theory can be viewed as restrictive when compared to the 'will theory' or 'choice theory'³⁴ of rights, that protects a child's choice, as long as such child has sufficient capacity to be able to exercise that right themselves.

Notwithstanding, the formation process of rights legislation under the 'interest theory' can also be seen to be of paramount importance, as to the subsequent practical application of such rights. Such rights are meant to protect the holder's interests, even if, though being rights-holders, such rights are exercised on their behalf by third parties, in protection of their interests, so the drafting process could be seen as paramount in guaranteeing such.

He states, however, that notwithstanding this phenomenon, the malleability of the UNCRC's text allows for both the views of children, and diverse cultural perspectives, to inform the understanding and implementation of children's rights.³⁵ Such malleability allows for broad interpretation, that could counter claims made as to a more rigid background to the text, such as it being anti-family, or having a liberationist or protectionist agenda,³⁶ or to attempts to interpret it from a purely interest theory-based on will theory-based perspective.³⁷

5.2.4 *Presumption of Relevant Competence*

Having observed different groups' access and eventual claims to capacity, influenced both by their innate rights, as well as their particular situations, in the sections above, it is important to once again see such in parallel with the central theme of this thesis, that of autistic rights.

In the case of women, the notion of 'presumed incompetence' was initially the order of the

Which do their rights protect?', in D. Archard and C. MacLeod (eds.), *The Moral and Political Status of Children*, Oxford University Press, Oxford, 2002.

³³ John Tobin, op. cit. in Michael Freeman (ed.), *The Future of Children's Rights*, op. cit., at 275.

³⁴ See Brennan, op. cit.

³⁵ John Tobin, op. cit. in Michael Freeman (ed.), *The Future of Children's Rights*, op. cit., at 276.

³⁶ Ibid.

³⁷ Ibid.

day.³⁸ It is still being used in certain countries such as Saudi Arabia nowadays, where male guardianship of women, the concept of the *mahram*, is still very much alive and well.³⁹ Here, although token representation of women is now allowed at certain advisory levels,⁴⁰ women's capacity still relies, for all intents and purposes, upon the final go-ahead of a male guardian. Such term is also used regularly in the context of psychosocial disabilities nowadays,⁴¹ and many times in connection with autism.

However, women's innate rights were eventually rightfully assumed by this group, and acknowledged by larger groups, to a much wider extent nowadays, through a combination of activism, circumstance and changing social norms.

In the case of children's rights, there were what would be termed 'functional limitations' in certain sections of the disability world,⁴² although such term is being used mainly for illustrative purposes, due to its having medicalized undertones.

Nevertheless, within the capacity that such children anyway did possess, they were capable of expressing their desires and concerns, to the point of being able to shape the drafting of an international treaty safeguarding their rights. They were to no longer be simply shunned by society, and possibly be beneficiaries of protection, if granted, by the dominant hegemony which disregarded their capacity totally. In this context, the argument of capacity could be seen to amount to nothing more than an expression of the concept of the overarching notion of the dominant group calling the shots, as also discussed elsewhere in this thesis.

³⁸ See, for example, Carmen G. Gonzalez and Angela P. Harris, 'Introduction: Presumed Incompetent: Continuing the Conversation (Part II)', *Seattle Journal for Social Justice*, Vol. 12, Issue 2, 2013, Article 1.

³⁹ Eleanor Abdella Duomato, in 'Saudi Arabia', in Sanja Kelly and Julia Breslin (eds.), *Women's Rights in the Middle East and North Africa*, Rowman & Littlefield, Lanham, 2010, at 427, states that although Article 8 of the 1992 Basic Law of Saudi Arabia requires that the government be premised on equality in accordance with Sharia law, under Sharia law, women are considered to be legal minors, under the control of their *mahram* or male guardian.

⁴⁰ See, for example, Pascal Ménoret, *The Municipal Elections in Saudi Arabia 2005: First Steps on a Democratic Path*, Arab Reform Brief, Arab Reform Initiative, accessed online at <http://www.arab-reform.net/en/file/328/download?token=h5kiRc3i>.

⁴¹ See, for example, Human Rights Watch, *Living in Hell: Abuses against People with Psychosocial Disabilities in Indonesia*, 21 March 2016, accessed online at <https://www.hrw.org/report/2016/03/21/living-hell/abuses-against-people-psychosocial-disabilities-indonesia>.

⁴² See Sections 1.1.2.1 and 5.3.1 of this thesis for a further elaboration of this topic.

While the limitation of capacity through age-appropriateness is a *sui generis* feature applicable to children, as discussed in this Chapter, this must not, in any way, detract from one of the fundamental aims of the UNCRC, that of shifting the rights discourse surrounding children, from one rooted in protection, to one rooted in empowerment.

On this topic specifically, Verhellen argues that the notion of protection has been used as a way of managing and controlling children through disempowering them,⁴³ a view also shared by other authors.⁴⁴ He further puts forward his view that, specifically in the area of education, adults manage and control children through education-specific legislation, which he describes as nothing more than socialisation instruments.

Within the purview of such instruments, children can be seen as objects rather than participants in the process of their education,⁴⁵ and such specific legislation can be seen as having been introduced in response to the image prevalent at the turn of the twentieth century, of children as nothing more than passive 'adults-in-waiting,' ready to be moulded according to the norms and criteria acceptable by society.⁴⁶

In order to avoid falling into such a trap, one must look particularly closely at Article 5 and a number of related Articles. While Article 5 can also be said to address the role of parents in supporting the evolving capacity of children to exercise their rights,⁴⁷ as stated by Ireland's Commissioner for Children, it can also be read while noting the emphasis placed on the guidance being simply incidental to a child's rights, and only being exercised in as far as such is done 'in a manner consistent with the evolving capacities of the child.'⁴⁸

The United Nations, and especially the Committee on the Rights of the Child, have always

⁴³ E. Verhellen (1992), 'Children's Ombudswork: Motives and Strategies, even after Adler's time', in Fortuyn Droogleever and M. de Langan (eds) (1992), *Towards the Realisation of Human Rights of Children*, Amsterdam: Children's Ombudswork Foundation/Defence for Children International – Netherlands, cited in Nóirín Hayes (2002), 'Children's Rights - Whose right? A review of child policy development in Ireland', *Studies in Public Policy*, Volume 9, The Policy Institute, Trinity College Dublin, at 18.

⁴⁴ M. Woodhead, 'Psychology and the Cultural Construction of Children's Needs: Postscript', 1997, in A. James and A. Prout, (eds), *Constructing and Reconstructing Childhood*, Falmer Press, London, 1997, cited in Hayes, op. cit., at 18.

⁴⁵ Verhellen, op. cit., in Hayes, op. cit., at 18.

⁴⁶ Ibid.

⁴⁷ Ursula Kilkelly, 'Ireland's Law and Policy: Moving towards a Children's Rights Based Approach', Symposium to mark the 10th Anniversary of OCO, Farmleigh House, 25 April 2014, at 2.

⁴⁸ UNCRC, op. cit., at art. 5.

been considered to be extremely progressive, within the limits of Article 5,⁴⁹ certain more conservative authors also voicing concerns about the effect of such on parent-child relationships.⁵⁰

The Committee's General Comment on the Child's Right to be Heard⁵¹ makes waves especially as to children's standing in a court of law,⁵² taking capacity to form one's own views,⁵³ age and maturity,⁵⁴ as well as other evolving capacities⁵⁵ into account in this regard, and mandating an appropriate assessment of these criteria⁵⁶ in such cases. Similar points are made as regards a child's access also to healthcare⁵⁷ and to education.⁵⁸

The Comment concludes by emphasizing the need to "challenge assumptions about children's capacities, and to encourage the development of environments in which children can build and demonstrate capacities."⁵⁹ UNCRC Implementation, it states, should address the attainable challenge of fostering "a culture of respect for children and their views."⁶⁰

This situation would be analogous to those autistic persons with an intellectual disability, who are nonetheless accorded supervised decision-making rights in jurisdictions such as British Columbia in Canada. This jurisdiction allows for Representation Agreements,⁶¹ rather than applying outdated and non-CRPD-compliant notions of guardianship in their regard.

⁴⁹ See, for example, Garton Kamchedzera, *A Commentary on the United Nations Convention on the Rights of the Child: Article 5 - The Child's Right to Appropriate Direction and Guidance*, Martinus Nijhoff Publishers, Leiden, 2012, at 3.

⁵⁰ See, for example, Lynn D. Wardle, 'The Disintegration of Families and Children's Right to their Parents', *Ave Maria Law Review*, Vol. 10, Issue 1, Fall 2011, at 1, 39.

⁵¹ General Comment No. 12 (2009) on 'The right of the child to be heard', adopted by the UN Committee on the Rights of the Child, at its 51st Session, Geneva, 25 May-12 June 2009, UN Doc. CRC/C/GC/12, 1 July 2009.

⁵² *Ibid.*, at 3.

⁵³ *Ibid.*, at 7.

⁵⁴ *Ibid.*, at 5.

⁵⁵ See, for example, General Comment No. 12 (2009), *op. cit.*, at 9.

⁵⁶ General Comment No. 12 (2009), *op. cit.*, at 12.

⁵⁷ *Ibid.*, at 20.

⁵⁸ *Ibid.*, at 21.

⁵⁹ *Ibid.*, at 28.

⁶⁰ *Ibid.*

⁶¹ Representation Agreement Act [RSBC 1996] Chapter 405.

5.2.4.1 EU Activists' Recommendations – Competence and Legal Capacity

In a consultation meeting convened by the EU Commission's DG-Employment and Social Affairs (to which the Inclusion portfolio has since been added), a number of issues raised in the UN CRPD Committee's Concluding Observations to the EU's first State Report on its implementation of the CRPD were discussed with civil society representatives. This was done in order to gain feedback to be used in implementing said Concluding Observations.

As to such happening within the framework of deprivation or restriction of legal capacity, it was further agreed that additional funding should be allocated to the research of supported decision making models, and the exchange of good practice in the field of legal capacity. This especially as regards participation in elections and the use of facilitated/ adaptive/ assistive communication in enabling persons with disabilities to exercise their legal capacity,⁶² instead of the unnecessary use of restrictive mechanisms such as guardianship.⁶³

The Commission was also encouraged to issue guidance to EU institutions and to Member States in this regard, on the review & appeals procedures for regulating and determining legal capacity and on assisted decision-making rules.⁶⁴

5.2.4.2 Comparative Advocacy: The CRPD and the UN's SDGs

This same topic was discussed when clarifying to the UN the import of its mandate to 'leave no one behind'. In a discussion paper⁶⁵ addressed to the UN's High Level Political Forum (HLPF), disability advocates and academics from around the globe stated that the

⁶² Ibid., recommendations delivered by author, and reported in the Final Minutes, Meeting with NGOs on the follow-up to the UN concluding observations on the EU's initial report on the Convention on the Rights of Persons with Disabilities, Brussels, 26 October 2016.

⁶³ Ibid.

⁶⁴ Ibid.

⁶⁵ United Nations Economic and Social Council, IX. Persons with Disabilities, in Discussion papers on the theme of the high-level political forum on sustainable development, submitted by major groups and other stakeholders, *High-level political forum on sustainable development*, convened under the auspices of the Economic and Social Council, 11-20 July 2016, UN Doc. E/HLPF/2016/2, 2 May 2016 (The author participated in this process as co-facilitator and co-author of the Discussion Paper on Persons with Disabilities).

UN'S Sustainable Development Goals (SDGs) will only be achieved when all international treaties, national laws and policies are inclusive, eliminate discrimination, and provide for reasonable accommodation.⁶⁶

While this might seem like a utopian policy statement, the paper also made more specific observations. It continued to state that compliance would be achieved when also discriminatory laws and practices would be eliminated, mentioning in particular in this regard the abolishing of those laws and practices allowing for restriction of legal capacity.⁶⁷

5.3 Shifting Perspectives at the ECJ: From Medical to Social Models

Moreover, the most important message to take home from the analysis of children's rights, is that of recognising and affirming the individuality, humanity and above all personhood of this group, as the best basis to build upon. And it is within this framework that the following sections, on the capacity of autistic persons as a group, should be read.

After examining the journey from protection to empowerment by studying children's rights more closely, the discussion shall once again return to the concept of 'good or bad', 'right or wrong', and the dominant/ minority dichotomy, in terms of the disabled rights journey, within the framework of the relevant blueprint outlined in previous sections.

This also as following on from the general overview of the medical and social models of disability, discussed in Section 1.1.2 of this thesis. This section will look particularly at how notions were translated through decisions of the European Court of Justice, also in light of how notions of protection versus empowerment affected said Court's reasoning and decisions along this journey.

⁶⁶ Ibid., at 58. The UN CRPD, at art. 2, defines reasonable accommodations as "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms".

Sometimes a person's need for a reasonable accommodation might be less apparent, especially in the case of 'invisible' disabilities, such as with autism, where a reasonable accommodation might be in the form of a quieter and less expansive working environment. This was also explained to the author by Jason Nolan, Professor at Ryerson University in Toronto, and activist with ASAN (Autistic Self-Advocacy Network) Canada, when in Nolan's working space, during an Interview, in July 2013. Nolan very simply summarised the situation, in saying that "reasonable accommodations are things which everybody *wants* to have, but that autistic persons *need* to have".

⁶⁷ Ibid.

5.3.1 A Medicalised Approach: The *Chacón Navas* Saga

On the European level, one can observe the same process and shift in perception being reflected through case law. The main judgement of the European Court of Justice for a good number of years was that in the *Chacón Navas* case,⁶⁸ in which the definition of disability put forward echoed the Medical Model through the following words:

“a limitation which results in particular from physical, mental or psychological impairments and which hinders the participation of the person concerned in professional life”.⁶⁹

This definition follows closely from the definition put forward by Advocate General Geelhoed in his Opinion, where he stated that “Disabled people are people with serious functional limitations (disabilities) due to physical, psychological or mental afflictions.”⁷⁰ Janneke Gerards states that such a definition is highly medical or functional in character, as it only refers to serious functional limitations that are the result of a physical, medical or psychological impairment, and find their basis in a medical problem.⁷¹

One could say that the Advocate General, and eventually the ECJ, relied on the internationally-established definition of ‘handicap,’ rather than of ‘disability,’ in this regard.⁷² Although the ECJ did seem to move towards the social model of disability following its ruling in the *HK Danmark* cases discussed shortly, overtones of the medical model, especially in terms of functional impairment language, seem to still be present, as evidenced, for example, in the discussion of the European Commission’s proposal for a European Accessibility Act.⁷³

⁶⁸ *Sonia Chacón Navas v. Eurest Colectividades SA*, decided as Case C-13/05 by the European Court of Justice on 11 July 2006, following a preliminary reference by the Juzgado de lo Social nº 33 of Madrid (hereinafter ‘*Chacón Navas*’).

⁶⁹ *Ibid.*, at para. 43.

⁷⁰ *Ibid.*, Opinion of AG Geelhoed, at 60.

⁷¹ Janneke Gerards, ‘Discrimination Grounds’, in Dagmar Schiek, Lisa Waddington and Mark Bell (eds.), *Ius Commune Casebooks for the Common Law of Europe, Cases, Materials and Texts on National, Supranational and International Non-Discrimination Law*, Hart, Oxford, 2007, at Section 1.3.9.

⁷² This would be the definition emanating from the Declaration on the Rights of Handicapped (later Disabled) Persons, G.A. res. 3447 (XXX), 30 U.N. GAOR Supp. (No. 34) at 88, U.N. Doc. A/10034 (1975), the forerunner of the UN CRPD, at art. 1.

⁷³ Proposal for a Directive of the European Parliament and of the Council on the approximation of the laws, regulations and administrative provisions of the Member States as regards the accessibility

Plaintiff also alleged in the proceedings that her dismissal was unlawful in terms of the Framework Equality Directive, which also prohibits all forms of discrimination on the basis of disability.

Deciding to request a preliminary reference from the ECJ in this regard, as to the second question, the Court held that sickness could not be added to the list of grounds covered by the Directive, since it was not explicitly mentioned in the Directive or the EC Treaty.⁷⁴ Therefore, reasonable accommodation in terms of Article 5 was not covered, according to its reasoning, since it did not qualify it as a disability.

Waddington insists the definition of disability developed by the Court in *Chacón Navas* is based on the medical or individual model of disability.⁷⁵ In this regard, Cabrielli argues that with *Chacón Navas*, the ECJ firmly scotched the notion that the Framework Directive embraced the social model.⁷⁶

It did so by holding that long-term illness or sickness was not the same thing as a disability, and that the claimant was required to show “a limitation... resulting from physical, mental or psychological impairments and which hinders the participation of the person concerned in professional life... that will last for a long time.”⁷⁷

In this regard, Waddington states that, according to the Court’s definition, the cause of the disadvantage (or the “limitation”) is the “impairment” which an individual has, and it is the “impairment” which hinders participation in professional life.⁷⁸ Therefore, she opines, the problem lies in the individual, and not in the reaction of society to the impairment or in the organisation of society.

As to victims’ potential standing in claiming discrimination, the Court stated that:

“an individual is required to first prove what s/he cannot do (that s/he has an

requirements for products and services, COM (2015) 615/2 (draft), published on 2 December 2015.

⁷⁴ Ibid.

⁷⁵ Waddington, op. cit., at 491.

⁷⁶ David Cabrielli, *Employment Law in Context: Text and Materials*, (2nd ed.), Oxford University Press, Oxford, 2016, at 480.

⁷⁷ *Chacon Navas*, at 21, in Cabrielli, op. cit., at 480.

⁷⁸ Waddington, op. cit., at 495.

impairment which hinders professional activity) in order to be allowed to later argue that they are qualified for a job or position and able to carry out the essential functions, and should not be discriminated against.”⁷⁹

If plaintiffs could not meet this first hurdle, as to qualifying as ‘disabled’ within the Court’s definition, they would also not qualify for protection under the law. Instead, Waddington states, one could argue that the key question should be whether discrimination has occurred, and not whether an individual is “disabled enough”⁸⁰ to qualify for protection under the Directive.⁸¹

Hosking argues that the Court failed to provide concrete detail on how adjudicators are to distinguish between a disability and chronic long-term sickness, illness, or temporary disability, while pitching the minimum common standard of protection from discrimination throughout the EU at a very low level.⁸²

However, the following excerpt from Waddington’s conclusion seems to carry a slightly prophetic tone in retrospect:

“[...] Chacón Navas is probably only the beginning of the Court’s reflections on the concept of disability within EC equality law, and one can only hope that the Court will catch up quickly with the other European institutions and the UN.”⁸³

5.3.2 *Towards the Social Model: The HK Danmark Cases*

In 2013, the European Court of Justice handed down its decision in the joined *HK Danmark* cases, otherwise referred to as *Ring and Skouboe Werge*.⁸⁴

⁷⁹ Ibid., at 493.

⁸⁰ Ibid. Similar policy was described by Israeli autistic rights activist Ronen Gil during an interview for the purposes of this work in July 2011 in Ra’anana, where after enquiring multiple times about accessible parking prior to a visit to the Office of the Commissioner for Equal Rights of People with Disabilities, he was told that he could be allowed a parking spot if he was “really handicapped”.

⁸¹ Waddington, op. cit., at 492.

⁸² D. Hosking, ‘A High Bar for EU Disability Rights’, *Industrial Law Journal*, Vol. 36, 2007, at 228, 237, in Cabrielli, op. cit., at 480.

⁸³ Ibid.

⁸⁴ *Ring v Dansk almennyttigt Boligselskab DAB and Skouboe Werge v Dansk Arbejdsgiverforening*, decided as Joined Cases C-335/11 and C-337/11 by the European Court of Justice on 11 April 2013, following a preliminary reference by the Sø- og Handelsret of Denmark (hereinafter the ‘*HK*

The significance of these cases stems from the fact that they are the first to define disability in terms of the Employment Equality Directive since the EU's ratified of the CRPD. However, it also finally saw the ECJ's approach shift from the very medicalised approach undertaken in *Chacón Navas*, to one which finally wedded the position at EU law to the social model of disability, in line with Article 27 CRPD,⁸⁵ according to Cabrielli.⁸⁶

As to the definition of disability itself, the medicalised and functionalised definition adopted in *Chacón Navas*, was instead traded for a definition reflecting Article 1 of the CRPD,⁸⁷ in the words of both EU authorities,⁸⁸ as well as of commentators such as Flynn.⁸⁹ The Court this time round defining disabilities as having to be:

“understood as referring to a limitation which results in particular from physical, mental or psychological impairments which in interaction with various barriers may hinder the full and effective participation of the persons concerned in professional life on an equal basis with other workers[.]”

adding that, however, “it follows from the second paragraph of Article 1 of the UN Convention that the physical, mental or psychological impairments must be ‘long-term.’”⁹⁰

Danmark cases).

⁸⁵ This article of the Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, U.N. GAOR, 61st Sess., U.N. Doc. A/Res/61/106 (Dec. 13, 2006) (hereinafter ‘UN CRPD’), deals with Work and Employment, and was one of the topics commented about by the author, as lead author in *Review of the European Union: About Autism, Without Autistics*, joint written submission to the 14th session of the UN Committee on the Rights of Persons with Disabilities by Autistic Minority International, Enthinderungsselbsthilfe von Autisten für Autisten (und Angehörige) (Germany), Alliance Autiste (France) and Autism Women Matter (United Kingdom), Geneva, 3 August 2015, available http://tbinternet.ohchr.org/Treaties/CRPD/.../EUR/INT_CRPD_CSS_EUR_21278_E.doc, drafted by way of submissions for consideration by the UN CRPD Committee, prior to its consideration of the EU's first State Report on UN CRPD implementation during its 16th Session.

⁸⁶ Cabrielli, op. cit., at 481.

⁸⁷ Article 1 of the UN CRPD states that “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.”

⁸⁸ European Commission, COMMISSION STAFF WORKING DOCUMENT, Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union, SWD(2014) 182 final, Brussels, 5 June 2014, at para. 20, at 8.

⁸⁹ Eilionoir Flynn, ‘New Decision on Disability Discrimination from the CJEU’, *European Law Blog*, 12 April 2013, accessed online at <http://europeanlawblog.eu/?p=1696>.

⁹⁰ *HK Danmark*, op. cit., at 39.

The facts of the joined cases involved two women who were dismissed from employment when they returned to work following a period of sick leave. Ms. Ring was dismissed after sick leave she took due to constant lumbar pain which could not be treated. Ms Skouboe Werge took sick leave due to whiplash injuries she received in a road traffic accident.

The reasons provided for the employers for both dismissals were that the applicants could no longer carry out full time employment due to illness. The employers argued that such dismissals are provided for under Danish law, if the employee had received her salary during periods of illness for a total period of 120 days during any period of 12 consecutive months.⁹¹

The trade union which brought claims on behalf of the applicants argued that both employees fell within the scope of the Employment Equality Directive as disabled persons. It further claimed that the respective employers should have offered both employees reduced working hours, as a ‘reasonable accommodation’ under the Danish Anti-Discrimination Law⁹² transposing the Directive, rather than dismissing them.⁹³

In *Chacón Navas*, as discussed earlier, the Court had drawn a clear line between the concepts of illness or ‘sickness’ and disability, stating that “the legislature deliberately chose a term which differs from ‘sickness’. The two concepts [disability and sickness] cannot therefore simply be treated as being the same.⁹⁴” This was in light of the functionalised definition then adopted by the Court in light of the Advocate General’s Opinion. Where illness or sickness did not entail such a limitation, it could not, therefore, come within the definition of disability.

In the *HK Danmark* rulings, the Court did not set aside its decision in *Chacón Navas*, but rather pointed out that this previous ruling was adopted prior to the entry into force of the

⁹¹ Ibid., at 24.

⁹² Law on the legal relationship between employers and salaried employees (Lov om retsforholdet mellem arbejdsgivere og funktionærer), LBK nr 1349 af 16/12/2008, Publication Date 20-12-2008. The law states, in Article 2a, that: “Employers shall take appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to enable a person with a disability to undergo training. This does not however apply if such measures would impose a disproportionate burden on the employer. This burden shall not be regarded as disproportionate if it is sufficiently remedied by public measures.”

⁹³ *HK Danmark*, op. cit., at 23.

⁹⁴ See Section 5.3.1 of this thesis.

CRPD.⁹⁵ However, Mark Bell notes that it also, for the first time, acknowledged the complex relationship between sickness and disability.

While leaving application of the definition reached to the specific facts of the case within the hands of the national court in question, there was an implicit undertone that the claimants' circumstances did meet the definition of disability for the purposes of the Directive.⁹⁶ This when stating that a reduction in working hours would fall within the type of reasonable accommodation to disabled people prescribed by the Directive, but within going into the specificities of its application.⁹⁷ This view was, in fact, subsequently adopted by the relevant Danish court.

In redefining the concept of disability at EU law, the Court also emphasised that “the primacy of international agreements concluded by the European Union over instruments of secondary law means that those instruments must as far as possible be interpreted in a manner that is consistent with those agreements.”⁹⁸

According to Flynn, the Court thus read ‘disability’ in the Employment Equality Directive to reflect Article 1 of the CRPD as stated above, thus providing an inclusive, non-exhaustive list of impairments, which when combined with societal barriers, can constitute disability.⁹⁹

With regard to the shortened period of notice provided for in Danish law for such dismissals (following a period of sick leave in which an individual received her salary), the Court also held that this could constitute indirect discrimination on the ground of disability. As Bell states, the fact that workers with disabilities risk having a higher level of sickness absence, the relevant provision of Danish law under consideration placed disabled workers at a particular disadvantage.¹⁰⁰

⁹⁵ Flynn, op. cit.

⁹⁶ Mark Bell, ‘Sickness Absence and the Court of Justice: Examining the Role of Fundamental Rights in EU Employment Law’, *European Law Journal*, Vol. 21, No. 5, September 2015, at 652.

⁹⁷ *HK Danmark*, op. cit., at 93 (2).

⁹⁸ *Ibid.*, at 29.

⁹⁹ Flynn, op. cit.

¹⁰⁰ Bell, op. cit., at 653.

In order to justify such indirect discrimination, the Court found that the national court would have to consider whether Danish law was pursuing a legitimate aim, and whether the action was proportionate to that aim.¹⁰¹

5.4 At the UN – from Handicapped Persons to Persons with Disabilities

A second observation to be made is that nowadays, legislation seems, in theory at least, to be moving away from a medical model of disability, and closer towards a social model. This can be seen when one compares the definition of disability given by the 1975 UN Declaration on the Rights of Handicapped (later Disabled) Persons:

“The term “disabled person” means any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities”,¹⁰²

with that contained in the 2006 UN Convention on the Rights of Persons with Disabilities:

“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.”¹⁰³

¹⁰¹ *HK Danmark*, op. cit., at 93 (4).

¹⁰² Declaration on the Rights of Disabled Persons, G.A. res. 3447 (XXX), 30 U.N. GAOR Supp. (No. 34) at 88, U.N. Doc. A/10034 (1975), at art. 1.

¹⁰³ UN CRPD, op. cit., at art. 1.

Chapter 6: ‘Pro-Cure’ vs ‘Anti-Cure’ – Medical Model vs Social Model?

6.1 Introduction

The previous Chapters have discussed shifts in perceptions, in terms of ‘good and bad’, ‘right and wrong’, and the dominant/ minority dichotomy. They have likewise illustrated how provision of correct information, together with changing perceptions, were key to the journeys undertaken by societies with respect to linguistic and ethnic groups and LGBTQI persons.

The shift in approach, from one rooted in protection, to one based on empowerment, was also observed, in terms of both children’s rights, as well as the wider category of disability rights. As to the latter, all of the features in this paragraph featured in the journey from the medical to the social model of disability, as discussed in Section 1.1.2 of this thesis, and further discussed in Sections 5.3 and 5.4.

One has to also bear in mind societal resistance to change, such as in the case of languages, where such is rooted in the majority group’s desire to cling to dominant status, of LGBTQI persons, in light of societal discussions as to what is right and wrong, and of children, in terms of the shift from protection to empowerment. Mirror elements in all these areas are also able to be seen in the case of disabilities, in terms of the journey from the medical to the social model.

It is now time to come full circle, and bring the discussion back to autism, analysing the interplay of the different elements discussed within the field of autism rights, together with relevant efforts for change, both those having a negative, as well as those having a positive import. In the latter case, reference is being made to efforts aimed at changing perceptions through correct awareness and knowledge dissemination, as the starting point on the journey towards acceptance and inclusion. The Chapter will also analyse how far ahead the field of autism rights is on the journey set out in the blueprint discussed in the previous Chapters.

The Chapter will also look at the different camps fighting for the rights of autistic persons, although their views of what constitutes such rights might differ considerably, as already discussed further in Section 1.1.3 of this thesis.

On the one hand, it will discuss traditionally 'Pro-Cure' groups, consisting of parents, guardians and professionals, and traditionally mostly focused on researching a cure into autism, as well as therapies for normalisation/ indistinguishability of autistic persons. Anti-vaccines groups, whose activism is based on the discredited hypothesis that vaccines can cause autism, also fall within this camp.

The ideologies and efforts of this camp will be analysed, together with looking at how certain groups within this camp have attempted reform towards further inclusion of and rapprochement towards autistic persons themselves, also consequently becoming less identifiable with the description of 'pro-cure' outfits.

On the other hand, 'pure' autistic self-advocacy groups will also be discussed, together with their focus on rights, identity and personhood, as well as the positives and negatives of such groups, their strategies for operation, as well as the issue of extreme elements and tendencies within certain of such groups. The issue of rapprochement towards more moderate, traditionally 'pro-cure' groups, and well as these groups' moving away from more radical positions, will also be tackled.

Against such backdrop, the Chapter will also look at how the journey in the field of autistic rights is mirroring that in disability rights and other rights fields discussed earlier, within the framework of the blueprint outlined in this regard. It will discuss how far matters are moving forward, and how far matters are being held back, especially due to the diametrically opposed ideologies still present in this field, the basis of the 'bitter ideological war' in Laurence's words, as mentioned in Section 1.1.4 of this thesis.

6.2 'Pro-Cure' Groups: Researching the Cause of the Aberrance

The camps, usually almost exclusively made up of parents and guardians of autistic persons, which focus on researching into the prevention and cure of autism, as well as the

'normalisation'/'indistinguishability'¹ and social compliance of autistic children, are labelled the 'pro-cure' camp in the wider discourse pertaining to the autism rights movement.²

In this regard, the primary organisation seen as leading the 'pro-cure' camp is the American-registered international organisation Autism Speaks, founded as 'Cure Autism Now (CAN)' by millionaire US businessman Bob Wright and his wife, the late Suzanne. The Wrights are parents of an autistic child, and the organisation has links or offshoots in different countries around the world, especially in the global South.³

Such 'pro-cure' organisations are seen by their self-advocate counterparts as negating the personhood and identity of autistic persons, perceiving them as broken, and focusing all efforts on either preventing more of them, excluding them or fixing them,⁴ glorifying the struggles of parents who have to 'bear the cross' of such a terrible tragedy⁵ – rather than focusing on the real challenges of parenting an autistic child.

This while upholding the child's personhood, and assisting the parent, especially if new, with assistance and support to face this unfamiliar situation, rather than continuing to spew vitriol about how bad and broken their child, and by association that parent, is. Such an

¹ *CONNOR AUTON, an Infant by his Guardian Ad Litem, MICHELLE AUTON, and the said MICHELLE AUTON in her personal capacity, MICHELLE TAMIR, an Infant, by her Guardian Ad Litem SABRINA FREEMAN, and the said SABRINA FREEMAN in her personal capacity, JORDAN LEFAIVRE, an Infant by his Guardian Ad Litem, LEIGHTON LEFAIVRE, and the said LEIGHTON LEFAIVRE in his personal capacity, RUSSELL GORDON PEARCE, an Infant, by his Guardian Ad Litem, JANET GORDON PEARCE, and the said JANET GORDON PEARCE in her personal capacity v. THE ATTORNEY GENERAL OF BRITISH COLUMBIA and THE MEDICAL SERVICES COMMISSION OF BRITISH COLUMBIA*, Supreme Court of Canada, per McLachlin CJ and Major, Bastarache, Binnie, LeBel, Deschamps and Fish JJ, 9 June 2004, Docket: 29508 [2004] 3 SCR 657, 2004 SCC 78 (*Auton et al. v. Attorney General of British Columbia*), at 658. See also Footnotes 40 and 57 of Chapter 2 of this thesis, discussing the genesis of the term within the original Lovaas method, and its use in the paper by Lovaas and his colleagues covering the controversial 'sissy boy' case.

² As explained in, for example, Kristina Chew, 'Do we really need a cure for autism?', Opinion: Autism, *The Guardian*, 22 February 2013, accessed online at <https://www.theguardian.com/commentisfree/2013/feb/22/does-autism-need-a-cure>.

³ An example of one such initiative is the Global Autism Public Health Initiative, as further detailed on Autism Speaks' website at <https://www.autismspeaks.org/science/research-initiatives/global-autism-public-health>.

⁴ Intervener's Factum by Michelle Dawson, in *Auton et al. v. Attorney General of British Columbia*, Supreme Court of Canada, op. cit.

⁵ See, for example, Carol Sarler, 'Why can't we face the truth? Having an autistic child wrecks your life ...', *The Mail Online*, 15 January 2009, accessed at <http://www.dailymail.co.uk/femail/article-1116602/Why-face-truth-Having-autistic-child-wrecks-life-.html>.

attitude, in general, reinforces the medical model of disability, which has been discredited internationally in favour of the social model, in the spirit of which the UN CRPD, which currently 166 States Parties have ratified,⁶ was brought into being.

As to such traditionally ‘pro-cure’ groups, two main lines of researched are championed by them, based on their principal stances.

6.2.1 *The Search for the Autism Gene*

The first is genetic research, the search for an autism gene, as further discussed in Section 9.2 of this thesis.

However, the discovery of the Down’s Syndrome gene has so far neither allowed researchers to ‘turn it off,’ nor treat it in any manner. Although it did allow for a number of tests, some even home-based, to screen for the Down’s Syndrome gene, in order for termination of pregnancy to be able to be requested should presence of such gene transpire.

A number of transnational research projects were undertaken in this field, the principal among them being the Autism Genome Project, discussed later in this work.⁷ Research so far has pointed to the fact that autism is not the result of a single gene in the same fashion as Down’s Syndrome, or even solely genetic in nature.

Rather, it is linked to a wider number of networks within the human body,⁸ with the necessary ‘code’ possibly dormant in every human being.⁹ Nonetheless, a number of

⁶ CRPD Ratifications web page on United Nations Treaty Collection website, https://treaties.un.org/pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en, as of 31 October 2016.

⁷ See Section 9.2 of this thesis for a discussion of this topic.

⁸ See, for example, Joon Yong An and Charles Claudianos, ‘Genetic heterogeneity in autism: From single gene to a pathway perspective’, *Neuroscience & Biobehavioral Reviews*, June 2016.

⁹ See, for example, Elise B Robinson, Beate St Pourcain, Verner Anttila, Jack A Kosmicki, Brendan Bulik-Sullivan, Jakob Grove, Julian Maller, Kaitlin E Samocha, Stephan J Sanders, Stephan Ripke, Joanna Martin, Mads V Hollegaard, Thomas Werge, David M Hougaard, Thomas D Als, Marie Baekvad-Hansen, Richard Belliveau, Ditte Demontis, Ashley Dumont, Jacqueline Goldstein, Jonas Grauholm, Christine S Hansen, Thomas F Hansen, Daniel Howrigan, Francesco Lescai, Manuel Mattheisen, Jennifer Moran, Ole Mors, Merete Nordentoft, Bent Norgaard-Pedersen, Timothy Poterba, Jesper Poulsen, Christine Stevens, Raymond Walters, Benjamin M Neale, David M Evans, David Skuse, Preben Bo Mortensen, Anders D Børglum, Angelica Ronald, George Davey Smith, Mark J Daly, ‘Genetic risk for autism spectrum disorders and neuropsychiatric variation in the

initiatives in the field of early detection and prevention, also discussed later, have been made public, although the rationale behind some, as later discussed, is shaky at best.¹⁰

Autistic self-advocates have states that, instead, such groups should rather focus their money and resources on developing supports and services for autistic persons, and towards making sure this research is being performed in pursuit of the 'right aims'. At the very most, self-advocates suggest that these mainly 'pro-cure' groups should only place a small percentage of such money towards research into autism's aetiology, and rather devote the rest towards researching and developing supports and services.¹¹

6.2.2 *The 'Vaccines Cause Autism' Controversy*

The second field of research championed by a different section of 'pro-cure' organisations is into the link between autism and vaccines, particularly the mercury-based thiomersal component in vaccines, special attention being given to the Mumps, Measles and Rubella (MMR) combined vaccine. The main concern here was the hypothesis that such component could send the human body into regression once introduced therein, bringing on the symptoms clinically associated with autism.

Since certain subtypes of autism, such as Heller's Syndrome, also known as Childhood Disintegrative Disorder, are also observed to take this course,¹² then it was subsumed that, in an otherwise healthy child with no previous symptoms, the timing of the administration of such a vaccine close to the initiation of the symptom course proved a causal link between such vaccines and autism.

general population', *Nature Genetics*, 2016.

This study, by a team of international researchers including academics from the University of Bristol, the Broad Institute of Harvard and MIT, and Massachusetts General Hospital (MGH), sheds new light on the genetic relationship between autism and 'ASD-related traits' in the wider population, by looking into whether there is a genetic relationship between autism and the expression of such traits in populations not considered to have an autism diagnosis. The relevant findings suggest that "genetic risk underlying ASD, including both inherited variants and de novo influences (not seen in an individual's parents), affects a range of behavioral and developmental traits across the population, with those diagnosed with ASD representing a severe presentation of those traits."

¹⁰ See Section 9.2.2 of this thesis for a discussion of this topic.

¹¹ Interview with Ari Ne'eman, Founder and President, ASAN (Autistic Self-Advocacy Network), New York, May 2011.

¹² ICD-10, op. cit., at F84.2–F84.3; DSM-IV-TR at 299.10. In the DSM-5, this diagnosis was subsumed into the category of 'autistic spectrum disorder,' at 299.00.

The argument was bolstered strongly after an article published in *The Lancet*, the journal of the British Medical Association, by Andrew Wakefield, a medical doctor eventually struck off the medical register. Wakefield studied a cohort of young children, and their progress or regression in relation to the MMR vaccine having been administered.¹³ The data for such paper, also according to Wakefield's own admission, had been fabricated,¹⁴ and this led a mortal blow to the movement in mainstream science, having not had much evidence to make their case with otherwise.

However, the movement persists, particularly in the United States, where there remains a very vocal community. Members are particularly active through online fora, such as 'Age of Autism,'¹⁵ pushing the vaccines theory, as well as backed by academics who still endorse the argument, such as NYU academics Mary Holland and Louise Kuo Habakus.¹⁶ The movement was further supported by politicians such as former Indiana Congressman Dan Burton,¹⁷ and more recently, Presidential nominee Donald Trump.¹⁸

¹³ AJ Wakefield, SH Murch, A Anthony, J Linnell, DM Casson, M Malik, M Berelowitz, AP Dhillon, MA Thomson, P Harvey, A Valentine, SE Davies, JA Walker-Smith, 'RETRACTED: Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children', *The Lancet*, Volume 351, No. 9103, 28 February 1998, at 637–641.

¹⁴ See Paul A. Offit, *Autism's False Prophets: Bad Science, Risky Medicine and the Search For a Cure*, Columbia University Press, New York/ Chichester, 2008, at 53.

¹⁵ Age of Autism Website and Online Forum at <http://www.ageofautism.com>.

¹⁶ See Louise Kuo Habakus and Mary Holland (eds.), *Vaccine Epidemic: How Corporate Greed, Biased Science, and Coercive Government Threaten Our Human Rights, Our Health, and Our Children*, Skyhorse Publishing, New York, 2011.

The sentiments in this Section were also expressed during an Interview with Prof. Holland (New York, May 2011), who was contacted after having been identified as the director of the Elizabeth Birt Center for Autism Law and Advocacy (EBCALA) at NYU, an institution whose seemingly general remit is more specifically focused on the perceived nexus between vaccines and autism discussed in this Section.

¹⁷ Burton, now retired, still maintains a page on his former Congressional website, at <http://burton.house.gov/issues/autism>, which provides access to a number of his speeches in Congress supporting the autism-vaccines theory, as well as interventions at Congressional hearings on the topic and media resources.

Burton was also mentioned by Mary Holland in the author's Interview with her, op. cit., where she mentioned that Burton was a 'big supporter' of the cause she advocated for.

¹⁸ Current US Presidential Candidate Donald J. Trump caused outrage with the following tweets from @realDonaldTrump supporting the autism-vaccines theory:

"Autism WAY UP - I believe in vaccinations but not massive, all at once, shots. Too much for small child to handle. Govt. should stop NOW!" 27 March 2014

"Healthy young child goes to doctor, gets pumped with massive shot of many vaccines, doesn't feel good and changes - AUTISM. Many such cases!" 28 March 2014

"I'm not against vaccinations for your children, I'm against them in 1 massive dose. Spread them out over a period of time & autism will drop!" 4 September 2014.

Unfortunately, while this is not a phenomenon exclusive to the anti-vaccines, or ‘anti-vaxxer’ camp, a lack of education and zealous over-adherence to fixed false beliefs seems to be a hallmark of this camp.

This can be seen, for example, in the circulation of internet flyers arguing that since it would be criminal to give mercury to one’s children to consume, then it should likewise be criminal to administer to them vaccines containing mercury-based products. Such argument fails to observe that mercury-based products in vaccines have been processed according to a number of standards in order to make them safe for human consumption, while also missing a number of other basic points rooted in conventional science as scientific knowledge currently stands.¹⁹

In this regard, a number of jurisdictions have passed legislation restricting a parent or guardian’s rights to claim certain state benefits should they not vaccinate,²⁰ while parents have also been sued criminally for the death of a child allegedly linked to the parents’ decision not to vaccinate said child.²¹

6.3 Autistic Advocates – From Focus Group to Rights Movement

As already discussed in Section 1.1.2 of this thesis, the ‘neurodiversity’ movement has championed the cause of self-advocacy in the field of autistic rights, also attempting the successes of the disability rights movement in this regard. The birth of this movement, as outlined earlier, can be traced back to the activism of Jim Sinclair, and the propagation of

¹⁹ See themetapicture.com, ‘Angry Scientist Finds Uneducated Internet Comment And Delivers Badass Response...’, 24 February 2013, accessed online at <http://themetapicture.com/angry-scientist-finds-uneducated-internet-comment-and-delivers-badass-response/>.

²⁰ See, for example, ‘Australia to Cut Benefits for Parents Who Don’t Vaccinate Kids’, *Time Magazine Online*, 13 April 2015, accessed at <http://time.com/3819178/australia-vaccination/>. The aim of this legislation was to end the ‘conscientious objector’ exemption regarding vaccination requirements under Australian law; California SB-277 Public health: vaccinations.(2015-2016), 30 June 2015, amending the California Health and Safety Code, bars access to free public and private preschools, K-12 schools, daycare facilities and after school care programmes to children, with the exception of home-based private schools, independent study programmes without classroom-based instruction and IEPs (Individualised Education Programmes), should their parents not comply with state vaccination requirements for them.

²¹ Michael E. Miller, ‘A toddler got meningitis. His anti-vac parents gave him an herbal remedy. The toddler died. Now his parents are on trial’, *The Washington Post Online Edition*, 18 March 2016, accessed online at <https://www.washingtonpost.com/news/morning-mix/wp/2016/03/18/a-toddler-got-meningitis-his-anti-vac-parents-gave-him-an-herbal-remedy-the-toddler-died-now-his-parents-are-on-trial/>.

Sinclair's vision through the subsequent founding of Autism Network International (ANI) in the United States in the 1990s.²²

6.3.1 *Early Steps*

ANI, while remaining a largely US-based organisation, with links in other countries such as Israel, managed, for the first time, to foster a self of community and increasingly louder self-advocacy as the years went by, for the first time anywhere in the world.

The association's flagship was the organisation of the annual Autreat – composed of the words 'autistic' and 'retreat' – in the United States.²³ It brought together on an annual basis a number of American and international autistic self-advocates, as well as a small number of allies (non-autistic persons who actively support the autistic community and its values). There were presentations on and discuss about a number of current topics affecting the autistic community, through plenary sessions followed by question time, and poster sessions.

But most importantly, Autreat hosted a number of activities throughout the 5-day event, tailored to be autistic-friendly, such as social events using sensory-friendly lighting and promoting sensory input, and a general event structure that was planned around minimising stress and fatigue, as well as participants being overwhelmed and/ or suffering sensory overload.

Autreat allowed for accessible participation and use of as wide a number of communication styles as possible, allowing for activists generally considered 'non-verbal'/ 'low-functioning' by the mainstream community, such as Amy Sequenzia²⁴ or Amanda Baggs,²⁵ to find a proper voice for the first time, and the spark to push their advocacy further.

²² Jim Sinclair, 'AUTISM NETWORK INTERNATIONAL: THE DEVELOPMENT OF A COMMUNITY AND ITS CULTURE', January 2005, accessed online at http://www.autreat.com/History_of_ANI.html.

²³ See <http://www.autreat.com/> for information on Autreat up till its last incarnation in 2013.

²⁴ As reported on Autism Women's Network Facebook page at <https://www.facebook.com/AutismWomensNetwork/photos/a.131169816899804.23226.112933545390098/693438857339561>.

²⁵ See, for example, Donna Williams, 'Putting autism on trial: an interview with Amanda Baggs', Polly's pages (aka 'Donna Williams'), 3 July 2007, accessed at <http://blog.donnawilliams.net/2007/07/03/putting-autism-on-trial-an-interview-with-amanda-baggs/>.

When Sinclair eventually retired from the association in 2013, it was reconstituted as the Association for Autistic Community (AAC) thereafter, and continued in the same vein.²⁶

6.3.2 *Identity and Personhood – Reappropriation of Terminology (Example)*

One of the main points components of the autistic identity fostered by ANI, through the movement started by Sinclair, was the use of 'identity-first language' as opposed to 'person-first language' within the field of autism, following the lead of the disabled persons' rights movement initiated by UPIAS in the UK,²⁷ with the goal of reclaiming the term 'autistic', until then considered to be a dirty word in mainstream circles.

While texts being quoted in the analysis of legal instruments in this thesis, as well as many current published items dealing with autism, use the terminology 'person/s' with autism, one of the main points under discussion in this thesis is that autism is part and parcel of a person. It is not to be viewed, according to this line of thought, as a disease or extraneous condition that needs to be eliminated or changed. This was Sinclair's philosophy in pushing forward the use of 'identity-first language' over 'person-first language' in autistic rights activism.²⁸

The argument put forward by ANI, in line with UPIAS' earlier argument, was that the use of such language was as opposed to terminology such as 'persons with disabilities', that indicates a disability experienced by a person due to constraints imposed by society, such as a lack of universal design.

Sinclair argued that autism is hard-wired into a person's brain just as 'male-ness' or 'female-ness' is, with persons being referred to as 'males' or 'females' rather than 'people with maleness' or 'people with femaleness' in such cases. Following the same line of thought, this work deals with 'autistic persons' and not with 'persons with autism'.

²⁶ Further information about the Association for Autistic Community (AAC) can be found on their website, at <http://autisticcommunity.org>.

²⁷ As referred to, for example, in Tom Shakespeare and Nicholas Watson, 'The social model of disability: an outdated ideology?', *Research in Social Science and Disability*, Vol. 2, 2002, at 9, 13.

²⁸ Jim Sinclair, 'Why I dislike "person first" language', published on Sinclair's 'About Autism' website at http://web.syr.edu/~jisincla/person_first.htm.

In this regard, in Malta, the final text of the Persons within the Autism Spectrum (Empowerment) Act takes into account different choices of language used to describe persons within the autism spectrum. To this end, “persons within the autism spectrum” was used²⁹ throughout the Act, as well as in piloting the Bill through Parliament,³⁰ and in relevant official statements concerning the Act.³¹

This was done in conjunction with medicalised references to autism as a disorder having also been done away with, the original title of the Bill presented at the First Reading in Parliament, the ‘Autism Spectrum Disorders (ASDs)’ Bill,³² making way instead for a title referring to the autism spectrum, and to its empowerment.

Notwithstanding efforts such as the adoption of identity-first language, however, the self-advocate community globally was still largely made up of persons who had been neglected and broken by society. These were persons who were venting their anger and frustration using their rights to free speech but who, unfortunately, were being drowned out by the slick PR machine of the ‘pro-cure’ camp, and the funding it was receiving.

6.3.3 *Moving Towards External Advocacy*

A few self-advocates, following ANI’s lead, and emboldened by the new-found sense of identity and personhood that the nascent autistic rights movement brought with it, attempted to take their advocacy to the mainstream.

In this regard, there were two such routes chosen by self-advocates, in order to ‘hit back’ and counter the mainstream ‘pro-cure’ rhetoric. In order to counter this, some self-advocates realised the need to play the ‘curebies,’ as ‘pro-cure’ advocates came to be known within the self-advocacy community, at their own game.

²⁹ Persons within the Autism Spectrum (Empowerment) Act, Cap. 557 of the Laws of Malta.

³⁰ See Minutes of Parliamentary Debates, Second Reading Debates, Persons within the Autism Spectrum (Empowerment) Bill, Bill No. 136 of 2015, 4 April 2016, 19 April 2016 and 26 April 2016.

³¹ See, for example, references to the Act made within the context of ‘Building an Inclusive Rights Agenda for Autistic Adults: COSP9 side event held by the Government of Malta in collaboration with Autistic Self-Advocacy Network’, Press Release Issued by the Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing, PR161396, Department of Information, Valletta, 17 June 2016.

³² Autism Spectrum Disorders (ASD) Bill, later Persons within the Autism Spectrum (Empowerment) Bill, Bill No. 136 of 2015.

6.3.3.1 'Infiltrating the Mainstream'

The first was to become involved in organisations dominantly viewed to be 'pro-cure', both ones such as Autism Speaks, as well as federations of local or national organisations doing more general autism advocacy, such as the Autism Society of America in the United States, and Autism-Europe in Europe. Self-advocates who chose this route were at times shunned as traitors by more radical, 'go it alone' self-advocates, emphasising that these were the people hurting the community, and now these autistics were allying with them.³³

The term 'shiny autistics' was also used by such self-advocates for these persons, especially when the person's move was seen as mainly reflecting a desire to be in the limelight. However, this has also been applied to committed long-time self-advocates such as Dr. Temple Grandin,³⁴ simply for associating with and speaking at events organised by more mainstream organisations.

Although slow, this involvement has, nonetheless, brought around a number of changes. For example, the Autism Society of America (ASA) has a commitment to represent both parents and guardians, as well as self-advocates, having created separate sub-structures for both within the organisation.³⁵ This also makes sure that both get necessary airtime in the programme of any event organised by the organisation, such as the ASA's Annual General Meeting, even if the balance is still seen to shift towards the parent and guardian camp, in terms of attendance, involvement and programme content.³⁶

Although members of the autistic community do see parents and guardians as being too forceful and trying to crowd out self-advocates to push forward their own agenda instead, it must be also noted that a large number of self-advocates do stay away from such

³³ These comments are similar to those expressed by, for example, Erich Kofmel, Founder and President of Autistic Minority International, considered to be at the more radical end of the self-advocate spectrum, during a Meeting with the author, in Geneva, in August 2016.

³⁴ See, for example, 'Ask Dr. Temple Grandin About Animals and Autism', Community Interview initiated on Slashdot.org on 17 July 2015, accessed online at <https://science.slashdot.org/story/15/07/15/1755216/interviews-ask-dr-temple-grandin-about-animals-and-autism>.

³⁵ See Autism Society of America website, 'About the Autism Society' section, accessed online at <http://www.autism-society.org/about-the-autism-society/>

³⁶ See, for example, Programme of the ASA's 47th National Conference (14-16 July 2016) and Preconference (13 July 2016), available online at http://www.autism-society.org/wp-content/uploads/2016/09/AS_ConfProgGuide2016_1i-1.pdf.

organisations or events, which also contributes to this imbalance. This is also noted by certain self-advocates, and is cited as one of the reasons why certain self-advocates have chosen the path being described at the moment.

However, what does take place is passionate and meaningful, leading to small but important changes, such as the compromise reached within the Autism Society of America to use the term 'persons on the autism spectrum' in all official literature, instead of 'persons with autism' or 'autistic persons.' Each of these terms might be offensive to a certain section of the autism community, be it parents and guardians, or autistic persons, who might choose to identify with the one and not the other of the previous two designations.³⁷

A number of activists, such as Dena Gassner, have also made a name and gained the trust of sections of the non-self-advocate camp through their involvement within the ASA, being invited to speak at events both as an ASA representative, as well as in her own right as self-advocate.³⁸

Autism-Europe, while also having in its statutes that member organisations and individuals can be from the parent and guardian, self-advocate or mixed camps, is still viewed by many self-advocates with mistrust, due to a long history of being parent and guardian-led. However, it is embarking on a process of reform in line and consultation with the ASA.³⁹ Additionally, it has also for the first time recently elected an autistic self-advocate, Pietro Cirrincione, as its Vice-President, the highest position achieved by a self-advocate within the organisation so far.

³⁷ See, for example, National Autistic Society, 'The language we use to describe autism', available online at <http://www.autism.org.uk/about/what-is/describing.aspx>.

³⁸ For example, Gassner, regularly speaks during the Panel of People on the Spectrum of Autism Town Hall Meeting, at the annual National Conference of the Autism Society of America, as well as participating in events hosting by external organisations, including Autism Speaks, as in, for example, 'New Yorkers talk need for housing options at Town Hall meeting', Autism Speaks website, 11 November 2015, accessed online at <https://www.autismspeaks.org/news/news-item/new-yorkers-talk-need-housing-options-town-hall-meeting>.

Gassner also authored a mailshot entitled 'A Personal Take on Independence from Dena', sent to the ASA's mailing list on 26 July 2016, in which she drew on her personal position as well as position of trust, in order to encourage recipients to donate to the ASA, by highlighting their work and commitment towards capacity-building and development in the area of self-determination of autistic persons.

³⁹ This process was suggested by the author, in conversations with Autism-Europe Director Aurélie Baranger in late 2015 and early 2016, also putting her in touch with former ASA Vice-President Jeff Sell towards this end.

As for self-advocates who have decided to join the Board or structures of more avowedly 'pro-cure' organisations such as Autism Speaks, such as Stephen Shore in the latter case, and Kerry Magro in the former case, the situation has been trickier. Aside from these persons being shunned by sections of the autistic community at times, and even being threatened,⁴⁰ much more resistance has been observed due to the strength in number of 'curebies' within such organisations.

However, activists such as Shore insist that, even having one autistic person on such Boards keeps such organisations in check, as in having to explain and consider further certain decisions before taking them, a step they would otherwise be totally free to ignore, should there be no such 'checks and balances' present.⁴¹ He stated his reason to accept the offer made to him to join Autism Speaks' Board in December 2015, after having rejected previous such offers, on the basis that the new Chairman of the Board decided to focus more on supports and services, and not just on researching cures, as opposed to the previous founding Chairman.⁴²

Although criticised for his decision, as mentioned earlier, Shore's decision seems to have already been vindicated to a small degree, due to the recent decision of the Autism Speaks Board, on 14 October 2016, to drop the element of cure from the aims of the organisation.⁴³

It must also be noted that some self-advocates, though not directly participating in such structures, still avail of funding programmes run by these organisations, in order to fund their own research benefitting the autistic community. Noted self-advocates such as Canadian Michelle Dawson, carrying out her research within the framework of Hôpital

⁴⁰ Monique Blakemore, autistic self-advocate and founder of Autism Women Matter, in conversations in March 2016, in Brussels, stated how she had received threats and even death threats, due to her activism, and the stances she took at times.

⁴¹ See, for example, this account of Shore's appointment by pro-cure self-advocate Jonathan Mitchell, in 'Autism speaks appoints autistic board members, pro-cure autists again scorned', *Autism's Gadfly blog*, 7 December 2015, accessed online at <http://autismgadfly.blogspot.ie/2015/12/autism-speaks-appoints-autistic-board.html>.

⁴² Ibid.

⁴³ Allison Fox, 'Why Autism Speaks Dropped The Word 'Cure' From Its Mission Statement', *The Huffington Post*, 18 October 2016, accessed online at http://www.huffingtonpost.com/entry/cure-for-autism_us_58062f2be4b0dd54ce3522b1. When interviewed, Shore stated that he believed that "the organization grew to believe that autism is something to be worked with for promoting fulfilling and productive lives of people on the spectrum – rather than something that has to be done to", adding that he felt that the biggest change from Autism Speaks' old mission statement was a new emphasis on supporting autistic individuals throughout their lifetime.

Rivière des Prairies in Montreal,⁴⁴ as well as Dena Gassner, who also accepts invitations to attend and talk at events organised by such associations, are examples of this.⁴⁵

6.3.3.2 Autistics Going Solo

On the other hand, there is that group of autistic self-advocates who still decided to play the 'curebies' at their game, but to do it from the outside. The largest such experiment was the Autistic Self-Advocacy Network (ASAN),⁴⁶ founded by American self-advocates Ari Ne'eman and Scott Robertson in 2006, when still teenagers.⁴⁷

From a fringe group initially, they worked their way into the mainstream policy field, liaising with the major figures of the autistic self-advocacy community in the United States, as well as representative organisations such as ANI, on the one hand. On the other hand, they reached out to state authorities and professional bodies,⁴⁸ such as the US National Council on Disabilities (NCD), members of the US Houses of Congress, the Inter-Agency Autism Coordinating Council (IAACC) and the American Psychiatric Association (ASA)'s DSM drafting committee.

By acting as a go-between, they attempted to channel the concerns and stand up for the rights of the autistic community with these institutions, while attempting to act as interlocutor as regards any feedback. In this regard, ASAN President Ari Ne'eman was eventually also invited to sit on both the NCD⁴⁹ and IAACC⁵⁰ representing the organisation, with ASAN heavily lobbying Congress concerning important autism legislation, and managing a number of achievements, as described later in this work.⁵¹

⁴⁴ The matter of Dawson making use of funding from Autism Speaks in furthering her research projects at Hôpital Rivière des Prairies was also discussed during a Telephone Interview with her, in her personal capacity, in June 2011.

⁴⁵ See, for example, 'New Yorkers talk need for housing options at Town Hall meeting', op. cit.

⁴⁶ Interview with Ari Ne'eman, op. cit.

⁴⁷ Ibid

⁴⁸ Ibid.

⁴⁹ As mentioned in the Biographical Note of Ari Ne'eman, in the 'Leadership' Section of the Autistic Self-Advocacy Network (ASAN) website, accessed online at <http://autisticadvocacy.org/home/about-asan/leadership/>.

⁵⁰ Ibid.

⁵¹ See Section 11.5.1 of this thesis.

ASAN also started regular PR campaigns through social and general media channels used by other mainstream organisations, and also reached out to private companies, managing to have them on board in supporting accessibility initiatives, such as with telecommunications giant Sprint.⁵²

They also worked on influencing public opinion through mainstream television programming, such as through ASAN's collaboration with broadcaster CBS in working on the content relating to the portrayal of the autistic character in Sesame Street.⁵³ This also served to counter the presence of Autism Speaks, who had already been similarly involved, in this initiative.

ASAN eventually expanded its reach beyond the United States, starting national affiliate bodies in Canada and Australia,⁵⁴ while maintaining a close partnership with other autistic self-advocacy organisations, namely the ACI (Autistic Community of Israel) in Israel, to which further reference is made in Sections 12.5 and 12.6 of this thesis, as well as The Autism Acceptance Project (TAAP) in Canada, and Autism Rights Group Highland (ARG Highland) in Scotland.⁵⁵

While ASAN is the epitome of how to structure a titan to take on the mainstream non-autistic-dominated world, in terms of perceptions, and put forward the autistic perspective, while fighting for equal rights and acceptance, what holds it back from being even stronger is the same problem plaguing the autistic self-advocacy community everywhere – lack of coherence and unity within the community.⁵⁶

⁵² ASAN Statement on Sprint “Neurodiversity ID Pack,” ASAN website, 23 June 2013, accessed online at <http://autisticadvocacy.org/2014/06/asan-statement-on-sprint-neurodiversity-id-pack/>.

⁵³ ASAN Statement on Sesame Workshop’s “See Amazing” Initiative, ASAN website, 21 October 2015, accessed online at <http://autisticadvocacy.org/2015/10/asan-statement-on-sesame-workshops-see-amazing-initiative/>, as also mentioned in Emily Willingham, ‘Sesame Street’ Introduces Autistic Girl Into The Neighborhood’, *Forbes.com*, 22 October 2015, accessed online at <http://www.forbes.com/sites/emilywillingham/2015/10/22/sesame-street-introduces-autistic-girl-into-the-neighborhood/#108b7467855a>.

⁵⁴ ‘International ASAN Affiliates,’ in the ‘Chapters’ Section of the ASAN website, accessed online at <http://autisticadvocacy.org/chapters/#affiliates>.

⁵⁵ ‘International Partner Organizations,’ in the ‘Chapters’ Section of the ASAN website, accessed online at <http://autisticadvocacy.org/chapters/#partners>.

⁵⁶ Interview with Kate Palmer, President/ CEO, The Global & Regional Asperger Syndrome Partnership (GRASP), New York, July 2013.

Not every autistic-led organisation or autistic self-advocate would necessarily want to join the same organisation or network. And there are still too many divergent voices and opinions within the autistic community, to have enough common ground in order to present a united front. This severely depletes the strength of the movement, both internally and also externally in the eyes of the mainstream. ASAN must also play a PR game, and show that it has behind it the weight and voices of as many autistic self-advocates as possible, to keep on being invited to the table as the autistic community's interlocutor.

But unless the disparities in the community are addressed at grassroots level,⁵⁷ and all sectors of the self-advocacy movement come together in the United States, at least on central points of common interest, there will not be maximal strength behind ASAN. And ASAN also knows that there is a certain line beyond which it cannot speak for certain sectors of the autistic community. ASAN has made great strides as a model of how to set up such a vehicle within the autistic community, and can count numerous achievements to its name, militating with and for its network and the community backing it.

However, the ASAN model has to be replicated widely elsewhere, either as stand-alone organisations, or as self-regulated sections within mixed organisations. Concurrently, strength through convergence and unity of views on central common points within the autistic community should be sought in the meantime, in order for such self-advocacy initiatives to be able to have maximum effectiveness.

6.4 Concluding Remarks

This chapter has aimed to, after defining autism, map out the journey of the members of this diverse group, that could otherwise be termed a minority group or a vulnerable group, as well as of those other persons involved in the group's wider picture, as parents, guardians, professionals or allies.

While aiming at providing a better understanding of autism and the autistic community, as well as of the wider autism community, the characteristics being pointed out are also meant

⁵⁷ Ibid.

to serve as qualifying the group in question as a 'protected group' in terms of the next Chapters. This is being done for the purposes of analyses carried out later in this thesis.

The path started at the point of having two poles. The pole of 'normalcy' on the one hand, and 'aberrant behaviour' on the other, is contrasted by an opposite pole, in which there is understanding, awareness, acceptance and inclusion of neurodiversity, as part of the wider human norm, on the other.

Autistic persons were once seen as psychopaths, now they can increasingly be seen simply as human beings who process the world differently.⁵⁸

As discussed in the previous Chapters, it is the dominant/ minority dichotomy that is at the core of society's asserting the status quo as to what is 'normal'. It is current societal perceptions that dictate what is good or bad, linking to the issue of perceived good and bad behaviours in autism, for the behaviour's sake, without taking stock of the issues underlying such behaviours.

It is these same perceptions that are behind the slow pace of the shift necessary from a protection-based approach to rights, to an empowerment-based approach. This is the shift that will uphold the dignity of persons finally having the facility to speak for themselves, as far as this is possible, and being accorded every legal and practical measure in order to be able to so do.

Likewise, it is these same attitudes which stand in the way of autistic persons being able to fully experience their identity and personhood as well as, as far as possible, vindicate their right to independent living, and to having a fulfilling role in society. It is this which stands in the way of achieving the UN CRPD's mantra of 'Nothing About Us, Without Us'.

And it is societal perceptions that also feed into the continued adherence of elements of the medical model of disability, seen persons simply in terms of being sick or well, pathologising disabilities, and categorising persons as either broken or not broken. These

⁵⁸ Temple Grandin, *op. cit.*

are the perceptual issues affecting the realm of disability, which seep directly through and equally affect the area of rights of autistic persons.

And it is in terms of this journey – as to how far perceptions have changed, or how far they still need to change; as to how far there is awareness, and whether it is good or bad awareness, or whether the awareness-acceptance-inclusion drive has started; as to whether or how far we are on this journey, what's going well or wrong, and what needs to be done and what needs to be changed – in the context of the current status quo, and of the prevailing rights situation – that the discussion will be taken forward, as to whether the sum total of such conclusions is pointing to a genocide as Walker and other activists insist, should this concept be applicable and/ or extendable to autistic persons as a group.

And whatever the final conclusions of this thesis, by observing the similar journeys undertaken by different social groups as outlined in the previous Chapters, it will hopefully, eventually, not have to take an 'Anthropologist from Mars,'⁵⁹ in the words of the title of the late Oliver Sacks book, to understand the autistic community, and consequently their claim to rights, in an appropriate light.

⁵⁹ This is the title of the eponymous work by Oliver Sacks, Knopf, New York, 1995, wherein the author described the stories of seven persons who could be classified as 'neurologically diverse' within the definitions outlined in this thesis.

PART III: WAR ON AUTISM: ELIMINATION OR ASSIMILATION

Chapter 7: Genocide, Writ Large

7.1 Introduction

This Chapter will analyse in further detail the concept of genocide, in order to answer questions concerning applicability, status of autistic persons as a qualifying group under such concept, or extendibility of such concept to them, as per the discussion of the claims made by Walker and others in Section 1.1.4 of the thesis. This will be done by looking at authors on the topic, and domestic and international statutes and case-law, and identifying instances of possible, or of actual extension of the concept, through such sources.

This Chapter will first analyse the notion of a protected group, in terms of the Convention, as well as in a broader light, also looking at different supranational and national instruments. The broadening of the concept of genocide in terms of *jus cogens* will also be dealt with, making particular reference to the reasoning employed in the *Eichmann* judgements. Re-classification and re-calibration of the concept will also be studied, making particular reference to how this was applied to the crime of rape in particular circumstances, by authors and by the International Criminal Tribunal for Rwanda (ICTR).

The particular significance of the elements of *actus reus* and *mens rea* in determining whether genocide occurred will also be discussed, and especially whether general or specific intent would be required in the latter case, making references to authors and to judgements of the International Criminal Tribunal for the former Yugoslavia (ICTY). Finally, the notion of a possible concept of justifiable genocide will also be tackled.

Chapter 8 will then analyse how and why past claims as to the applicability of the concept of genocide to claimed rights breaches was unsuccessful, in particular by discussing the petition to the United Nations in terms of the Genocide Convention, filed by the Civil Rights Committee as to mistreatment of African-American citizens of the United States. This will be tied in to the rationale as to why the concept of genocide can be considered to be extremely flexible and malleable, not least due to Lemkin, the original formulator of this concept, torpedoing his own initial concept due to a number of personal reasons.

Thus, it is concluded that the concept of genocide is currently a concept open to be interpreted and used in any way, especially by any enforcing authority, and any court or tribunal. This would, especially, also be the case for any potential petitioners, who would be trying out 'pot luck' in the face of the 'legal mess' in this area, as described by Milanović, cited in Section 7.4.3 of this thesis.

In virtue of the status of applicability, and mode of extension of the concept of genocide, analysis of possible genocide will then be carried out in next the final Chapter, after actions or omission as to the rights of autistic persons, in a number of areas of concern, would have been discussed in Chapters 9, 10 and 11. These actions or omissions discussed will be in both the supranational sphere, as well as in different individual jurisdictions.

These actions and omissions will be identified in line with the journey towards awareness, acceptance and inclusion, in terms of the blueprint laid out in earlier Chapters, not having progressed sufficiently far yet, having stalled, or not having moved, or otherwise regressed, due to said actions or omissions. Therefore, an analysis of genocide would then be conducted, but while this would serve to point out that relevant problems would need to be taken stock of, possible solutions and a way forward will also subsequently be discussed, in the same conclusions.

7.2 The Notion of a 'Protected Group'

The problem remains as to what Fanny Martin calls the 'Notion of a Protected Group'.¹ As to such groups, the Convention is very restrictive, mentioning only national, racial, ethnic and religious groups, as being possible victims of abuse under the Convention.²

Although there have been extensions of the definitions given to such groups, such as by the International Criminal Tribunal for the Former Yugoslavia, the number of categories protected has remained the same, with the only room for interpretation being afforded within these groups themselves.³

¹ Fanny Martin, 'The Notion of 'Protected Group' in 'The Genocide Convention and its Application', in Paolo Gaeta (Ed.), *The UN Genocide Convention: A Commentary*, Oxford University Press, Oxford, 2009, Part II: The Definition of Genocide, Chapter 5, at 113.

² Ibid.

³ Ibid.

Martin states that the limited scope of Article II of the Genocide Convention has been widely criticized in institutional and academic circles particularly because it prevents certain contemporary mass killings from being characterized as genocides. To remedy this deficiency, commentators have alternatively put forward definitions encompassing social and political groups, or tried to demonstrate that a *jus cogens* prohibition of genocide of political groups has emerged.⁴

Scholars such as Pieter Drost and Israel Charny have advocated a reworking of such list of protected groups, to make genocide a crime against which protection should be offered to the whole of mankind, to all groups of people.⁵ However, although several efforts have been made to so amend the Genocide Convention, including through scholarly pieces formally proposing to the United States of America to table an amendment to the Genocide Convention,⁶ there has not been the political will for this to happen.

This lack of political will can be traced back to the drafting of the Convention as explained previously, such as through the example of Stalin's insistence on the non-inclusion of political groups. One can also speak of the proposed insertion of cultural groups, with this proposition being rejected, and Greece tabling a compromise motion to instead include the forcible transfer of children within the scope of the Convention.⁷

7.2.1 *Going Beyond the Convention's Categories*

However, one can still argue that the fact that the Convention is worded in a specific manner, does not mean that the concept of genocide cannot be, in fact, broader at law. The United Nations has no specific method in which states are to apply conventions into their national laws, and states are free to choose the form and content they wish in doing so. While certain monist states, such as the Netherlands, implement the Convention as is into their national laws, other dualist states use a variety of styles in reaching such an implementation.

⁴ Ibid.

⁵ Israel W. Charny, 'Definitions of Genocide and the Study of Genocide', in Israel W. Charny (Ed.), *Encyclopedia of Genocide*, ABC-CLIO, Santa Barbara, 2000, Volume I, Part I, at 13.

⁶ Ibid.

⁷ Ibid.

For example, the Bolivian Criminal Code includes even less categories of Protected Groups, mentioning only national, ethnic and religious groups, and eliminating racial groups,⁸ this Protected Group being also absent from the Criminal Codes of Guatemala, Paraguay and Peru.⁹ The Ethiopian Penal Code, on the other hand, also includes a mention of political groups,¹⁰ as does the Costa Rican Penal Code,¹¹ while the Paraguayan and Peruvian Criminal Codes add social groups to their list of Protected Groups.¹²

At the same time, such implementation also has to take place by permanent or ad hoc supranational bodies, such as the ICTY and the International Criminal Tribunal for Rwanda (ICTR), as well as the International Criminal Court (ICC). Although both in their statutes and in their decisions, such tribunals have kept with the spirit and the letter of the Genocide Convention, they did this through a brand-new mention of the definition of genocide in their statutes, and not through any reference or wholesale adoption of the Convention directly.¹³

What was just described shows clearly that UN member states, as well as supranational bodies, are not bound in any way, or by any mechanism, to follow the criteria set out in the Genocide Convention as regards Protected Groups, and can define their own criteria, as some of them indeed have. Therefore, there is nothing holding one back from looking at the definitions given by various scholars to genocide, and redefining the concept in order to include new specifications that one could deem relevant to this day and age.

7.3 Beyond Protected Groups – Genocide as a Concept in *Jus Cogens*

In a number of cases before *ad hoc* international tribunals, a specific number of which shall be further discussed in Section 7.4, the possibility of acts of genocide being perpetrated in

⁸ Article 138 of the Bolivian Criminal Code, as cited by Israel W. Charny, 'Definitions of Genocide and the Study of Genocide', in Israel W. Charny (Ed.), op. cit., Volume I, Part I, at 9.

⁹ Hugo Relva, 'The Implementation of the Rome Statute in Latin American States', *Leiden Journal of International Law*, Vol. 16, Issue 2, June 2003, at 339.

¹⁰ Article 281 of the Ethiopian Penal Code, as cited by Israel W. Charny, 'Definitions of Genocide and the Study of Genocide', in Israel W. Charny (Ed.), op. cit., Volume I, Part I, at 9.

¹¹ Relva, op. cit., at 339.

¹² Ibid.

¹³ Israel W. Charny, 'Definitions of Genocide and the Study of Genocide', in Israel W. Charny (Ed.), op. cit., Volume I, Part I, at 11.

respect of certain groups was considered by the relevant courts or tribunals, due to such groups being afforded protection through particular statutes.

This ties in with the model also considered earlier, in which such groups are either identified through an international legal text, or through a country's domestic laws. However, as also mentioned, scholars such as Drost and Charny have advocated extending such concept, with destruction of any collectivity by purposeful action, as described in later contributions by Thompson, Quets and Fein, extending to covering 'the whole of humanity,' in the spirit and according to the letter of Resolution 96(I).

Back in 1961, however, a domestic tribunal did follow and implement this dictum, relying on international law, and also citing Resolution 96(I) – this, however, being secondary to the invocation by these domestic tribunals of another, higher principle in this regard at international law – the overarching principle of *jus cogens*.

The cases in question were the judgements delivered in respect of Adolf Eichmann by the Jerusalem District Court and the Supreme Court of Israel. Here, the applicability of the crime of genocide to all sectors of humanity was asserted through the fact that, following these courts' legal analysis, genocide could be traced to have always been present "since time immemorial" as a crime within *jus cogens*, the law of nations.¹⁴

It was thus not bound by any limited criteria or to particular groups, going beyond specific statutes such as the Israeli one under which Eichmann was being tried, and in respect of which Eichmann's defence had raised a number of objections on these lines.

7.3.1 *The Court's Definition of Genocide*

The Jerusalem District Court first proceeded to define the crimes with which Eichmann was being charged, by engaging in a comparative study of similar, recognised notions in the international sphere at the time.

The Court declared the term 'crime against the Jewish People'¹⁵ described in the Nazis and Nazi Collaborators (Punishment) Law, the law under which Adolf Eichmann was being

¹⁴ *Attorney General v. Adolf Eichmann*, Supreme Court of Israel, per Olshan, Agranat, Silberg, Witkon and Sussman JJ, Criminal Appeal 336/61, 29 May 1962, at 16.

¹⁵ Nazis and Nazi Collaborators (Punishment) Law, August 1, 1950, 4 L.S.I. No. 64, at Art. 1.(b).

charged in an Israeli Court, corresponded to the crime of 'Genocide' as spelt out in the UN Genocide Convention. However, this was done following a more detailed analysis.

The District Court first considered Principle II within the Nuremberg Principles,¹⁶ which was the most recent encapsulation of a provision covering the alleged crimes at hand, prior to the adoption of the Genocide Convention by the UN, and the most recent provision of international statutes against which perpetrators had been tried for crimes of a similar nature, during the Nuremberg Trials a few years earlier.

The Supreme Court, however, not only confirmed this approximation of criminal notions, but also used this argument to reinforce the view that, due to the fact the provisions of Israeli domestic statutes were derived from and echoed by international statutes, this pointed to the wider concept of the crime of genocide, and its components, being present within the system of *jus cogens*. It reinforced this argument, by also pointing to earlier texts and judgements within the international sphere.

In fact, Marie-Claude Roberge states that the definition of the relevant crimes under Israeli law, as also applied in the *Eichmann* trials, was different from that under the Nuremberg Charter, in that no nexus was required between the commission of a crime against humanity and any of the other crimes (war crimes or crimes against peace).¹⁷ This definition only required the former to have been committed during the Nazi regime.¹⁸

¹⁶ Principles of International Law Recognized in the Charter of the Nuremberg Tribunal and in the Judgment of the Tribunal (hereinafter 'Nuremberg Principles'), 5 UN GAOR Supp. (No. 12) at 11, U.N. Doc. A/1316 (1950).

¹⁷ Eichmann was charged under the Nazi and Nazi Collaborators (Punishment) Law for the following offences: (1) Crimes against the Jewish people; (2) Crimes against humanity; (3) War crimes; and (4) Membership of hostile organizations.

Crimes against humanity were punishable if "done during the period of the Nazi regime, in an enemy territory" and were defined as "any of the following acts: murder, ill-treatment, or the deportation to forced labour or for any other purpose, of civilian population of or in occupied territory; murder or ill-treatment of prisoners of war or persons on the seas; killing of hostages; plunder of public or private property; wanton destruction of cities, towns or villages; and devastation not justified by military necessity."

¹⁸ Marie-Claude Roberge, 'Jurisdiction of the ad hoc Tribunals for the former Yugoslavia and Rwanda over crimes against humanity and genocide', *International Review of the Red Cross*, No. 321, 31 December 1997, accessed online at <https://www.icrc.org/eng/resources/documents/article/other/57jnz3.htm>.

7.3.2 Eichmann's Objections and the Notion of *Jus Cogens*

The above appreciation was necessary, following an objection raised by Eichmann in his appeal to the Supreme Court, whereby he submitted that, under Article 6 of the Genocide Convention, a person accused of this crime shall be tried by a 'court of competent jurisdiction' of the state in which it was committed. According to Eichmann's submission, that Article confirmed the application of the 'territorial' principle, rather than the 'universal' principle. One could opine, therefore, that the latter principle, linked to the notion of 'acts of State,' was consequently implicitly negated.¹⁹

In this regard, the Supreme Court cited the District Court's argumentation, as to the fact that Article 6 imposes upon the parties contractual obligations with future effect, obligations which bind them to prosecute for crimes of 'genocide' which will be committed within their 'territories' in future. However, such obligation has nothing to do with the universal power vested in every state to prosecute for crimes of this type committed in the past – a power which is based on customary international law.²⁰

During the relevant proceedings, while referring to domestic legislation in force in Nazi Germany during the time of the alleged commission of the crimes Eichmann stood charged with, the Attorney-General had cited the Nuremberg Principles, to the effect that

"The fact that internal law does not impose a penalty for an act which constitutes a crime under international law does not relieve the person who committed the act from responsibility under international law."²¹

¹⁹ 'Prosecution of War Crimes', in Jean-Marie Henckaerts and Louise Doswald-Beck (eds.), *Customary International Humanitarian Law – Volume II: Practice – Part I*, ICRC/ Cambridge University Press, Geneva/ Cambridge, 2005, at 3987.

²⁰ Para. 21 et seq of *Attorney General v. Adolf Eichmann*, Supreme Court of Israel, op. cit., as quoted in Christopher L. Blakesely, *Jurisdictional Issues and Conflicts of Jurisdiction*, in M. Cherif Bassouini (ed.), *Legal Responses to International Terrorism: US Procedural Aspects*, Martinus Nijhoff Publishers, Dordrecht/ Boston/ London, 1988, at 147. See also Hans W. Baade, 'The Eichmann Trial: Some Legal Aspects', *Duke Law Journal*, Vol. 10, Issue 3, 1961, at 400, 414.

²¹ Principle II of the Nuremberg Principles, op. cit., as cited by Attorney-General Gideon Hausner during proceedings before the Jerusalem District Court in *Attorney General v. Adolf Eichmann*, Jerusalem District Court, per Landau, Halevi and Raveh JJ, Criminal Case No. 40/61, 15 December 1961, as per session transcripts, 12 April 1961, English translations accessed at <http://www.nizkor.org/hweb/people/e/eichmann-adolf/transcripts/Sessions/Session-003-01.html>.

This Court had subsequently elaborated that "if there was any doubt as to this appraisal of the Nuremberg Principles as principles that have formed part of customary international law 'since time immemorial,' such doubt has been removed by two international documents[.]"²² said documents being:

- 1) General Assembly Resolution of 11.12.46, which the Court stated "affirms the principles of international law recognized by the Charter of the Nuremberg Tribunal, and the judgment of the Tribunal,"²³ and;
- 2) General Assembly Resolution 96(I), discussed earlier, in which the General Assembly, in the Court's words, "affirms that genocide is a crime under international law."²⁴

By doing this, the superior courts of a national polity were also both citing and endorsing this Resolution as being part of international law having effect in the domestic sphere.

The Court then backed up its argumentation by referring to Sloan who, as to both the above-mentioned documents, stated that²⁵:

"If fifty-eight nations unanimously agree on a statement of existing law, it would seem that such a declaration would be all but conclusive evidence of such a rule, and agreement by a large majority would have great value in determining what is existing law."

The Court next strengthened its argument by referring to an Advisory Opinion of the Permanent Court of International Justice (PCIJ),²⁶ a mechanism that had been set up at a period prior to the unfolding of the case at hand, and the enactment of international

²² *Attorney General v. Adolf Eichmann*, Supreme Court of Israel, op. cit., at 18.

²³ Ibid.

²⁴ Ibid, at 19.

²⁵ *British Yearbook of International Law* 1948, at 24, as cited in *Attorney General v. Adolf Eichmann*, Supreme Court of Israel, op. cit., at 22.

²⁶ Advisory Opinion of the Permanent Court of International Justice dated 28.5.51 (hereinafter 'PCIJ Advisory Opinion'), as cited in *Attorney General v. Adolf Eichmann*, Supreme Court of Israel, op. cit, at 19.

supranational legal texts around it. Referring to the PCIJ's Advisory Opinion on Reservations to the Genocide Convention, the Supreme Court stated that:

“the import of this provision is that the principles inherent in the Convention – as distinct from the contractual obligations embodied therein – *had already been part of customary international law at the time of the perpetration of the shocking crimes which led to the United Nations resolution and the drafting of the Convention on crimes of genocide which were perpetrated by the Nazis* [emphasis added].”²⁷

In this regard, the PCIJ then continued that:

“The origins of the Convention show that it was the intention of the United Nations to condemn and punish genocide as "a crime under international law" involving a denial of the right of existence of entire human groups, a denial which shocks the conscience of mankind and results in great losses to humanity, and which is contrary to moral law and to the spirit and aims of the United Nations (Resolution 96 (1) of the General Assembly, December 11th 1946). The first consequence arising from this conception is that the principles underlying the Convention are principles which are recognized by civilized nations as binding on States, even without any conventional obligation.”²⁸

It is interesting to note that, similarly to the Eichmann judgement, which made reference to the overarching nature of Resolution 96 (I), a modern international Tribunal in the form of the ICTY has also done the same.

In the *Krstić* judgement, the Tribunal reiterated the General Assembly's definition of genocide as “a denial of the right of existence of entire human groups[,]”²⁹ further quoting the Secretariat to the effect that “[t]he victim of the crime of genocide is a human group. It is not a greater or smaller number of individuals who are affected for a particular reason but a group as such.”³⁰

²⁷ *Attorney General v. Adolf Eichmann*, Supreme Court of Israel, op. cit., at 19.

²⁸ PCIJ Advisory Opinion, op. cit., as cited by *Attorney General v. Adolf Eichmann*, Jerusalem District Court, op. cit., at 15.

²⁹ *Prosecutor v. Radislav Krstić*, IT-98-33, Trial Chamber judgement, 2 Aug. 2001, at 200.

³⁰ *Relations Between the Convention on Genocide on the One Hand and the Formulation of the Nurnberg Principles and the Preparation of a Draft Code of Offences Against Peace and Security on the Other*, U.N. Doc. E/AC.25/3/Rev.1, 12 April 1948, at 6, in *Prosecutor v. Krstić*, Trial Chamber

The approach taken by the Israeli courts has also later been backed by authors such as Randall, who stated that universal jurisdiction is a functional doctrine based on the need to remedy, in some small measure, the inability of the decentralised international system to enforce even its most fundamental laws.³¹ Writing at a time preceding the adoption of the Rome Statute setting up the International Criminal Court, he had stated that “[a]t present, domestic jurisdiction to prosecute international crimes is particularly important, because ‘mankind has not yet proved mature enough to have set up an international criminal court.’”³²

The reasoning in Eichmann was, in 1998, used by the German delegation to the negotiations over the Rome Statute establishing an International Criminal Court.³³ Germany argued for a strong an independent ICC, based on universal jurisdiction, particularly in the areas of genocide, war crimes and crimes against humanity.³⁴ However, this broad scope did not make it to the final wording of the Statute due to the opposition of the United States delegation which, although opposing such broad wording as to the inclusion of war crimes and crimes against humanity, did not object with respect to the inclusion of genocide.

Furthermore, Lasok points to another interesting feature emanating from these judgements, besides the emergence of the discussion around *jus cogens*. As to the nature of Eichmann’s crimes, he cites Attorney-General Hausner who described Eichmann as “a new style murderer – one who carries out killings from his desk[,]” adding that with the exception of one murder, the rest were all committed “over the telephone, by signing an order, by

judgement, op. cit., at 193.

³¹ Kenneth C. Randall, ‘Universal Jurisdiction Under International Law’, *Texas Law Review*, Vol. 66, 1988, at p. 829, in Bartram S. Brown, ‘The Evolving Concept of Universal Jurisdiction’, *New England Law Review*, Vol. 35, 2001, at 383, 384.

³² Shneur-Zalman Feller, ‘Jurisdiction Over Offenses with a Foreign Element’, in M. Bassiouni and V. Nanda (eds.), *A Treatise on International Criminal Law*, Vol. 2, Ch. 5, 1973, at pp. 32-33, in Randall, op. cit., at p. 829, in Brown, op. cit., at 384.

³³ Brown, op. cit., at 385.

³⁴ In this regard, the German delegation had stated that “[u]nder current international law, all States may exercise universal criminal jurisdiction concerning acts of genocide, crimes against humanity and war crimes, regardless of the nationality of the offender, the nationality of the victims and the place where the crime was committed. This means that, in a given case of genocide, crime against humanity or war crimes, each and every State can exercise its own national criminal jurisdiction, regardless of whether the custodial State, the territorial State or any other State has consented to the exercise of such jurisdiction beforehand. This is confirmed by extensive practice.”

writing a note.”³⁵ The mode of perpetrating genocidal acts is also a point to be kept in mind, when making further analyses of possible problem scenarios.

7.4 Elements of Action and Intention

7.4.1 Broadening the Concept of Actus Reus

The notion of extending crimes within the hierarchy of genocide, particularly crimes against humanity, has also been on the agenda more recently, through the efforts of activists who sought to crystallise current events connected to their fields of activism in the jurisdictions in which they carried out their activism.

This extends such a notion from a simple matter of academic argumentation for possible legal change, to a current effort on the ground to actually have such a realm of crimes extended to issues of concern to these activists. Although a number of national statutes highlighted earlier have already done this,³⁶ such efforts, although as fundamental, addressed issues of historical significance for the jurisdictions in question, such as indigenous rights and political persecution.

The work of the activists in question concerns the here and now, and the significance of studying such a process is to analyse a current ‘work-in-progress’. This involves analysing how an argument initially viewed as a fringe position could gain strength and edge further towards the mainstream, and in doing so, offer clear guidelines and highlight possibilities about such a process. This not only as to how such could be considered real and possible, but also practical guidelines as to how such a process could be applied in the field of autistic rights.

One could state that issues of historical significance only become so after a long, arduous process through which such rights are recognised and finally enforced, with the resulting

³⁵ Attorney-General Gideon Hausner during proceedings before the Jerusalem District Court, as quoted in D. Lasok, ‘The Eichmann Trial’, *The International and Comparative Law Quarterly*, Vol. 11, No. 2, April 1962, at 355, 358.

³⁶ See Section 7.2.1 of this thesis.

necessary changes in social perception and approach to the matter at hand being necessary to be shifted as part of the larger process.

7.4.2 *Re-Classification and Re-Calibration of Crimes*

In this regard, one could cite the work of American feminist activist and theorist Catherine MacKinnon, as regards the growing crisis concerning the situation surrounding rape and related violent crimes in jurisdictions such as South Africa.³⁷ MacKinnon's argument as to the re-classification of such crimes is rooted in her analysis of the domestic social order in such countries and related jurisdictions, in that they would have allowed for such crimes to be rendered 'banal.'

Although the crime of rape itself is approached with the relevant degree of seriousness in many legal statutes, this being reflected in the severity of penalties prescribed for persons charged with the crime should they be found guilty of it, the places such as South Africa has reached such a level of alarm, according to MacKinnon and authors such as Louise Du Toit,³⁸ that the domestic social order is being affected in a much more pronounced way than it would in jurisdictions such as Ireland.

For this reason, the severity of the crime, as well as the way society, and consequently, jurisdictions such as South Africa should deal with this, is to add emphasis in describing the severity of such actions, while accordingly prescribing appropriate sanctions. One could see this as increasing a storm warning from Code Orange to Code Yellow.

On this basis, she argues that, in such circumstances, the crime of rape should be considered as falling within the realm of crimes against humanity.³⁹ One might opine that this would

³⁷ Catherine A. MacKinnon, 'Genocide's Sexuality', in *Are Women Human? And Other International Dialogues*, Harvard University Press, Boston, 2006, at 246.

³⁸ According to Du Toit in *A Philosophical Investigation of Rape: the making and unmaking of the feminine self*, Routledge, London, 2009, at 2, there are 46 000 police recorded rapes in South Africa per year, while the South African Law Reform Commission estimates 1.7 million rapes per year. Du Toit also states that according to Interpol, South Africa has the highest rate of rape in the world. However, Rachel Jewkes and Naaemah Abrahams, in 'The epidemiology of rape and sexual coercion in South Africa: an overview', *Social Science and Medicine*, Vol. 55, Issue 7, October 2002, at 1231, state that these statistics are still not reflective of the accurate degree of the rape epidemic as numerous rapes still go unreported.

³⁹ MacKinnon, 'Women's September 11th: Rethinking the Law of Conflict', in *Are Women Human? And Other International Dialogues*, Harvard University Press, Boston, 2006, at 265. Here

be a ludicrous argument for polities such as the United Kingdom and its constituent legal jurisdictions. However, the different nature pertaining to the domestic social order in countries such as South Africa would make such an argument sound much more realistic, taking stock of the relevant background context.

The question to be asked in this regard, according to MacKinnon, is not whether the behaviour or mode of action in question is right or wrong, but rather, whether it would be natural or ordinary for the situation.⁴⁰

Should such a question be met with an alarmingly positive response, then a similar equal and opposite reaction by the legislator would be required. This in order to update the status of the crimes in question to reflect the situation in the domestic legal order, in order that this would then be enforced through the state's organs as well as through its justice system.

In the case of rape, the alarming situation in current South African society would warrant upgrading the crime, according to MacKinnon's reasoning, from simply being a crime against the person, to the realm of crimes against humanity. This in light of the severity of South Africa's current rape crisis, reflected both through mentality, as well as frequency of offences committed.

However, Mac Kinnon also makes two further observations as to extending the severity of rape in her work. The first is as to rape being considered a form of torture under criminal law, due to the power interplay involved, between a dominant oppressor and a victim.

The second is as to the concept of genocidal rape, whereby rapists substitute the persons being raped for the specific group they are attacking, and attempt oppression and destruction of the group through such actions.

7.4.2.1 Rape as Torture

As to rape being considered torture, MacKinnon draws a parallel between a 'classic' case of torture, and the situation whereby a man rapes a woman. She notes that torture is

MacKinnon is advocating such an extension to jurisdictions where the crime of rape has become 'banal.'

⁴⁰ Ibid.

recognised as usually beginning with abduction, detention, imprisonment, progresses to extreme physical and mental abuse, and can sometimes end in death. In the case of torture, the torturer has absolute power and the person being tortured becomes a victim of this abuse of power.⁴¹

Physical and verbal abuse makes the victim feel worthless and hopeless, and this is essential to the torture having its intended effect. What torture does to a human being is internationally recognised.⁴² The sole purpose of torture, according to MacKinnon is to break a person. She describes torture as being capable of changing a person's life, and states that the generally recognized purpose of torture is to control, intimidate or eliminate those who insult or challenge or are seen to undermine certain powers.⁴³

Torture, according to MacKinnon is therefore political, although it often seems that its political overlay is facilitating pretext for the pure exercise of sadism, a politics of itself. She states that when torture happens, the international governing rules protecting human rights acknowledge that human rights were violated.⁴⁴ In rape though, she argues that, as in torture, in both instances one finds a person with power, who takes control over a victim. The abuse is neither random nor individual. It is a systematic abuse of power.

Emphasising the nature of the abuser and the abused, in emphasising the political element, she states that it would seem that something is not considered a political act if it is done to women by men.⁴⁵ Here, one could look at authors such as Du Toit, who similarly to MacKinnon, discussed the issue of rape, focusing on South Africa.

⁴¹ Catherina MacKinnon, 'Crimes of War, Crimes of Peace', in *Are Women Human? And Other International Dialogues*, Harvard University Press, Boston, 2006, at 145.

⁴² Ibid.

⁴³ Ibid.

⁴⁴ Ibid.

⁴⁵ Ibid., at 156. Louise Du Toit, in 'A Phenomenology of Rape: Forging a New Vocabulary for Action,' in Amanda Gouws, *(UN)Thinking Citizenship, Feminist Debates in Contemporary South Africa*, Ashgate Publishing, Burlington, 2004, at 253. states that the high rate rape in South Africa is symptomatic of the fact that women and children are viewed as second-class citizens in the country. In this regard, South African activists usually talk about the fact that the transfer of responsibilities concerning women, children and disabilities to one separate Ministry under the current administration, as opposed to such groups having separate offices within the Presidential administration previously, has led to such Ministry being derogatorily referred to as the 'Ministry for Everything Except Men.'

This point, raised by disability rights activist Vanessa Dos Santos, during the 'Civil Society and the CRPD' panel, at the Beit Issie Shapiro 6th International Conference on Disabilities, Ra'anana, Israel, 10 July 2016, is symptomatic of the situation described by Du Toit.

She similarly points out the political undertones to such a classification, also stating that while gross human rights violations under international law include fundamental violations of human rights, such violations include torture, but not rape.⁴⁶

As to the issue of dominant and subservient groups, Du Toit states that “rape (like torture) is officially illegal but officially tolerated, so that masculinity and the male-biased or male-dominated public-sphere themselves become implicated in the perpetuation of the crime.”⁴⁷ This ties in with MacKinnon’s observation, cited earlier, of the crime of rape becoming ‘banal’ in certain jurisdictions.

In this regard, both MacKinnon and Du Toit are identifying men as the dominant abusive group, and women as the victim group subjected to the crime in question, in this circumstance, rape. MacKinnon elaborates that, in such circumstances, the action:

“is not considered political, because what is political is when men control and hurt and use other men, meaning persons who are deserving of dignity and power, on some basis men have decided is deserving of dignity and a measure of power, like conventional political ideology, because that is a basis on which they have been deprived of dignity and power. So their suffering has the dignity of politics and is called torture.”⁴⁸

The power interplay between dominant and subservient groups, as well as the political element of such situations, ties in with the discussions already outlined in the previous Chapters, when discussing, for example, dominant and subservient linguistic and ethnic groups, and how their situation runs parallel to the current social dichotomy of neurotypical and neurodiverse groups.

7.4.2.2 The Concept of Genocidal Rape

Focusing on the generally-held concept that genocide is purposeful action aimed at the destruction of a group, or at bringing about conditions calculated to bring about such

⁴⁶ Du Toit, ‘A Phenomenology of Rape: Forging a New Vocabulary for Action’, op. cit., at 255.

⁴⁷ Ibid.

⁴⁸ MacKinnon, ‘Human Rights and Global Violence Against Women’, in *Are Women Human? And Other International Dialogues*, Harvard University Press, Boston, 2006, at 22.

destruction, MacKinnon also discussed whether instances of rape could qualify as acts directed towards a genocide.

She considered rape within a wartime scenario, and stated that, while not all acts of wartime rape could be classified as acts of genocidal rape, some definitely came within this category, focusing here on the issue of specific intent.

MacKinnon mentions examples such as the Japanese Imperial government's provision of 'comfort women' to Japanese troops during World War II, the resultant sexual acts constituting instances of wartime rape, but not of genocidal rape, since the aim of such practice was to provide 'comfort' to these soldiers, and not to destroy the group from which the women were being taken in any way.

On the other hand, however, she mentions instances such as the Balkan wars of the 1990s, in which the circumstances and intent of Serbian troops raping Bosnian women, in light of the testimony of these women, constituted more than instances of wartime rape. MacKinnon once again brings up the power interplay discussed earlier in her equating rape with torture.

She comments that the one-sidedness of such crimes is essential to them being considered acts in furtherance of genocide, in that they do not target combatants, but people – civil society.⁴⁹ To this, she also adds the issue of control of one group over another, as well as the issue of the perpetrator's personal and group identity, which one can see as opposed to the victims' personal and group identity.⁵⁰

As to the issue of identity, this point has also been reiterated by groups such as Medecins Sans Frontiers,⁵¹ when observing that systematic rape had been used by groups as a weapon, forming part of a strategy of ethnic cleansing, with Serbian soldiers impregnating Bosniak women with the goal of them having Serbian babies.⁵²

⁴⁹ MacKinnon, 'Genocide's Sexuality', *op. cit.*, at 222.

⁵⁰ *Ibid.*, at 227.

⁵¹ Medecins Sans Frontiers, 'Rape as a Weapon of War', accessed online at www.msf.org/en/article/20040305-rape-weapon-war.

⁵² *Ibid.*; MacKinnon, 'Crimes of War, Crimes of Peace', *op. cit.*, at 146.

The same method of employing a 'strategic attack' for 'weakening the integrity of the opposing ethnic group' was similarly used by Pakistani soldiers during Bangladesh's War of Independence, who raped Bangladeshi women, telling them that 'we will make you breed Punjabi children.'⁵³

To emphasise this attack on a group's identity, using a one-sided strategic attack in order to control a defenceless group of victims, MacKinnon states that rape, which usually has an out-of-control element in war, with nothing able to stop a group of armed men engaging in it, is different when genocidal intent is present.

She specifies that:

"in genocide, rape is under control. It has become a tool, not an accident. In genocide, men rape in groups because they are ordered to or because they are systematically permitted to do so. It is calculated. The men rape not as individual men, but as members of their race, ethnicity, religion or nationality. They sexually assault women (and sometimes other men) of a particular group.

The goal in genocidal rape is not merely to hurt people. Much less is the goal simply to have sex. Group destruction is the goal. Sexual violence is not simply some ancillary tool to this goal. Indeed, because of the peculiar nature of rape and sexual torture, it is particularly suited to genocide. In war, the destructive effects of rape are largely beside the point. In genocide, the destruction is the point."⁵⁴

While the previous examples have focused exclusively on the *mens rea* of the perpetrators in question, the *actus reus* itself could also be similarly loaded, thus making the genocidal nature of the rapes in question much clearer. Here, one could mention the fact that, of the 800 000 men, women and children who died in the Rwandan Genocide in 1994, a significant number were rape victims.

⁵³ Gita Sahgal of Amnesty International, cited in 'How Did Rape become a Weapon of War?', Laura Smith-Spark, *BBC News*, accessed online at <http://news.bbc.co.uk/2/hi/4078677.stm>.

⁵⁴ MacKinnon, 'Rape, Genocide and Women's Human Rights', in *Are Women Human? And Other International Dialogues*, Harvard University Press, Boston, 2006, at 184.

Over the course of a hundred days between 250 000 and 300 000 women were raped and up to 20 000 children were born as a result of rape. A striking element was the fact that more than 67% of women who were raped during this time were infected with HIV and AIDS. In many cases, this resulted from a systematic and planned methodology, leading such rapes to have been part of a wider specific genocidal plan.⁵⁵

7.4.2.2.1 *Re-Classification at the ICTR*

A particular international tribunal can already be said to have followed a line of reasoning similar to that taken by Catherine MacKinnon. While the ICTY, as discussed earlier, opted for an expanded notion of the crime of genocide in its statutes, rather than using the definition in the UN Genocide Convention, the International Criminal Tribunal for Rwanda (ICTR), while dealing with the topic of genocide, also dealt with the crime of rape.

However, rather than providing for an expansive definition of the crime of genocide in this regard,⁵⁶ the Tribunal opted for a novel approach, re-qualifying the nature and severity of this crime of rape.⁵⁷ It proceeded to considering it, *inter alia*, in light of the events that happened during the Rwandan Genocide, the significance of committing such a crime during a conflict situation, and the way such a crime was also used specifically as a tool of oppression and subjugation during such.

In *Prosecutor v. Akayesu*, the Tribunal submitted that with regard to:

“rape and sexual violence, the Chamber wishes to underscore ... [that] they constitute genocide in the same way as any other act as long as they were committed with the specific intent to destroy, in whole or in part, a particular group, targeted as such.

⁵⁵ As per data gathered by the Rwandan Genocide Survivors' Fund, accessed online at <http://www.survivors-fund.org.uk>rwandan-history>.

⁵⁶ The Statutes of the International Criminal Tribunal for Rwanda (ICTR), as established by Security Council Resolution 955 (1994) of 8 November 1994 and last amended by Security Council Resolution 1717 (2006) of 13 October 2006 (hereinafter the 'ICTR Statutes'), reproduced Articles 2 and 3 of the Genocide Convention *verbatim* in Article 2 of said Statutes defining and elaborating upon Genocide.

⁵⁷ Prior to judicial activism by the ICTR, the ICTR Statutes allowed for the possibility of prosecuting persons for Rape as a Crime Against Humanity under Article 3, when committed as “part of a widespread or systematic attack against any civilian population on national, political, ethnic, racial or religious grounds,” as well as prosecution for Rape as a Violation of Article 3 common to the Geneva Conventions and of Additional Protocol II, under Article 4 of said Statutes.

Indeed, rape and sexual violence certainly constitute infliction of serious bodily and mental harm on the victims.”⁵⁸

Mark Ellis states that *Akayesu* is considered the most important case for prosecuting rape as an international crime,⁵⁹ citing Samantha Power in affirming that it was the first international tribunal case to link the crime of rape explicitly to genocide.⁶⁰

Although unexpected, since the original indictment was only amended by the Prosecutor following the spontaneous testimony of a witness, such testimony led to the Tribunal making explicit findings on the issue of rape and genocide, and stating in passing judgement that it found that the acts of rape and sexual violence could constitute genocide.

In particular, Ellis looks at how the Tribunal's deliberations around rape as constituting a genocidal act, covered four elements listed in the Genocide Convention. While emphasising the ground of Inflicting serious harm, which the Tribunal stated to be "one of the worst ways of inflicting harm on the victim,"⁶¹ both physical and mental, it also outlined a mental element to the attempt to Prevent births within a particular protected group. He refers to the Tribunal's statement that if a woman who has been raped refused subsequently to have children because of trauma, then a crime had also been committed.⁶²

Rape also made women outcasts, such women often being the key link to the cultural and physical continuity of these protected groups, thus such rape could also be seen as bringing about Conditions calculated to bring about the physical destruction of the group,⁶³ with raping such women in this community able to be seen as raping the body of the community.⁶⁴ Finally, since the protected groups in question were patriarchal societies, forced pregnancy through rape could constitute genocide when the intent is for the victim

⁵⁸ *Prosecutor v Jean-Paul Akayesu* (Judgement) ICTR-96-4-T, T Ch I (2 September 1998), at 731.

⁵⁹ Mark Ellis, 'Breaking the Silence: Rape as an International Crime', *Case Western Reserve Journal of International Law*, Volume 38, 2007, at 225, 232.

⁶⁰ Samantha Power, Op-Ed., 'The real meaning of genocide', *Boston Globe*, 14 September 1998, at A17, in Mark Ellis, op. cit., at 232.

⁶¹ *Prosecutor v Akayesu*, op. cit., at 731, in Ellis, op. cit., at 233.

⁶² *Prosecutor v Akayesu*, op. cit., at para. 52, in Ellis, op. cit., at 234.

⁶³ Ellis, op. cit., at 231-232.

⁶⁴ Marie Vlachovi and Lea Biason (eds.), *Women in an Insecure World: Violence Against Women – Facts, Figures and Analysis*, DCAF, 2005, at 115, 118, in Ellis, op. cit., at 232.

to “give birth to a child who will consequently not belong to its mother's group[.]”⁶⁵ thus Forcibly transferring children from one group to another group.

The same reasoning applied in *Akayesu* was both quoted and applied by the Tribunal, in *Prosecutor v. Nyiramasuhuko et.*,⁶⁶ which was also the first Tribunal judgement to find a woman guilty of involvement in genocidal rape, shattering the usual stereotype that rape is a crime reserved for men.

The defence attempted to counter various instances of the prosecution trying to have notice of rape as genocide recognised, insisting rather that instances of rape should be considered as crimes against humanity, or of outrages against personal decency. However, the Tribunal emphasised the link between rape and genocide in certain instances, stating that:

“The acts enumerated in Article 2 (2) [of the Genocide Convention] include “[k]illing members of the group”, and “[c]ausing serious bodily or mental harm to members of the group”. For this latter category to support a conviction for genocide, the bodily or mental harm inflicted on members of a group must be of such a serious nature as to threaten its destruction in whole or in part.”⁶⁷

The Appeals Chamber has described rape as a “quintessential” example of serious bodily harm,⁶⁸ and has stated that serious mental harm includes “more than a minor or temporary impairment of mental faculties such as the infliction of strong fear or terror, intimidation or threat”.⁶⁹

⁶⁵ *Prosecutor v Akayesu*, op. cit., at para. 507, in Ellis, op. cit., at 234.

⁶⁶ *Prosecutor v. Pauline Nyiramasuhuko, Arsène Shalom Ntahobali, Sylvain Nsabimana, Alphonse Ntezirayo, Joseph Kanyabashi, Elie Ndayambaje*, Judgement (Trial Chamber), ICTR-98-42-T, 24 June 2011 (hereinafter the ‘*Nyiramasuhuko*’ judgement).

⁶⁷ *Prosecutor v. Athanase Seromba*, Judgement (Appeal Chamber), ICTR-2001-66-A, (12 March 2008), at 46, as cited in *Prosecutor v. Nyiramasuhuko* (TC), op. cit., at 5731.

⁶⁸ *Prosecutor v. Seromba*, Judgement (AC), op. cit., at para. 46; see also *Prosecutor v. Dragoljub Kunarac, Radomir Kovač and Zoran Vuković*, IT-96-23/1-T, Appeals Chamber judgement, 12 June 2002 (hereinafter ‘*Prosecutor v. Kunarac et al.*’), at para. 150 (stating, in its discussion of torture, that “[s]exual violence necessarily gives rise to severe pain or suffering, whether physical or mental”); *Prosecutor v. Akayesu*, Judgement (TC), op. cit., at para. 731, as cited in as cited in *Prosecutor v. Nyiramasuhuko* (TC), op. cit., at para. 5731

⁶⁹ *Prosecutor v. Seromba*, Judgement (AC), op. cit., para. 46, as cited in *Prosecutor v. Nyiramasuhuko* (TC), op. cit., at para. 5731.

The Appeals Chamber has also noted that “nearly all convictions for the causing of serious bodily or mental harm involve rapes or killings”.⁷⁰

The Tribunal took the above into account, when finding the defendants, including Pauline Nyiramasuhuko, Rwandan government Minister for Family and Women’s Affairs at the time, guilty also of genocide, and carrying individual criminal responsibility.⁷¹

The Tribunal did not set a precedent for considering rape in such light in the wider international scenario. Rather, it confined it to the events of the Rwandan Genocide, in the same way that MacKinnon re-qualified rape in light of the current crisis in South Africa. In this regard, the ICTY had come close, making the connection between forced pregnancy and genocide in the *Karadzic and Mladic* decision,⁷² solidifying such theory’s credibility in international law.

This was the case, even if in this judgement, the Tribunal had only gone as far as stating that forced impregnation may constitute evidence of genocidal intent through ethnic cleansing, whereby it also concluded, however, “that the systematic rape of women is in some cases intended to transmit a new ethnic identity to the child, and could constitute genocide.”⁷³

However, in so doing, the Tribunal’s actions illustrated once again the argument that the situation pertaining or that pertained to a particular domestic social order at a given point in time, would necessitate the re-calibration of legislation and relevant enforcement to match the situation at hand.

In the case of autistic rights, the debate would have a wider scope, as the focus is on fundamental, immutable rights that are being denied or broken, on the basis of which, it is being argued, such behaviour can lead to transgressions that are not only fundamental

⁷⁰ *Prosecutor v. Nyiramasuhuko*, op. cit., at para. 5731.

⁷¹ *Ibid.*, at para. 5970.

⁷² *Prosecutor v. Radovan Karadžić and Ratko Mladić*, IT-95-5/18, Trial Chamber judgement, 11 Jul. 2013; Appeals Chamber judgement, 24 Mar. 2016.

⁷³ Christine Strumpfen-Darrie, ‘Rape: A Survey of Current International Jurisprudence’, *Human Rights Brief*, Vol. 7, Issue 12, 2000, at 13, in Ellis, op. cit., at 234.

rights violations, but also actions falling within the criminal realm, that of genocide and its associated hierarchy of crimes.

However, the ICTR's analysis of how a crime can be re-classified according to the particular circumstances, together with Ellis' linking of the Convention elements to novel concepts, could very well be applied to discussions around other diverse groups, such as autistic persons. This, for example, as to how a re-classified crime could constitute mental harm in preventing future births due to trauma, or in destroying a group through making its members outcasts.

Autism needs to be viewed as an area where social change is required in line with the process followed by other mass social movements, such as the LGBTQ rights movement, as detailed later in this thesis. However, the process of re-calibrating the situation, as a first step, is one which can soundly be based on MacKinnon's reasoning, with relevant examples of legal practice being cited serving to bolster both precedent and context for this specific operation.

7.4.3 *Defining the Mens Rea for Genocide*

While it is important to define the nature of the *actus reus* necessary for the crime of genocide, or any crimes within this hierarchy, to be considered, proving the intentional element behind the performance of such acts or omissions has proven over time to be a far more contentious issue.

This can be seen, for example, from decisions handed down by the ICTY, where even where the *actus reus* was proven and agreed upon, different appreciations were applied to comparable situations, leading to a continual widening or narrowing of the criteria required for the specific intent leading to genocide, depending on the forum in question.

7.4.3.1 Croatia v. Serbia

A clearer look at the concept of genocidal intent can be gleaned from the International Court of Justice's decision in *Croatia v. Serbia*,⁷⁴ where the facts considered and charges

⁷⁴ *Case Concerning Application of the Convention on the Prevention and Punishment of the Crime of Genocide (Croatia v. Serbia)*, General List No. 118, International Court of Justice (ICJ), 18

contemplated were all in the context of the UN Genocide Convention. While the Court found for the *actus reus* of genocide being present,⁷⁵ it did not similarly concur that the relevant *dolus specialis* necessary for the crime of genocide to have been carried out, was present. However, the dual ‘nos’⁷⁶ emanating from the majority opinion of the Court – in respect to nature of the pattern of conduct, and specific intention behind such conduct – need to be studied further, in order to analyse their underpinnings.

This is necessary in order to be able to more clearly define what is necessary for genocide to occur both with respect to both actions and intentions, within a specific *sui generis* model. Such a model would not rely specifically on the tenets of the UN Genocide Convention, an ideal comparator when keeping in mind that this work is similarly trying to study the issue through hypothesising a similar model.

As to the element of specific, genocidal intent that represents the necessary *dolus specialis* for the crime of genocide to subsist, the Court analysed the following points. It first considered whether Croats in the regions in which Serbian regular and paramilitary forces launched military operations constituted “a substantial part of the protected group.”⁷⁷ The Court returned a majority opinion in the affirmative. This corresponded to the intent to destroy the protected group “in part”.⁷⁸

The Court then considered the ‘pattern of conduct in question’, in order to determine whether the only reasonable inference that could be drawn from such conduct by said Serb forces was “an intent of the Serb authorities to destroy, in part, the protected group.”⁷⁹ Counsel for Croatia argued that the “scale, intensity and systematic nature of the attacks” directed against the Croat population, based on the same *modus operandi*, demonstrate[d] the existence of a pattern of conduct.”⁸⁰ Counsel for Serbia disagreed, and rebutted by arguing a number of points in the state’s defence.

November 2008.

⁷⁵ Ibid., at 401.

⁷⁶ Ibid., at 440.

⁷⁷ Ibid., at 404.

⁷⁸ Ibid.

⁷⁹ Ibid., at 407.

⁸⁰ Ibid., at 411.

The first was the issue of Context, in which Serbia argued that it “does not contest the systematic and widespread nature of certain attacks”⁸¹ but that, however, it claimed that these were intended to force the Croats to leave the regions concerned, citing the judgements of the International Criminal Tribunal for the Former Yugoslavia (ICTY) in *Martić and Mrksić et al.*⁸² For example, in *Mrksić*, it had been argued that during military operations on Vukovar in Croatia, “the purpose of that attack was also to punish the town’s Croat population, but not to destroy it.”⁸³ In both cases, counsel for Serbia argued, “there was nothing to prevent the Trial Chamber from concluding that the attacks indicated an intent to persecute or to exterminate “or worse”, but that it had not done so.”⁸⁴

The main element that can be observed here is the reversion to basic criminal law principles, that there is never an offence, unless one is presented with a completed, or at the very least an attempted offence.⁸⁵ In fact, counsel for Serbia further maintained that the evidence “show[ed] a multitude of patterns giving rise to inferences of combat and/or forcible transfer and/or punishment”, but not of genocide.⁸⁶ Serbia further pointed to the fact that the Court had agreed with it in *Martić*, stating that its conclusion in that case “indicates that those acts were not committed with intent to destroy the Croats, but rather with that of forcing them to leave the regions concerned so that an ethnically homogeneous Serb State could be created.”⁸⁷

Serbia even went as far as portraying the scenario as resulting from nothing but a war in which two sides were involved, citing the Ovčara incidents discussed in the *Martić* judgement, and stating that here, “the intent of the perpetrators of the ill-treatment [...] was not to physically destroy the members of the protected group, as such, but to punish them because of their status as enemies, in a military sense.”⁸⁸

⁸¹ Ibid., at 412.

⁸² Ibid., citation

⁸³ Ibid., at 412, citing *Prosecutor v. Mile Mrksić and Veselin Sljivancanin*, IT-95-13/1, Trial Chamber judgement, 5 May 2009; Appeals Chamber judgement, 8 December 2010 (hereinafter the ‘*Mrskić*’ judgements).

⁸⁴ Ibid.

⁸⁵ See, for example, *Halsbury’s Laws of England* (5th ed), vol 25 Criminal Law, 2016.

⁸⁶ *Croatia v. Serbia*, op. cit., at 412, citing *Mrskić*, op. cit.

⁸⁷ Ibid., at 426, citing *Prosecutor v. Milan Martić*, IT-95-11, Trial Chamber judgement, 12 June 2007; Appeals Chamber judgement, 8 October 2008 (hereinafter the ‘*Martić*’ judgements).

⁸⁸ Ibid., at 430, citing *Martić*, op. cit.

The Serbian defence then discussed the issue of Opportunity, rebutting Croatian claims that routine instances of the *actus reus* of genocide, specifically covering sub-articles (a) to (d) of Article II of the Genocide Convention in this case, proved genocidal intent on the part of the Serbian authorities, and hence also the necessary *dolus specialis* for the crime of genocide to subsist.⁸⁹ Serbia insisted that, rather, the facts in many such instances mentioned by Croatia were not such, and that, in fact, there were many documented instances of JNA (Yugoslav National Army) or Serb forces sparing and not killing Croats in such situations.⁹⁰

In this judgement, the majority of the Court was of the opinion that the reasonable inference that the only pattern of conduct that could be drawn from Serbian actions was the intent to destroy, in whole or in part, the Croat group, had not been established by Croatia. It further found that the acts consisting the *actus reus* of genocide specified by Croatia, “had not been committed with the specific intent required for them to be characterised as acts of genocide.”⁹¹ But while Croatia’s claim was dismissed in its entirety as a result,⁹² the principle of strict liability adopted by the Court in this case, was not shared by the ICTY in the *Srebrenica* joined⁹³ cases.

7.4.3.2 The *Srebrenica* (Popovic and other joined) Cases

In this matter, the Tribunal, in contrast to the ICJ when handing down judgement in *Croatia v. Serbia*, drew on factual evidence that was similar in nature. However, it used it, instead, to point out that the final outcomes of the military operations in question were to be labelled an act of genocide. On the one hand, this was due to the collectivity of actions performed, as well as the specific manner in which they were directed. On the other hand, it was due to the position held by the perpetrators, and to what they should have reasonably known.

⁸⁹ Ibid., at 431.

⁹⁰ Ibid., at 432.

⁹¹ Ibid., at 432.

⁹² Ibid., at 441.

⁹³ *Prosecutor v. Vujadin Popovic, Ljubisa Beara, Drago Nikolic, Ljubomir Borovcanin and Radivoje Miletic*, IT-05-88-T, Trial Chamber Judgement, 10 June 2010; Appeals Chamber Judgement, 30 January 2015 (hereinafter the *Srebrenica* judgements).

In its judgement in this case, the Trial Chamber concluded that members of the Bosnian Serb Forces (BSF) had “committed genocide [...] against the Muslims of Eastern Bosnia, which constituted a substantial component of Bosnian Muslims as a group”.⁹⁴

The Trial Chamber was satisfied beyond reasonable doubt that defendants Popović and Beara committed “genocide through their participation in the JCE [(Joint Criminal Enterprise)] to Murder with genocidal intent”.⁹⁵ The Trial Chamber also found that defendant Nikolić “did not have genocidal intent,” but it concluded that “he aided and abetted genocide”.⁹⁶

In this regard, the First Instance Tribunal convicted the defendants of genocide, of extermination and persecution as crimes against humanity, and of murder as a violation of the laws or customs of war, to the extent that these concerned the Trnovo killings.⁹⁷

The Appeals Section, however, reversed these decisions reached by the First Instance Tribunal, in part due to the assertions made by the defendants that will be mentioned shortly.

In his dissenting opinion to the Appeals Chamber’s judgement, Judge Niang recalled that the Trial Chamber “did consider Nikolić’s participation in, and key contributions to, the killings, with the knowledge that the killings would contribute to the destruction of a group.”⁹⁸

He further refers to its pointing out that said Chamber similarly recalled that “Nikolić made a significant contribution to the commission of the crimes within the scope of the JCE to Murder [and] concluded that as of the morning of 14 July 1995, the events that occurred were “more than sufficient” for [Nikolić] to conclude that the plan was not just to kill but to destroy.”⁹⁹

⁹⁴ *Srebrenica*, Trial Chamber Judgement, at 344.

⁹⁵ *Ibid.*, at 785, 786.

⁹⁶ *Ibid.*, at 787.

⁹⁷ *Ibid.*, at 785 – 793.

⁹⁸ *Srebrenica*, Appeals Judgement, Separate and Dissenting Opinions of Judge Mandiaye Niang, at 7.

⁹⁹ *Ibid.*, at 8.

In this regard, he points out that the Trial Chamber had found that “Nikolić knew that this was a massive killing operation being carried out with a genocidal intent. His key contributions to the JCE to Murder are made concurrent with, and after the acquisition of this knowledge.”¹⁰⁰

However, the Appeals Chamber nonetheless reversed the judgement of the First Instance Chamber, notwithstanding the following observations by the First Instance Chamber, which the Appeals Chamber had cited, but also notwithstanding the assertions made by the defendants themselves.

In this regard, Beara had argued that the killings of six men at Trnovo were not a part of the common purpose of the JCE to Murder, since the Scorpions Unit of the Serb Paramilitary Forces, which he commanded, and which perpetrated the crime, was not a member of the JCE or linked to a member.¹⁰¹ Popović also presented a similar challenge in this regard.¹⁰²

The above assertions, together with the earlier observations, had been used by the Appeals Chamber to back up their reasoning that such factual findings would qualify more adequately as acts of complicity, rather than principal acts of genocide, thus brushing aside Nikolić’s responsibility as main perpetrator based, among other considerations, on his rank in the Military, his involvement less important compared to others and more decisively, because he was blindly dedicated to the security services.¹⁰³

Such reasoning, as also elucidated by Judge Niang in his Dissenting Opinion, relies on the view that “the JCE concept is to be distinguished from the definition of a specific crime”¹⁰⁴ – hence relying on a technicality to sidestep an otherwise damning scenario. In Judge Niang’s words,

“[This is] is in my opinion totally impracticable. The choice of JCE as a mode of liability means that the crime was committed through a particular *modus operandi*. The JCE *modus operandi* is a commission by association to the action of others. I do not see how

¹⁰⁰ Ibid.

¹⁰¹ *Srebrenica*, Appeals Judgement, at 366.

¹⁰² Ibid.

¹⁰³ Ibid.

¹⁰⁴ *Srebrenica*, Appeals Judgement, Separate and Dissenting Opinions of Judge Mandiaye Niang, at 7, Footnote 24.

it can be feasible to separate the *actus reus* and *mens rea* from their implementing vehicle.”¹⁰⁵

Thus, one could here observe a Tribunal within the same structure as the one that decided *Croatia v. Serbia*, following the same guiding documents, as well as body of case-law, which the Tribunal rendered ever more fluid with the passage of time. This Tribunal likewise agreed that the *actus reus* of genocide was satisfied, while being less rigid concerning the *mens rea*, at both First Instance and Appeals stages, even if the latter fell short of also declaring such, simply by splitting possible scenarios using a technicality.

7.4.3.3 The Genocide Case, Krstić, and murkier waters

In the largest indictment for genocide that the ICJ saw placed before it, the Court even went so far as not to define the required element of *mens rea*, in as far as this dealt with complicity of parties in the crime.

In this regard, Marko Milanović, commenting about the ruling in this case,¹⁰⁶ that dealt with matters relating to the 1995 Srebrenica massacres, observes that the Court was faced with “a complete and total conceptual mess of the kind only lawyers can make and relish, yet the Court unfortunately did nothing to clear it up.”¹⁰⁷

Here, the Court had stated that:

“the question arises whether complicity presupposes that the accomplice shares the specific intent (*dolus specialis*) of the principal perpetrator.

But whatever the reply to this question, there is no doubt that the conduct of an organ or a person furnishing aid or assistance to a perpetrator of the crime of genocide cannot be treated as complicity in genocide unless at the least that organ or person acted

¹⁰⁵ Ibid.

¹⁰⁶ *Case Concerning the Application of the Convention on the Prevention and Punishment of the Crime of Genocide (Bosnia and Herzegovina v. Serbia and Montenegro)*, Judgement of 27 Feb. 2007 (hereinafter the *Genocide* judgment).

¹⁰⁷ Marko Milanović, ‘State Responsibility for Genocide: A Follow-Up’, *European Journal of International Law*, Vol. 18, Issue 4, 2007, at 669, 681.

knowingly, that is to say, in particular, was aware of the specific intent (*dolus specialis*) of the principal perpetrator.

If that condition is not fulfilled, that is sufficient to exclude categorization as complicity.”¹⁰⁸

The ICTY had similarly considered issues of knowledge vs intent, in deciding on the *dolus specialis* required for the mens rea, in other cases involving complicity to commit genocide.

For example, in the *Krstić* case,¹⁰⁹ the Tribunal’s Appeals Chamber had lowered the bar, deciding that in the case of Bosnian Serb army General Radislav Krstić. He had commanded an army technically separate from the central Serbian army, and the Chamber had decided that aiding and abetting genocide required only that knowledge of the genocidal intent of the principal perpetrator, in this case the Serbian state, be demonstrated.¹¹⁰

In reaching such a conclusion, the Chamber had conducted an extensive study of English, French and German law, pointing to the fact that, in the criminal law spheres of these jurisdictions, the aider and abettor in a specific intent crime need not share the specific intent of the principal perpetrator.¹¹¹

These examples lead back to the argument that, once a protected group has been defined, and claims of genocide analysed with respect to that particular group:

- (i) more common strands run as to defining and confirming element constituting the *actus reus*, while;
- (ii) the element of *mens rea* remains more fluid and dependent on subjective human interpretation, with different judicial bodies reaching different

¹⁰⁸ *Genocide* judgement at 138, in Milanović, op. cit., at 681.

¹⁰⁹ *Prosecutor v. Krstić*, op. cit.

¹¹⁰ Milanović, op. cit., at 680.

¹¹¹ *Ibid.*

appreciations of the subject at different points in time, based on fluid criteria lacking deeper, more solid underpinnings.

7.4.4 The Concept of Justifiable Genocide

Finally, it is important to specify that, while analysing both planned genocides, as well as courses of action that can result in genocide or crimes within the genocidal hierarchy, due to unsuspecting perpetrators committing actions or omissions that tick all the boxes, there are also cases of a third nature. Here, the perpetrator is not only willing to carry out actions or omissions resulting in genocide or crimes within the genocidal hierarchy, but also justifies this matter, not out of hate, as with the Nazi crusade against the Jews, but out of stated kindness and meaning well to the group in question.

Prevention of disabilities, both among the living, and among those yet to be born, could be classified within this category, should the relevant criteria regarding genocide and associated crimes be met. The difference with other scenarios would be that, while the plan is overt and the intention is clearly stated, the resulting action is not thought of as genocide, either by the perpetrators, or by the society around those perpetrators.

This ties in with the earlier discussed concept, that it is social perceptions of what is 'normal', in a particular place and at a particular time, that shape the nature of notions of good and bad, of acceptable and extreme. In light of this, such an initiative would rather be seen as a well-meaning mission driven by love, albeit not by acceptance – a concept that will be discussed in further detail later in this work.

Thus, on the one hand, one would have the overtness and specific mens rea of the first category, that of a planned, pronounced genocide. However, on the other hand, this would be the case without the perpetrators and society believing that it is a genocide or calling it that. This would lead us to the criterion of unsuspectedness that defines the second category, twinned with the overtness and specific mens rea of the first.

Thus, preventing births of persons with a particular disability, or altering their behaviour in order for them to purportedly be able to have a better life, could be classified within this category, with both and other similar instances being discussed later in this work. The main

issues at stake here are regarding perception, once again, as to what is 'good' and 'bad'. The United Nations' Agenda 2030 document on achieving the Sustainable Development Goals is an example in point here, with regard to the mention of prevention of disability in the recitals to its preamble, also encompassing intellectual and developmental disabilities.¹¹²

One must keep in mind the nature of the negotiating process of such documents, with all different stakeholders vying to insert two or three words into the final text. The initial aim of this provision could be seen as aimed at preventing mostly 'preventable' disabilities especially in the global South countries, such as preventable blindness due to malnutrition or poor sanitation, one of the causes championed by the NGO Sightsavers.¹¹³ However, the issue of preventable disabilities, wherever they might occur in the world, was then added on to by the insertion of the reference to intellectual and developmental disabilities.

While this may just be seen as an insertion in virtue of the negotiating process mentioned above, the fact that this amendment was inserted, and subsequently carried, to the ire of many self-advocates in the field of intellectual and developmental disabilities, including autistic self-advocates, ties in with the argument of what society believes and accepts as to the notions of 'good' and 'bad.' Consequently, any talk of genocide or associated crimes must be discussed in light of this, as mentioned earlier, and as will be done later in this work.

¹¹² The Preamble of 'Transforming our world: the 2030 Agenda for Sustainable Development', UN General Assembly Resolution 70/1 (October 21, 2015), UN Doc.A/RES/70/1 (Agenda 2030), includes the text:

"We are committed to the prevention and treatment of non-communicable diseases, including behavioural, developmental and neurological disorders, which constitute a major challenge for sustainable development."

This was a point of contention with the drafting team of the Discussion paper on Persons with Disabilities, Chapter IX of the Discussion papers on the theme of the high-level political forum on sustainable development, submitted by major groups and other stakeholders, to the *High-level political forum on sustainable development*, Convened under the auspices of the Economic and Social Council, that took place on 11-20 July 2016, UN Doc. E/HLPF/2016/2, 2 May 2016, of which the author was co-facilitator and co-author.

A cordial but heated discussion ensued between different drafting team members, when representing the views of different groups and self-advocates, in trying to reach an agreement, during one of the online meetings discussing the formulation of the Position Paper, in April 2016.

¹¹³ The NGO's website, at <http://www.sightsavers.org>, states that: "We want to eliminate avoidable blindness and support people who are irreversibly blind or disabled to live independently."

Chapter 8: Genocide – From Theory to Practice

8.1 Introduction

As earlier outlined when referencing Joseph Stalin's political hand in ensuring a watered-down Convention being adopted rather than a document on the lines of the wider 1946 GA Resolution, external circumstances can have as much an influence on shaping the conceptual path of a legal notion, as would the specific rationale and hard facts behind the legal notion itself.

And while Stalin was responsible for stunting the scope and final nature of the Genocide Convention at the intergovernmental level, irreparable harm was done to the actual concept behind the Convention and its precursor, the 1946 GA Resolution, by none other than Rafal Lemkin himself, the lawyer who espoused the original notion of genocide, having defined both its elements, as well as offering hard facts as examples to back up such notion.

Lemkin's earlier published treatise, as well as his original presentation to the League of Nations in the wake of the Armenian Genocide, already stood out in stark contrast to the largely watered-down draft he proposed to the United Nations for a Genocide Convention in the late 1940s.

However, although one could argue that, especially at intergovernmental level, sometimes hard compromises have to be made in order to get even the smallest ball rolling, it was his eventual reaction to specific groups within the United States testing his notion, and doing so by directly petitioning the UN within the framework of the watered-down Convention that had been adopted, that constituted the rudest of awakenings.

8.2 'We Charge Genocide': Testing the Waters

Following the Nuremberg Trials, the first real challenge in the international system under the Genocide Convention was that brought by a non-state petitioner, the Civil Rights Congress of the United States of America, against the American Government before the

UN.¹ The Civil Rights Congress claimed the UN had jurisdiction of the matter, and petitioned the General Assembly to take action towards this end.² It stated that the General Assembly was obliged to consider their claim, basing itself of the Assembly's resolution following the Mindszenty trial in Hungary,³ as well as, in particular, on the complaint brought before the General Assembly by the Government of India against that of South Africa.⁴

The Congress argued that the General Assembly had the right and duty to hear their complaint under the provisions of the Charter of the United Nations, since it involved violations of "fundamental human rights" outlined in said Charter,⁵ and forbidden by the Genocide Convention. As to the two instances just mentioned, the Congress cited them as instances where it was held that any matter coming within the scope of the Charter is admissible before the General Assembly.⁶

As to the Mindszenty resolution, General Assembly President H.V. Evatt had stated, in respect to the UN's censorship of Hungarian actions in this regard, that:

"There is not a single question or matter coming within the scope of the Charter, relating to its aims, its principles or any one of its provisions, which could not be discussed by the General Assembly. If any question was covered by an article of the Charter, that matter would no longer be a matter essentially within the domestic jurisdiction of a state."⁷

¹ The petition submitted to the General Assembly, together with updates in subsequent editions of the publication, was also published as William L. Patterson (ed.), *We charge genocide: the historic petition to the United Nations for relief from a crime of the United States government against the Negro people* (3rd ed.), International Publishers, New York, 1951 (hereinafter 'We Charge Genocide').

² Ibid., at 38.

³ The resolution, tabled by Bolivia, was aimed at discussing the matter of Cardinal József Mindszenty. Mindszenty was condemned to life imprisonment by the communist government of Hungary for treason, conspiracy and other crimes against the State, after what was alleged by the West to have been a show trial on the basis of false charges and a confession from Mindszenty obtained under duress, as described in Alice Rethinger Watson, *The Life and "Crimes" of Cardinal Jozsef Mindszenty*, CatholicCulture.org, accessed online at <https://www.catholicculture.org/culture/library/view.cfm?recnum=661>.

⁴ Ibid., at 38-39.

⁵ Charter of the United Nations, 24 October 1945, 1 UNTS XVI, at Preamble.

⁶ Ibid., at 38-39.

⁷ As quoted in UN Document A/BUR/SR 58, at 13, cited in 'We Charge Genocide', op. cit., at 39.

This rationale was also the driving ethos behind India's complaint against South Africa, the subject-matter of which tied in more closely with the Congress' complaint. Here, India complained of the passage of the Asiatic Land Tenure and Indian Representation Act by the South African Parliament, claiming that such legislation denied South African citizens of Indian descent certain civil rights, discriminating against them on the basis of race.⁸

The Indian government contended that the Act breached the treaty obligations and violated the spirit and letter of the Charter of the United Nations, and urged the General Assembly to pass a resolution urging South Africa to desist from any policy of discrimination.⁹

While South Africa questioned the General Assembly's authority to pass such resolution, pleading immunity in terms of the Charter,¹⁰ the General Assembly rejected such plea, and adopted a resolution in terms of said Charter, authorizing the United Nations "to promote [...] a universal respect for, and observance of, human rights and fundamental freedoms for all without discrimination as to race."¹¹

In this regard, the resolution further specified that "it [was] of the opinion that the treatment of Indians in the Union [of South Africa] should be in conformity with the international obligations under the agreements concluded between the two governments, and the relevant provisions of the Charter."¹²

The Civil Rights Congress' petition was ultimately not adopted by the United Nations. John Docker explains the rationale behind this by arguing that "[g]iven the limitations of UN power and responsibility at this time and the Cold War context, there was no way [the Civil Rights Congress] could succeed in producing a UN indictment of the United States."

¹³

Nevertheless, the petition outlined many points, in line with the original concept of genocide espoused by Lemkin, and Congress President William L. Patterson described the

⁸ As cited in UN Documents A/C 1 and 6/12, cited in 'We Charge Genocide', op. cit., at 39.

⁹ Ibid.

¹⁰ Ibid.

¹¹ Ibid.

¹² Ibid.

¹³ John Docker, 'Raphaël Lemkin, creator of the concept of genocide: a world history perspective', *Humanities Research*, Vol. 16, Issue 2, 2010, at 63.

petition being received extremely well on his visit to Paris, where he presented the petition at a UN meeting.¹⁴ He even stated that, within the United States itself, 45,000 copies of it had been sold in book form.¹⁵

However, a number of interests and considerations were at play.¹⁶ On the one hand, these included legal technicalities, that would lead to its being ignored by the UN, the same factors that it is later argued are the bane of using and implementing the wider concept of genocide in this day and age. On the other hand, there were political factors, as mentioned by Docker and in Section 1.1.4 of this thesis, and discussed further in this Chapter.

The petition submitted in 1951 in this regard by the Congress, entitled 'We Charge Genocide', aimed to require the United Nations system to hold the United States government accountable for the crime of genocide against the "negro people" forming part and parcel of said United States' citizenry.¹⁷

8.2.1 Killing of Members of the Group

The petition spelt out that it covered both 'mass slayings on the basis of race,'¹⁸ as well as instances of 'lives deliberately warped and distorted by the wilful creation of conditions making for premature death, poverty and disease.'¹⁹ While stating that these 'terrible injustices' constituted 'a daily and ever-increasing violation' of the Convention, it addressed the salient point that

"It is sometimes incorrectly thought that genocide means the complete and definitive destruction of a race or people. The Genocide Convention, however, [...], defines genocide as any killings on the basis of race, or, in it specific words, as "killing members of the group."²⁰

¹⁴ Ibid., at 64.

¹⁵ Ibid.

¹⁶ For example, the *Washington Post* had mentioned, in 'U.S. 'Muzzle' on Genocide Charge Alleged', on 1 January 1952, that during Patterson's visit to Paris, the US State Department ordered him to surrender his passport at the US Embassy there, and when he refused, eventually seized his passport in London during his travels.

¹⁷ We Charge Genocide, at 3.

¹⁸ Ibid, at 183.

¹⁹ Ibid, at 126, 144.

²⁰ Ibid, at 45.

These killings were variously described. On the one hand, there were those carried out by private lynch mobs or organised thuggery such as the Ku Klux Klan,²¹ or those committed by ordinary citizens, such as the slaying of farmer William Brown by game ranger Charles Ventrill in 1947, with charges being pressed against the latter, even after his overt statement "“I just shot a nigger.”"²²

On the other hand, there were state-sanctioned killings, such as those that happened in jail cells after torture or excessive mistreatment by law enforcement,²³ executions where defendants had been framed or convicted despite lack of or fabricated evidence,²⁴ or at the hands of police, with the Congress stating that "once the classic method of lynching was the rope. Now it is the policeman’s bullet,"²⁵ echoing the ethos of the modern 'Black Lives Matter' movement.

8.2.2 *Intent to Destroy a Group*

To the element of killings, the Congress also added 'any intent to destroy, in whole or in part, a national, racial, ethnic or religious group is genocide, according to the Convention,' with the words:

"Thus, the Convention states, “causing serious bodily or mental harm to members of the group,” is genocide as well as “killing members of the group.” [...] We maintain, therefore, that the oppressed Negro citizens of the United States, segregated, discriminated against and long the target of violence, suffer from genocide as the result of the consistent, conscious, unified policies of every branch of government.”²⁶

In this regard, the Congress spoke of economic genocide. It spoke of conditions that contributed to increasing infant and maternal deaths, or deaths from disease in the American black community, depriving community members of an average of eight years of life in comparison to their white counterparts.²⁷ It also spoke of their treatment under

²¹ Ibid, at 4, 151.

²² Ibid, at 68.

²³ Ibid, at para. 90, 119.

²⁴ Ibid, at 9, 59, 67, 73.

²⁵ Ibid, at 8.

²⁶ Ibid, at xi.

²⁷ Ibid, at 125.

employment law,²⁸ as well as through their segregation in areas such as housing,²⁹ medical care³⁰ and education,³¹ either through formal statutes or through sanctioned violence:

"the existence of a mass of American law, written as was Hitler's law solely on the basis of "race," providing for segregation and otherwise penalizing the Negro people, in violation not only of Articles II and III of the Convention but also in violation of the Charter of the United Nations."³²

8.2.3 *Incitement and Complicity to Genocide*

Most importantly, the issue of public and over incitement was addressed, with the Congress offering evidence which in its opinion was to confirm that

"this genocide is not plotted in the dark but incited over the radio into the ears of millions, urged in the glare of public forums by Senators and Governors."³³

Such politicians included Georgia Congressman Henderson Lanham's reference to Congress President William L. Paterson in US Congress as "a God-damned black son-of-bitch," while adding that "[w]e gotta keep the black apes down."³⁴

Such statements, opined the Congress, were "offered as an article of faith by powerful political organizations, such as the Dixiecrats, and defended by influential newspapers, all in violation of the United Nations charter and the Convention forbidding genocide."³⁵

This was coupled with the fact that information about the plight of black Americans could only be gleaned through "Negro newspapers, from the labor press, from the annual reports

²⁸ Ibid., at 138.

²⁹ Ibid., at 140.

³⁰ Ibid., at 130.

³¹ Ibid., at 131.

³² Ibid., at 6.

³³ Ibid., at 5.

³⁴ Ibid., at 8.

³⁵ Ibid. at 5.

of Negro societies and established Negro year books,"³⁶ and that police neglected or refused to either investigate or record alleged crimes against black citizens.³⁷

This contributed towards public perceptions, outside of the black community, in which, according to the Congress, "[t]he tragic fact of segregation [wa]s the basis for the statement, too often heard after murder, particularly in the South, "Why I think no more of killing a nigger, than of killing a dog."³⁸

8.2.4 *Conclusion regarding Petition and Snowball Effect*

On the one hand, the Congress spoke of 'mass murder' or 'persistent slaughter',³⁹ while on the other hand it spoke of 'institutionalised oppression'.⁴⁰ It spoke of a 'pattern of genocidal murder', 'the technique of incitement to genocide', and 'the methods of mass terror'.⁴¹ The Congress argued that there was present an "education for genocide, [...] based on the Hitler-like theory of the "inherent inferiority of the Negro."⁴²

The Congress felt that this was not only 'an historic responsibility to the American people,' not least because of the fact that whites in areas where black citizens were being targeted were also feeling the effects of related actions such as segregationist policies, but also a 'service to progressive mankind' because, in the Congress' words, a "policy of discrimination at home must inevitably create racist commodities for export abroad-must inevitably tend toward war."

Also echoing the future reasoning laid out in the Eichmann judgements tackled in the previous Chapter, the Congress considered the United States' adherence to the UN Charter an act making the Genocide Convention inseparable from domestic US law, further stating that, according to both international and US law, the Convention, together with the

³⁶ Ibid, at 9.

³⁷ Ibid, at 80, 123.

³⁸ Ibid, at 8.

³⁹ Ibid, at 3.

⁴⁰ Ibid, at 134.

⁴¹ Ibid, at 8.

⁴² Ibid.

provisions of the UN Charter, "supersedes, negates and displaces all discriminatory racist law on the books of the United States and the several states."⁴³

In tying in the content of this early challenge, with arguments presented later in this work, it is worthy to note the following statement by the Congress:

"Seldom has mass murder on the score of "race" been so sanctified by law, so justified by those who demand free elections abroad even as they kill their fellow citizens who demand free elections at home. Never have so many individuals been so ruthlessly destroyed amid many tributes to the sacredness of the individual. The distinctive trait of this genocide is a cant that mouths aphorisms of Anglo-Saxon jurisprudence even as it kills.

The genocide of which we complain is as much a fact as gravity. The whole world knows of it. The proof is in every day's newspapers, in every one's sight and hearing in these United States. In one form or another it has been practiced for more than three hundred years although never with such sinister implications for the welfare and peace of the world as at present.

Its very familiarity disguises its horror. It is a crime so embedded in law, so explained away by specious rationale, so hidden by talk of liberty, that even the conscience of the tender minded is sometimes dulled. Yet the conscience of mankind cannot be beguiled from its duty by the pious phrases and the deadly legal euphemisms with which its perpetrators seek to transform their guilt into high moral purpose."⁴⁴

It is important to note that, in respect of possible admissibility of such claim, the Congress kept strictly to the Convention criteria, speaking on behalf of the category of "race", one of the four categories enumerated in Article II of the Convention, and also complying with the time criterion, in that the actions and omissions covered by the petition all occurred post-1945,⁴⁵ being mostly within the Convention's temporal scope, either due to date of commission, or else due to being continuing offences.

⁴³ Ibid, at xii.

⁴⁴ Ibid, at 3-4.

⁴⁵ Ibid, at 55, 58.

8.3 Irreparable Damage done by Lemkin

However, the one man who could have stood up and backed these claims, in line with his earlier assertions, both published and presented at international level, actually dealt this movement the largest stab in the back. Writing an op-ed piece in the New York Times, Lemkin rather argued that while African-Americans had been experiencing conditions of increasing progress and prosperity within the United States, as to the specific charge of genocide, this did not hold water. He argued that, while this group might have been said to have suffered discrimination, they had not, in his words, suffered “destruction, death [or] annihilation,” which he stated to constitute, at that point, the essence of genocide.⁴⁶

Aside from what Lemkin actually believed, this flew in the face of what was now an instrument at international law, acceded to by a large number of members within the United Nations system. While there were different crimes in the hierarchy of crimes foreseen by the Convention, the specific crime of Genocide, listed in Article 3(a) of the Convention, could be accomplished merely through a subject’s *animus nocendi*, this being the essence of Article 2(c) of the Convention. This was listed as an independent ground to the *animus necandi* required by the other and separate ground outlined in Article 2(a) of the Convention.

This is what Lemkin seemed to consider the decisive element he was equating the crime of Genocide with at this point and which, unfortunately, remains the most commonly understood definition of Genocide to this very day. Such a state of affairs makes interpretation in this regard an extremely murky affair for both legal scholars, as well as administrations and courts of law, even within the United Nations system.

This would also go as far as calling Lemkin’s original defining example of an act of Genocide, the Armenian Genocide which he so strongly proposed in his works and before the League of Nations, into question.

The main rebuttal to these events being labelled a genocide by the Turkish Republic, as the successor state to the Ottoman Empire, accused of planning and perpetrating the Armenian

⁴⁶ Ann Curthoys and John Docker, ‘Defining Genocide’, in Dan Stone (ed.), *The Historiography of Genocide*, Palgrave Macmillan, London, 2008, at 19.

Genocide, is that, at no stage of either planning or preparation, was there ever specific *animus necandi* on the path of either government or military officials involved in such planning and execution. This notwithstanding the fact that the said Turkish Republic, nonetheless, acceded to the Genocide Convention in 1950, without lodging a single reservation,⁴⁷ as opposed to countries such as the United States of America that lodged multiple reservations when so acceding.⁴⁸

While, although the Turkish Republic cannot be prosecuted retrospectively for crimes under the Convention that happened before its adoption in 1948, or before its accession to said Convention in 1950, the fact that this state acceded to the Convention in its entirety without any reservations would carry implications of its own. Most notably that the Turkish authorities, at least the Kemalist government at the time of such accession, which was also the same administration that initiated a vehement rejection of the Armenian Genocide argument, would have been aware of Article 2(c) and of its meaning. This would have allowed them the freedom of choosing to either not accede to such Convention, or else to so accede while lodging any reservations to it that they would have seen fit, should they have felt one of such options to have been in their best interests.

Furthermore, however, the Turkish Republic would have also, in light of the above, been presumed to view any discussion of events past or present that could be either hypothetically or actually tested against such Convention, within the actual context of such. Therefore, the test of the ordinary reasonable man would have been applied here, and would have held in the same way as it did to defendants contesting their role in passenger transports during the Nuremberg trials. Here, such a test trumped both personal defences on these lines, as well as any defences on the lines of having followed orders from superiors, and not having been aware of any greater masterplan.⁴⁹

In just the same way, it was deemed practically impossible not to have had wind of the fact that there was a plan to rid Europe of all its Jewry, and that Jews were actually being killed

⁴⁷ As specified in the record of ratifications of the UN Genocide Convention, available on the website of the UN Office of the High Commissioner for Human Rights (OHCHR), accessed online at <http://indicators.ohchr.org/>.

⁴⁸ Ibid.

⁴⁹ See, for example, *United Kingdom v. Tesch et al.* ('Zyklon B case') (1947) 1 L Rep Trib War Crimes 93.

by the hundreds throughout Europe, at the moment of any such person having been involved in the passenger transports, especially during the later stages of the Second World War.

In the same manner, it could be deemed practically impossible for any government official involved in planning, but especially for any military commander or subordinate on the ground, not to have reasonably known or expected that marching thousands of persons into the Syrian desert, in sweltering heat, for days on end, and without basic supplies, would have led to the death of a number of those persons.

Barring immense naïveté, even if the *animus nocendi* criterion required by Article 2 (a) was not fulfilled in these circumstances, the *animus necandi* criterion of Article 2 (c) was definitely proven beyond reasonable doubt. Not only was this evidenced through survivor testimonies, but also through reports by the press and organisations such as the International Society of the Red Cross and the Red Crescent (ICRC),⁵⁰ as well as Ottoman officers themselves.

In particular, one could refer to the testimonies of those officers arrested and sentenced for war crimes by Ottoman courts following the cessation of hostilities,⁵¹ the charges being similar to those levelled during the Nuremberg Trials, since no genocide statutes had been enacted locally or internationally up until that point in both cases.

The main point to be made, however, is that of comparing like with like. Many persons nowadays simply still consider the Armenian Genocide as a genocide simply because of the numbers in question. The event led to an Armenian population within Ottoman lands, as documented by statics from that era, to have been decimated to around 400,000 persons following the conclusion of the First World War, in contrast to earlier figures of 2.3 million persons prior to the start of said War, leaving 1.5 million persons or 82% of the pre-War figure unaccounted for.⁵² In the same way, the genocide directed against the Jewish

⁵⁰ Henry Morgenthau, 'The Greatest Horror in History', *Red Cross Magazine*, March 1918.

⁵¹ See, for example, George J. Andreopoulos (ed.), *Genocide: conceptual and historical dimensions* (1st paperback ed.), University of Pennsylvania Press, Philadelphia, 1997.

⁵² These figures are averages of different statistical data usually agreed upon by historians, with these specific values having been carried by the mainstream press, such as the New York Times in John Kifner, 'The Armenian Genocide of 1915: An Overview', accessed online at http://www.nytimes.com/ref/timestopics/topics_armeniangenocide.html, and the Armenian National

population in the Holocaust is reflected by a drop of 6 million persons or 63% in European Jewish population figures between the start and end of the Second World War.⁵³

The difference in this case, however, being that it was subsequently proven that there was a specific *animus necandi* vis-à-vis such persons from the Nazi administration, that would have fallen within Article 2(a) of the Convention. In the Armenian scenario, even taking the assertions by the Turkish Republic at face value, and going with the version that people just died in the process and were not specifically targetted to be killed, this action would similarly have constituted Genocide within Convention terms, falling within Article 2(c).

In this specific case in point, there was not only the inflicting of physical and mental conditions aimed at bringing about the partial and total destruction of a group, but it actually happened. But even if the perpetrators maintain in their defence that this was never the specific intended outcome, the circumstances surrounding the events would point clearly to the fact that the ordinary reasonable man test would have pointed to this possible

Institute in the United States at http://www.armenian-genocide.org/genocidfaq.html#How_many. This is the average of figures given by certain scholars such as Justin McCarthy, who give figures as low as 600,000, and others such as Rudolph J Rummel who give a figure of 2,000,000, arguing that the genocide continued into the period after which Ataturk's Nationalist forces took power. These variations can be explained by the availability and quality of relevant statistical sources.

A comprehensive overview and discussion of such figures can be found in Rudolph J Rummel, 'Statistics Of Turkey's Democide - Estimates, Calculations, And Sources' (Chapter 5), in 'Statistics of Democide: Genocide and Mass Murder since 1900', LIT Verlag, Muenster, 1998, with Rummel putting forward his own conclusions, after a discussion and analysis of various source documents such as vital statistics compiled in state, ecclesiastical and third-party documents, as well as an analysis of the most frequently cited scholars in this field, such as Toynbee, Ladas, Miller and McCarthy, and their sources. Rummel also breaks down calculations by event for avoidance of doubt, identifying which events resulting in deaths were genocidal, and which were not.

However, the 'Black Book' diaries of Ottoman wartime interior Minister Talaat Pasha, serialised by Turkish journalist Murat Bardakçı in the 2000s, from documents obtained from Talaat's widow, show the population figure for Ottoman Armenians plunge from 1,256,000 in 1915 - a figure Talaat himself stated to be undercounted by around 30% - to 284,157 in 1917. Talaat writes in a footnote, cited in Ana Sarafian, 'Talaat Pasha's Black Book documents his campaign of race extermination, 1915-17', *The Armenian Reporter*, 13 March 2009 (additions in square brackets by Sarafian), that "The 1914 [1330] census gives 1,187,818 Gregorian Armenians, and 63,967 Catholic Armenians [no talk of Protestants] with a total of 1,256,403 [sic, 1,251,785]. If one adds by way of precaution [presumably undercounting] 30% to the figures at hand, the true number of Armenians in 1914 can be taken as 1,500,000, and the number of Armenians remaining in the provinces, 284,157, to be around 350,000 to 400,000."

⁵³ The United States Holocaust Memorial Museum, at <https://www.ushmm.org/wlc/en/article.php?ModuleId=10005687>, cites the *American Jewish Yearbook*, in respect of the Jewish population of Europe being about 9.5 million in 1933, while only about 3.5 million in 1950.

Concurrently, one can see through statistics published by the *World Almanac*, cited by The Nizkor Project at <http://www.nizkor.org/features/denial-of-science/worldalmanac.html>, a global Jewish population of 16,643,120 in 1939, and of only 11,266,600 in 1949.

outcome, thus triggering an Article 2(c) instance of Genocide. The fact that so many persons actually did die in the process simply adds to the nature of this tragedy, but the operation would have still been an act of Genocide, even if they would not have.

So, although one could look back to Lemkin's original work and exhortations in defining the original concept of genocide, his backtracking is still of paramount significance. One could still attempt to frame matters in light of the text of the Convention, watered-down as it might have been, that he was influential in piloting through the General Assembly, and the subsequent wording and interpretation of such.

However, Lemkin himself did not limit himself to a general narrowing of the definition, but did so only in a specific concept. While stating the above points with regard to African-Americans within the United States, at the same time he was speaking of the concurrent post-war "crimes of genocide committed against Estonians, Latvians, Lithuanians, Poles and other Soviet-subjugated peoples."⁵⁴

While this would seem to fall within his initial appreciation of the concept of genocide, in light of his comments regarding the 'We Charge Genocide' petition, they would seem odd considering that he also, around the same time, labelled the Holodomor, the Soviet mass starvation programme carried out against Ukrainians in the 1930s in a bid to pacify them, as the "classic example of Soviet genocide."⁵⁵

This, while not detracting in any way from the horrors being experienced by the other groups mentioned earlier that fell under the Soviet sphere, could be seen as calling his credibility and sense of proportion into question, when one evaluates the massive scale and extent of the Holodomor, and Lemkin's own assertion that this amounted to the "destruction of the Ukrainian nation."⁵⁶

Behind of all this, one could trace a very important fact and, while humanly understandable, it still did irreparable damage to an academic and functional legal concept,

⁵⁴ John Cooper, *Raphael Lemkin and the Struggle for the Genocide Convention*, Palgrave Macmillan, Hampshire, 2008, at 225.

⁵⁵ Raphael Lemkin, 'Soviet Genocide in Ukraine', *Holodomor Studies Journal*, Vol. 1, Issue 1, Winter-Spring 2009, accessed online at <http://www.ukemonde.com/lemkin/>.

⁵⁶ Ibid.

as to its understanding and especially application to real-life situations for years to come. Lemkin had gone as far as to call co-petitioners Patterson and Robeson “un-American” elements, serving a foreign power.⁵⁷

Here, the picture starts to come together of Lemkin the refugee, who himself ended up having to flee a genocide, the Nazi genocide in his native Poland, where as a Jew, he was also a prime target. Having sought asylum in the United States, and with no international mechanisms yet regulating refugee rights and concepts such as the principle of *non-refoulement* in place, with the Soviet Union currently holding his native Poland in its grip, and having annexed the part of Poland he hailed from directly to its territory, Lemkin had no interest of returning to his motherland any time soon, and far less interest of leaving his new adopted homeland.

Particularly in these circumstances, and with the wider spectre of the Cold War in the background, Lemkin must have realised that political allegiances and taking sides would be what would guarantee his safety and his integrity from a certain point on, especially after his public activism and statements related to the cause of genocide in the past. So, while the Soviet Union was fair game, the United States was not.

Rather, it was totally off limits, and especially in the environment leading up to the McCarthyist ‘red purges, not only could he not utter a sound vis-à-vis the United States, but he also had to prove his allegiance by contrasting this with demonising the Soviet Union, and not simply calling it out when it violated the Genocide Convention. And all this, unfortunately, at the expense of the legal notions underpinning genocide.

Which is why one has to always dig deeper than the surface expressed through current legal opinion, texts and case-law. Such only represent the status quo, but that status quo could have been forged out of political expediency or convenience, or even for fear of one’s own safety, as it appears to have been the case with Lemkin. And peeling off these layers can be an arduous but necessary exercise in realigning perspectives and doing the truth justice.

⁵⁷ Cooper, op. cit., at 225.

As with the case of the Armenian Genocide where, although major world powers now recognise this Genocide and continually call on the Turkish Republic to do likewise, it must be remembered why the Kemalist government that disassociated itself from the trials of leading officers conducted by the previous Ottoman government felt it could get away with such and still go ahead and accede to the Genocide Convention without reservations.

The Foreign Secretary of one such major power, the United Kingdom, offered the following explanation back in 1921 as to why convicted officers that had been interned in the then colony of Malta, under an agreement with the Allies, had been returned to the government of the Turkish Republic, in return for British prisoners held there:

“The less we say about these people (the Turks released for exchange) the better [...] I had to explain (to Parliament) why we released the Turkish deportees from Malta, skating over thin ice as quickly as I could [...] The staunch belief among Members (of Parliament) is that one British prisoner is worth a shipload of Turks, and so the exchange was excused.”⁵⁸

8.4 Recapitulating the Flexible Concept of Genocide

Therefore, in light of the above considerations, one might draw the following three conclusions:

8.4.1 Qualifying Groups

Actions or omissions constituting genocidal practices, or crimes in this hierarchy, are not linked to specific intrinsic qualities of a particular group or groups, but rather to more general characteristics that can be pinpointed in identifying particular vulnerable groups, with these groups being identified by perpetrator or lawmaker alike, depending on a combination of national, historical and social circumstances, be it on the national or international levels.

⁵⁸ FO 371/7882/E4425 (folio 182), UK Foreign Office Archives, London, cited in Vahakn N. Dadrian, *The History of the Armenian Genocide: Ethnic Conflict from the Balkans to Anatolia to the Caucasus* (6th ed.), Berghahn Books, New York/ Oxford, 2004, at 311.

This can be seen from the way different legislators, ad hoc tribunals and commentators have deemed certain groups to either warrant requiring protection from genocidal practices, or else to warrant classification as such groups due to past or ongoing genocidal practices that were or are being experienced by such specific groups.

8.4.2 *Element of Actus Reus*

It is clearly established, especially through case law on the domestic and international levels, analysing and interpreting provisions in both supranational and national legal texts, that there is a general consensus about which actions and omissions constitute genocidal acts, when considering the commission or otherwise of genocidal practices, or crimes in this hierarchy.

8.4.3 *Element of Mens Rea*

The specific intent required for genocidal practices, or crimes within this hierarchy, to be declared as having been committed in pursuance of the crime of genocide, or of crimes within the genocidal hierarchy, is neither clear in guiding supranational or national texts, nor has there been any clear consensus reached when analysing the wider body of case law on the matter. Likewise, commentators have offered their different views as to mens rea, at times restrictive, at times ampler.

It transpires very clearly that, when reaching decisions on whether a particular act or omission constituted genocide or not, courts and tribunals have been motivated by a number of political and societal factors, as well as a heavy dose of personal interpretation, due to want of a more coherent body of decisions in the area. Likewise, in the field of drafting guiding legal texts in the area, political and societal considerations, as well as political and diplomatic compromise, have been the order of the day, at the expense of a purer legal consideration of matters at stake.

This is best reflected by the volte-face in the position of the father of the concept of genocide, Rafał Lemkin, in the face of political and social circumstances affecting his personal life and well-being. Not only did this deprive the legal world of an unwaverable base point to which all future considerations of the matter could refer to, but also sent the

message that genocide was a flexible concept – in every sense – and that any future parties deliberating upon the matter would simply be doing business as usual if they also followed his example.

8.4.4 *Conclusions*

In conclusion, one could answer the questions posed earlier in the following fashion.

As to the definition of genocide being applied to the analysis carried out later in this work, the work of Huttenback, Thompson, Quets and Fein is being used in terms of guiding principles. As per Huttenback's analysis, the work will look beyond the concept of actual killings in discussing genocide, going by the specific observations made by Thompson and Quets as to genocide aiming at the destruction of a group by purposive action, such actions including the suppression of biological and social reproduction of the collectivity outlined by Fein.

As to the groups which can be subject to genocide, the *jus cogens* principle enunciated in the Eichmann judgements shall be referred to, in line with the earlier PCIJ judgement cited by such, in the spirit of Resolution 96(I), extending protection to all groups and collectivities, in line also with Charny's observations in this regard.

In this regard, the reasoning espoused by Golichenko and Merkinaite, when analysing the 'other status' category in the application of Article 14 of the European Convention of Human Rights, is also noteworthy. They opine that such terminology, within the Convention framework, is not limited to cases of discrimination based on individual characteristics (sex, race, skin colour, religion, social background, etc.).⁵⁹

Rather, they state that, according to the Court's interpretation, its meaning could also embrace characteristics that, like some of the specific examples listed in the Article, can be said to be personal in the sense that they are innate.⁶⁰ For example, the Court has found

⁵⁹ Mikhail Golichenko and Simona Merkinaite, 'In Breach of International Law: Ukrainian Drug Legislation and the European Convention for the Protection of Human Rights and Fundamental Freedoms', Discussion Paper, Canadian HIV/ AIDS Legal Network/ Eurasian Harm Reduction Network, 2011, accessed online at http://www.harm-reduction.org/sites/default/files/pdf/european_convention_ukraine_0.pdf, at 33.

⁶⁰ *Clift v. the United Kingdom*, no. 7205/07, s57. July 2010; *Pine Valley Developments Ltd and Others v. Ireland*, 29 November 1991, 64, Series A no. 222; *Sidabras and Dziautas v. Lithuania*, nos. 55480/00 and 59330/00, ECHR 2004-VH1, ECHR 2004-V111; *Laricos v. Cyprus*, no. 29515/95,

that sexual orientation was “undoubtedly covered” by Article 14,⁶¹ as was physical disability.⁶²

According to the European Court,

“the question whether there is a difference of treatment based on a personal or identifiable characteristic in any given case is a matter to be assessed taking into consideration all of the circumstances of the case and bearing in mind that the aim of the Convention is to guarantee not rights that are theoretical or illusory but rights that are practical and effective.”⁶³

Such reasoning could definitely be applied to the discussion of qualifying groups carried out within this thesis. This could be paired with the general definition of discrimination, earlier expounded by the Court in *Willis v. the United Kingdom*:

“Discrimination means treating persons differently, without an objective and reasonable justification, in relevantly similar situations.”⁶⁴

As to the necessary *actus reus*, purposive acts in line with the observations made by Fein, Thompson and Quets shall be considered, with concerted and repeated actions as ruled on in case law such as that delivered by the ICTY, being considered in light of particular social and temporal circumstances, as per developments ruled upon by tribunals such as the ICTR, in line with observations made by commentators such as MacKinnon.

As to the specific *mens rea* required for such actions, as observed over the course of the past two chapters, this concept has been dealt with in an extremely fluid manner by different sources, highly dependent on political and social factors, but also matters of expediency. Therefore, the widest possible interpretation of this notion shall be carried out

ECHR 1994; *Shelley v. the United Kingdom*, no. 23800/06, 4 January 2008, in Golichenko and Merkinaite, op. cit., at 33.

⁶¹ *Glor v. Switzerland*, no. 13444/04, § 80, ECHR 2009, in Golichenko and Merkinaite, op. cit., at 33.

⁶² *Artico v. Italy*, 13 May 1980, § 33, Series A no. 37; and *Cudak v. Lithuania* [GC], no. 15869/02, § 36, 23 March 2010, in Golichenko and Merkinaite, op. cit., at 34.

⁶³ *Clift v. the UK*, no. 7205/07, 13 July 2010, § 59, in Golichenko and Merkinaite, op. cit., at 33.

⁶⁴ *Willis v. the United Kingdom*, no. 36042/97, § 48, ECHR 2002-IV.

by this work in carrying out the necessary analyses, aiming to follow the spirit and letter of the provisions of Resolution 96(I), and the intentions of its drafters.

Finally, it is important to clarify the main purpose of the later analyses concerning the rights of autistic persons, with respect to actions and omissions by different entities on a global, national and regional scale. The aim of this work is not to push forward prosecution on these matters, but to raise awareness and call for change in the area of autism rights. Therefore, one can remain within the purely academic sphere of law, and extend the discussion as far as possible, in order to better be able to understand the situation.

Chapter 9: The Pre-Natal Sphere – Prevention and Termination

9.1 Introduction

Having both discussed the concept of genocide, and its possible applicability to various groups and situations, as well as the achievements and struggles of other diverse groups on the road to emancipation, the situation concerning autistic rights shall now be analysed more specifically.

The aim of such analysis shall be to, on the one hand, highlight certain phenomena within the latter sphere by drawing parallels to similar experiences other diverse groups under study have gone or are going through. Secondly, this thesis shall also look into whether features are present in such events so as to warrant a classification of genocidal behaviour by authorities, directly or indirectly, within the context of such events.

The analysis shall be carried out through a rights-based perspective, by discussing a number of areas, identified through practice, literature and activism as being key concerns in the field of autistic rights, as well as strategies addressing autism nationally and supranationally.

Such analysis shall take into account, for the areas being discussed, legislation, policy and practice, on the supranational, regional and national levels. Rights shall be discussed within the context of the UN CRPD,¹ as well as of relevant supranational or regional instruments and declarations. Older texts such as the UN Declaration on the Rights of Handicapped (later Disabled) Persons,² as well as newer texts, of a more general nature such as the ECHR,³ and also more specific ones such as the European Parliament's Declaration on the Rights of Persons with Autism,⁴ will be used. References will also be made to applicable

¹ Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, U.N. GAOR, 61st Sess., U.N. Doc. A/Res/61/106 (Dec. 13, 2006) (hereinafter the 'UN CRPD').

² Declaration on the Rights of Handicapped (later Disabled) Persons, G.A. res. 3447 (XXX), 30 U.N. GAOR Supp. (No. 34) at 88, U.N. Doc. A/10034 (1975) (hereinafter the 'Disability Declaration').

³ Convention for the Protection of Human Rights and Fundamental Freedoms, (ETS No. 5), 213 U.N.T.S. 222, entered into force Sept. 3, 1953, as amended by Protocols Nos 3, 5, 8, and 11 which entered into force on 21 September 1970, 20 December 1971, 1 January 1990, and 1 November 1998 respectively (hereinafter the 'ECHR').

⁴ Declaration on the rights of people with autism', adopted as a Written Declaration by the European Parliament on 9 May 1996 (hereinafter the 'EP Autism Rights Declaration').

domestic legislation. Policy papers, such as Practice Notes, and position papers, will also be made reference to, as will the situation on the ground, both through media references, as well as references to conferences, consultations and interviews.

As to the analysis with respect to genocide, possible acts of genocide falling within the list enunciated in Article 2 of the Genocide Convention, but in respect of autistic persons, shall be identified in Chapter 12, after Chapters 9, 10 and 11 would have outlined and discussed a series of possible rights breaches.

The Article 2 list is not being used as part of the chosen methodology for analysis, to claim that such breaches fall within the purview of the Genocide Convention as an instrument, since such Convention's exhaustive list of protected groups also disallows this. Rather, it shall be used as a list, to identify the specific nature of a purported genocidal act or omission, in line with the re-interpretation of the notion of genocide, extending its reach to autistic persons as a protected group. This is being done in the same manner as has been done by international tribunals such as the ICTR, who have used the Article 2 list, while promulgating their own definition of the concept of genocide in their founding statutes.⁵

As to the specific crimes possibly attributable in this regard, the list in Article 3 of said Convention shall be used in the relevant analysis just described that will be performed in Chapter 12. The Article 3 list shall be used in the same way and for the same rationale as just discussed in terms of using the Article 2 list.

Chapter 9 shall deal with areas that could be said to be more overtly geared towards the direct obliteration of autistic characteristics and autistic persons, in the pre-natal field, in line with Articles 2 (a) – (e) of the relevant list carried in the Genocide Convention.

Chapter 10 will deal with possible rights breaches post-natally, focusing on the research or attempted implementation of a possible cure, or else techniques with the station aim of

⁵ This was done in the case of, for example, the Statutes of the International Criminal Tribunal for the Former Yugoslavia, as established by Security Council Resolutions 808/1993, 827/1993 and amended by Security Council Resolution 1166/1998, 1329/2000, 114/2002, and; the Statutes of the International Criminal Tribunal for Rwanda, as established by Security Council Resolution 955 (1994) of 8 November 1994 and last amended by Security Council Resolution 1717 (2006) of 13 October 2006.

normalisation/ indistinguishability in autistic persons. It will also tackle possible breaches in connection with the deprivation of liberty, and segregation and institutionalisation of autistic persons. Such breaches will subsequently be reviewed in Chapter 12, as will the previous breaches, in line with the methodologies described earlier, and with the list carried in Articles 2 (a) – (e) of the Genocide Convention.

Chapter 11 will tackle possible breaches resulting from lack of or dissemination of incorrect knowledge and awareness about autism, as well as the effects of basing legislation, policy and initiatives on the ground on such incorrect foundations. The same review, in terms of the methodologies described earlier, and of the list carried in Articles 2 (a) – (e) of the Genocide Convention, will likewise be subsequently performed in Chapter 12. Attempted and possible ways to break this impasse will also be discussed.

All these Chapters will, in the relevant discussion carried out therein, also look at a number of strategies, formal and informal, being implemented supranationally and nationally in a number of jurisdictions, and the positive and negative outcomes of such implementation within the context of the rights analysis described above.

The overall results of all these analyses shall then be summarised, in order to be able to extract a wider overarching picture of the state of play concerning a possible autistic genocide. This will be laid out in the final Chapter, side by side with making recommendations in this regard, while also pointing out, commending and encouraging positive practices that would have been identified.

9.1.1 Use of Mental Illness/ Mental Disability-related materials

The Principles for the Protection of Persons with Mental Illnesses and the Improvement of Mental Health Care (hereinafter MI Principles)⁶ and the UN Declaration on the Rights of Mentally Retarded Persons⁷ are also texts made reference to in subsequent sections.

⁶ Principles for the Protection of Persons with Mental Illnesses and the Improvement of Mental Health Care, G.A. res. 46/119, 46 U.N. GAOR Supp. (No. 49) at 189, U.N. Doc. A/46/49 (1991) (hereinafter 'MI Principles').

⁷ Declaration on the Rights of Mentally Retarded Persons, G.A. res. 2856 (XXVI), 26 U.N. GAOR Supp. (No. 29) at 93, U.N. Doc. A/8429 (1971).

Although these texts refer to 'mental illness' and 'mental retardation', the notions behind which could also be comorbid with autism, as mentioned in Sections 1.1 and 2.3.2 of this thesis, they can also be extended to cover autism itself, but *merely* by way of legal interpretation. This follows the ECtHR's decision in *X v. Germany*,⁸ and, therefore, any references to possible rights breaches of autistic persons in this thesis, by virtue of these texts, is simply an attempt to use current case law in order to extend further protection of rights to autistic persons as a group.

In *X*, the ECtHR sought to define the term 'unsound mind' as carried by the Convention. Here, it held that this term was not limited to mental illness, but must also be understood in its widest sense.

Although unflattering, the terminology, for the purposes of accessing rights, must thus also be taken to include mental disabilities, as traditionally defined, sometimes also described in statutes as mental impairment or mental retardation in contrast to mental illness.⁹ Therefore, from a point of view of interpreting legal texts and case law within the ECtHR's definition in *X*, such categories would also include the categories of intellectual, psychosocial and also developmental disabilities, within which category autism is usually classified, as per the explanation in Section 1.1 of this thesis.

9.2 The Issue of Genetic Research

Returning to the principal substantive matters under discussion in this Chapter, one might view relevant issues as being more clear-cut in the post-natal field, especially that arguments such as those covering abortion and the question as to when human life starts are not relevant at that point.

This is due to the fact that the outright killing of autistic persons is prohibited under the national laws of different states through provisions of criminal law covering all natural legal subjects of a jurisdiction, notwithstanding the fact that this is becoming an increasing

⁸ *X v. Germany*, 6 D & R 182, as quoted in Bartlett et al., op. cit., at 42.

⁹ Peter Bartlett, Oliver Lewis and Oliver Thorold, 'Mental Disability and the European Convention on Human Rights', Martinus Nijhoff Publishers, Leiden/ Boston, 2007, at 42, 43.

trend in countries such as the United States.¹⁰ This apart from also being mentioned specifically in texts such as the Autism-Europe Charter of Rights,¹¹ more generally in texts such as the ECHR, which provides for the right to live independent and full lives to the limit of one's potential.¹²

However, two particular instances might be seen as violating the right to life in a 'backdoor' manner at the pre-natal stage, not on the merits of whether the processes under discussion are morally or ethically justified, but rather as to whether their particular usage in the case of autism is making an additional specific point that could be seen as unnecessary.

9.2.1 Cases in Point? – The Autism Genome Project

The European Union has already, starting in 2005, been funding inter-institutional research into the genetics underlying autism, starting with the Autism Molgen project led by Oxford University,¹³ aimed at obtaining insight into autism through DNA studies, which linked

¹⁰ For example, the murders by their caregivers, as reported on the Autistic Self Advocacy Network (ASAN)'s website, of Randle Barrow and Mickey Liposchok in 2013, at <http://autisticadvocacy.org/2013/12/a-horrifying-trend-asan-statement-on-the-murders-of-randle-barrow-mickey-liposchok/>; of Alex Spourdalakis in 2013, at <http://autisticadvocacy.org/2013/06/asan-calls-for-federal-hate-crime-prosecution-for-the-murder-of-alex-spourdalakis/>; of Nicolas Richett in 2015, at <http://autisticadvocacy.org/2015/06/statement-on-the-murder-of-nicholas-richett/> and; the murder of Kayden Clarke by law enforcement in 2016, due to the erratic way he was perceived as acting, which stemmed from his being autistic, at <http://autisticadvocacy.org/2016/02/asan-joint-statement-death-of-kayden-clarke/>.

ASAN, together with other autistic and disability rights groups, mark such murders through a Disability Day of Mourning in the United States, where events such as vigils are held, as reported at <http://autisticadvocacy.org/home/projects/disability-community-day-of-mourning/>.

The attempted murder of Kelly Stapleton, by her autism blogger mother Issy Stapleton, was widely publicised in 2014, as was the ensuing trial in *People v. Stapleton* that took place in Michigan, as can be seen from the reaction expressed in the following statement issued by ASAN, also quoting other segments of the US disability community, at <http://autisticadvocacy.org/2014/10/asan-disability-community-statement-on-sentencing-of-kelli-stapleton/>.

However, Stapleton continued to insist, on an interview on the Dr Phil show while in prison, that "County Jail has been better than the jail of autism", as reported in Jelisa Castrodale, 'Kelli Stapleton: County Jail Has Been Better Than the 'Jail of Autism'', Crime, people .com, 12 September 2014, accessed online at <http://people.com/crime/kelli-stapleton-county-jail-has-been-better-than-the-jail-of-autism/>, and there was also an outpouring of support for her from a number of 'autism moms', some of whom also admitted that they had floated similar ideas at time, as reported in Rosemary Parker, 'Mom's alleged attempt to murder autistic teen prompts national, Kalamazoo response', mlive.com, 5 September 2013, at http://www.mlive.com/news/kalamazoo/index.ssf/2013/09/moms_alleged_attempt_to_murder.html.

¹¹ Charter of Rights, presented and adopted at the 4th Autism-Europe Congress (hereinafter Autism-Europe Charter of Rights), The Hague, 10 May 1992, available online at <http://www.autismeurope.org/files/files/charter-for-persons-with-autism.pdf>, at art. 1.

¹² ECHR, op. cit., at art. 2.

¹³ *Using European and international populations to identify autism susceptibility loci* (hereinafter

into the international Autism Genome Project coordinated by the United States National Alliance for Autism Research (NAAR),¹⁴ and continuing through to currently ongoing projects, such as a 7th Framework project led by King's College London, studying the genetics, genomics and neurobiology underlying psychosis and autism.¹⁵

While the aim of such research, and of the wider project, is to glean better insight into autism and its causes, through a primarily genetic study, concerns were raised by a number of prominent self-advocacy groups and individuals, such as the international Autistic Self-Advocacy Network (ASAN), which enjoys consultative status with the United States government, as well as Dr. Temple Grandin.¹⁶

Such concerns are as to why the academic and medical community is gathering such data, whether the early detection it will enable would be:

- for the purposes of providing better services, accommodations and integration into the community of autistic purposes, or;
- whether it would simply be used towards peddling dubious early intervention schemes that run counter to the dignity of autistic persons, not least due to ethical issues, or;
- even worse, be used to enable pre-natal screening and termination in the case of pre-natal autism detection, on the same lines as with the Down Syndrome community, with such practice and associated laws enabling it specifically having

'Autism Molgen Project'), project description from European Commission CORDIS (Community Research and Development Information Service) – EU CORDIS (Community Research and Development Information Service) Portal, available online at http://cordis.europa.eu/project/rcn/75703_en.html.

¹⁴ 'NAAR Autism Genome Project: Fact Sheet', available online on the Autism Speaks website at <https://www.autismspeaks.org/docs/agpl1a.pdf>.

¹⁵ *Translational Research into Psychiatric disorders: genetics, genomics and neurobiology of psychosis and autism*, EU CORDIS (Community Research and Development Information Service) Portal, available online at http://cordis.europa.eu/project/rcn/104623_en.html.

¹⁶ Temple Grandin and Richard Panek, *The Autistic Brain: Thinking Across the Spectrum*, Houghton Mifflin Harcourt, New York, 2013; Alistair de Gaetano (lead author), *Review of the European Union: About Autism, Without Autistics*, joint written submission to the 14th session of the UN Committee on the Rights of Persons with Disabilities by Autistic Minority International, Enthinderungsselbsthilfe von Autisten für Autisten (und Angehörige) (Germany), Alliance Autiste (France) and Autism Women Matter (United Kingdom), Geneva, 3 August 2015, available online at http://tbinternet.ohchr.org/Treaties/CRPD/.../EUR/INT_CRPD_CSS_EUR_21278_E.doc.

been criticised in replies by the CRPD Committee to initial reports by other States Parties, notably Austria¹⁷ and Spain.¹⁸

If handled in the wrong manner, this initiative can give rise to *a priori* breaches of the provisions of the UN CRPD regulating equality and non-discrimination,¹⁹ awareness-raising,²⁰ right to life²¹ and health,²² while unregulated or improperly regulated use of pre-natal data gleaned through initiatives implemented as a by-product of this process could lead to further violations of other articles of said CRPD.²³

In particular, autistic self-advocates have taken exception to the language used in the literature associated with this research project,²⁴ including the efforts to 'identify susceptibility loci' and 'susceptibility alleles' in DNA, 'understanding the molecular and cellular nature of the brain dysfunction associated with autism, and 'developing rational strategies linked to both prevention and treatment, leading to improvement of quality of life.'²⁵

Such self-advocates have called upon the European Union to engage in a dialogue with current beneficiaries of its funding, as well as other relevant stakeholders within its jurisdiction, including disability and autistic advocates and self-advocates and their organisations, in order to clarify the use of relevant terminology, as well as the next steps

¹⁷ *Concluding observations on the initial report of Austria*, adopted by the United Nations Committee on the Rights of Persons with Disabilities at its tenth session (2-13 September 2013), CRPD/C/AUT/CO/1, available online at http://www.ohchr.org/Documents/HRBodies/CRPD/10thSession/CRPD-C-AUT-CO-1_en.doc.

¹⁸ *Concluding observations of the Committee on the Rights of Persons with Disabilities - Spain*, Consideration of reports submitted by States parties under article 35 of the Convention, United Nations Committee on the Rights of Persons with Disabilities, Sixth session (19-23 September 2011), CRPD/C/ESP/CO/1, available online at http://www.ohchr.org/Documents/HRBodies/CRPD/6thsession/CRPD.C.ESP.CO.1_en.doc.

¹⁹ UN CRPD, op. cit., at art. 5.

²⁰ Ibid., at art. 8.

²¹ Ibid., at art. 10.

²² Ibid., at art. 25.

²³ Such other articles would include Article 7 – Children with Disabilities, Article 15 – Freedom from torture or cruel, inhuman or degrading treatment, Article 16 – Freedom from Exploitation, violence and abuse, Article 17 – Protecting the integrity of the person and Article 25 – Education.

²⁴ See, for example, de Gaetano (lead author), *Review of the European Union: About Autism, Without Autistics*, op. cit.

²⁵ See, for example, *Autism Molgen Project, Final Report*, available online at <http://cordis.europa.eu/documents/documentlibrary/129702941EN8.zip>, as discussed in de Gaetano (lead author), *Review of the European Union: About Autism, Without Autistics*, op. cit, at 4.

envisaged as a result of this data collection, particularly as at the current stage of research within this project, and review and evaluate the results of such dialogue carefully.²⁶

This way, the European Union would be better guided as to laying down guidelines that would govern the next steps of this research project in return of continued funding of its future tranches by the European Union. This exercise, the advocates stated, should also be conducted within the framework of a wider legislative and policy review.

9.2.2 *Mass abortions in the case of autism?*

As to the prognosis in this regard, one must first ask the question as to why such research is being carried out. One may cite the possibility of identifying important elements which will allow for new research in the field of medicine, which will significantly impact autistic persons. But one element that is also possible in this regard is opening up access to pre-implantation genetic diagnosis (PGD) checks or pre-natal screening checks of whether an embryo or foetus is carrying the autism genes.

Due to the currently pervasive view that autism is a disability, and the acceptance in modern laws that disabilities are 'bad', and that they need to be done away with, mass abortion/non-implantation of embryos and foetuses diagnosed with autism is a serious possibility.

This might be seen as a positive and necessary measure by some, but by others it can be seen as simply a wholesale genocide on a group of neurodivergent persons, autistic persons, who will now cease to exist. Abortion on the grounds of disability has already been likened by some authors, also those holding a pro-choice stance, as nothing more than a 'backdoor' eugenics policy,²⁷ but with autism in the picture, it takes on a completely new light. The issue of disability-specific abortion legislation is also discussed further, later in Section 9.3 of this thesis.

One might argue that allowing abortions simply based on the findings of pre-natal screening, or when genetic screening has made sufficient progress in the pre-natal field,

²⁶ See, for example, de Gaetano (lead author), *Review of the European Union: About Autism, Without Autistics*, op. cit, at 5, 6.

²⁷ Troy Duster, *Backdoor to Eugenics*, Routledge, New York City (New York), 1990.

also the latter discipline, as a specific enabling ground, is nothing more than validation that will continue to perpetuate a culture of eugenics – for some autism rights advocates, the Autism Genocide Clock has already started ticking.²⁸

Autistic persons here can easily fit into the description of 'any human collectivity' outlined by Drost, of the groups in jeopardy described by Huttenback, or of the scheme of suppressing reproduction described by Helen Fein, and of the destruction of a group by purposive action as described by Thompson and Quets.

The following sections will now tackle the current reality on the ground as to this discussion.

9.2.2.1 Discovery of Autism 'Genetic Signature'

On 8th August 2013, Professor Eric Courchesne told the world, at the Asia Pacific Autism Conference in Adelaide, that a genetic "signature" of autism had been identified for the first time, in babies as young as 12 months.²⁹ He explained that a simple blood test was being developed in order to 'detect' this, with availability being placed within one to two years from the announcement.

Courchesne, also Director of the Autism Centre of Excellence at the University of California in San Diego, pointed out that the work had specifically identified several gene networks as being a common thread in autism, in his words 'disrupting' the production of brain cells during the fourth, fifth and sixth months of pregnancy, producing too many or in some cases too few brain cells, understandably in comparison to the 'neurotypical' norm, as well as also 'disrupting' the way these cells are organized and connected.

In this regard, he pointed out the identification of four particular gene networks that he

²⁸ 'The Autistic Genocide Clock', at <http://www.ventura33.com/clock/>, provides a 'countdown' to the wholesale abortion of embryos and fetuses diagnosed with autism, once the Autism Genome Project or similar research 'cracks' the generic code behind autism.

²⁹ S.J. Glatt, M.T. Tsuang, M. Winn, S.D. Chandler, M. Collins, L. Lopez, M. Weinfeld, C. Carter, N. Schork, K. Pierce and E. Courchesne, 'Blood-based gene expression signatures of infants and toddlers with autism', *Journal of the American Academy of Child and Adolescent Psychiatry*, Volume 51, Issue 9, September 2012, at 934.

stated are a 'biological signature' of autism."³⁰

He stated specifically that:

"At this stage it's looking very promising that the blood screening test will have high accuracy, specificity and sensitivity for children at risk of autism."³¹

This statement may come as a ray of hope to some, pointing them in the direction of seeking the appropriate help, however, what are the risks on the other hand? This discovery opens the doors to a philosophical and legal quandary, as to how the discovery itself and the testing methods emanating from it will be used:

- whether they will be used for early detection as a way of providing better services to allow autistic children so 'diagnosed' to live a fuller life – in this regard, Courchesne also stated that "[th]is discovery really changes the landscape of our understanding of causes and effective treatments. This is going to lead to much better treatments at a much earlier stage and a large percentage of children having an excellent outcome[;]"³²,
- whether this early detection will be used as a way for providing services with, however, such services being used to achieve 'normalisation' or 'indistinguishability' of these children from their 'neurotypical' peers – the phrase "children at risk" used by Courchesne raises particular concerns here, not only because of the negative light it places these children's autism in, but also as to whether this 'risk' will be met with a similar mindset,

with the "effective treatment" mentioned meaning the 'risk' being 'countered' by strategies such as aggressive 'normalising' behavioural therapy or similar strategies, or whether, even if the term 'risk' would have to be tolerated, whether such

³⁰ 'Autism Breakthrough as Genetic Signature in Babies as Young as a Year Found; Blood Test in the Works', news.com.au, 8 August 2013, available online at <http://www.news.com.au/technology/science/autism-breakthrough-as-genetic-signature-in-babies-as-young-as-a-year-found-blood-test-in-the-works/story-fn5fsgyc-1226693188756>.

³¹ Ibid.

³² Ibid.

“effective treatment” would mean addressing the ‘risk’ with strategies appropriate to the overall well-being and improvement of quality of life of the children in question, or;

- whether it will be used in the same way as with similar Down Syndrome testing, as a way of pre-natally detecting autism, and being able to terminate such pregnancies in these instances – placing disability and autism specifically as potential personality in the second class, by giving the green light that such potential persons are expendable, and leading to a wholesale abortion exercise with regard to autism, going down the slippery slope towards extermination, and genocide in the wider sense.

The whole concept of accepting autism as a neurological difference, which simply requires adjustments and accommodations, much as ‘neurotypical’ individuals also require adjustments and accommodations with their lives, flies out of the window when autism is painted in a bad light, and disability is portrayed as an expendable option.

Much as this discovery can lead to positive early detection and tailored adjustments, accommodations and support services, if used following the right approach, the risk exists, very much in the current scenario in which autism is being viewed, of the former scenarios playing out instead. This view has also been echoed by autistic activists such as Zach Richter, who stated that this move was a first step down the road to genocide.³³

9.2.2.2 Western Australia – Authorisation of Autism Detection Genetic Tests

Authorities in the Australian state of Western Australia have given the green light for embryo screened aimed at “reduc[ing] the chance of a high-risk family having a child with autism.³⁴” As specific application allowing a fertility clinic to carry out pre-implantation genetic diagnosis (PGD) screening for autism was approved by the state’s Reproductive Technology Council (RTC).

³³ Zach Richter, Facebook Comment in response to ‘Autism Breakthrough as Genetic Signature in Babies as Young as a Year Found; Blood Test in the Works’, 8 August 2013.

³⁴ As carried in *Annual Report 1*, July 2012 to 30 June 2013, Western Australian Reproductive Technology Council, Perth (Western Australia), September 2013.

This method, having been conceived before the autism 'genetic signature' discussed earlier saw the light of day, does not rely on a genetic test to detect autism, but rather relies on identifying the sex of the embryo, in order to identify male embryos due to certain statistics pointing to boys being at least four times more likely to develop autism than girls.³⁵

Confirming that this was the first time such an initiative had been approved in the state "to reduce the risk of having a child with autism", a Health Department spokesman went on to say that:

"[a]ll applications for PGD are submitted by fertility clinics and considered by the RTC on a case-by-case basis and there is currently no list of pre-approved conditions," and adding that "[t]here is currently no specific genetic test for autism but males are about four to five times more likely to have the disorder."³⁶

Once again, although some would hail this as another scientific breakthrough, we are again walking a very fine line, in terms of both the philosophical and moral debate on the matter, as well as the legal and rights implications it carries. This sentiment was in fact also echoed, to a certain extent, by Western Australia's Chief Medical Officer, Gary Geelhoed, who stated that this was a sensitive area. He mentioned that the method had been carefully assessed, stating that selecting a female embryo to reduce the chance of autism would only be done in the context of a 'family at high risk'.³⁷

He specifically stated that autism was caused by various factors, and one way to reduce a high risk would be to have a girl, but that the move was about selecting an embryo pre-implantation, not terminating a pregnancy.³⁸

The above statement will do well to worry professionals and activists alike, as to the possible implications of both the statements themselves, and the related technologies, in the 'wrong hands'. The first concern is the fact that, although the RTC's authorisation was

³⁵ Cathy O' Leary, 'Baby sex checks for autism', *The West Australian*, 19 October 2013, available online at <http://au.news.yahoo.com/thewest/lifestyle/a/-/lifestyle/19457937/baby-sex-checks-for-autism/>.

³⁶ Ibid.

³⁷ Ibid.

³⁸ Ibid.

issued in October 2013, there was already evidence at the time, in the form of a study published in July 2013,³⁹ showing that the autism incidence ratio among male and female newborns was much closer to 2:1, rather than the 4:1 which is based on figures from the United States Center for Disease Control (CDC) covering 2010.⁴⁰

It is also a known fact in the medical and academic community nowadays that autism has been, for a very long time, underdiagnosed in females, especially in ‘higher-functioning variants’ mostly due to social and cultural factors, as to the behaviours expected from girls and women and the social roles and occupations they are expected to or actually fulfil, as well as the fact that females have proved better at social adaption and at ‘hiding it better’.⁴¹

The above research and current statistics – or ‘epidemiological data’ as still referred to in medical parlance – both show flaws in rooting any further current scientific initiatives on the basis of a gender ratio disparity in relation to autism, as well as showing cracks in the long-held belief that sex was a major determining factor in determining susceptibility to autism, especially when considering the factor of underdiagnosis or misdiagnosis.

In addition to the above, and by way of a more general background argument, one can refer to the way the media outlet in question reported this initiative, with the author stating that “[i]t is a new frontier in embryo screening because, unlike other conditions with a distinct genetic basis, autism is believed to be caused by a combination of genetic and environmental factors.”⁴² Pushing one argument as the ‘magic bullet’ method while ignoring other more basic medically- and academically-accepted concepts in the process can raise concerns, even among lay observers as demonstrated by the journalistic piece in question.

Therefore, it can be considered to be highly professionally irresponsible to ignore all the above data, especially in being a state regulatory body charged with making serious

³⁹ As cited by Dena Gassner, speaking during the Panel of People on the Spectrum of Autism Town Hall Meeting, 44th National Conference of the Autism Society of America, Pittsburgh, 13 July 2013.

⁴⁰ Jon Baio, US Center for Disease Control (CDC), ‘Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010’, *Morbidity and Mortality Weekly Report (MMWR)*, Volume 63, Supplement 2, 28 March 2014, at 1.

⁴¹ Judith Gould and Jacqui Ashton-Smith, ‘Missed diagnosis or misdiagnosis: girls and women on the autism spectrum’, *Good Autism Practice*, Vol.12, Issue 1, 2011, at 34.

⁴² O’Leary, op. cit.

decisions with such profound implications, and give the green light to peddling possible ‘quack cures’ on the basis of this.

More worrying is the issue of embryo selection, in relation to the reasons highlighted in the previous section concerning termination, but with the particular addition of the element of sex this time round. One might argue that this is not strictly termination of pregnancy, although doing this would open another Pandora’s box philosophically and legally, and also that the issue at hand here is of circumventing autism – although, depending on the point of view chosen, termination and circumvention could both be present, and in any case, circumvention of autism still leads back to the points discussed earlier.

However, returning to the issue of sex, much has been written academically and otherwise on the topic of femicide, with campaigns being run in countries like India and China, where it is an established practice, both socially and within the medical community, to prefer male offspring, and routinely target abortion of female foetuses consequently.

Although one might argue that femicide stems from an overarching cultural belief that male offspring are desirable to female, hence the resulting preferences that are societally deep-seated, proposing a detection/ prevention method that identifies sex as the principal marker for a much-maligned disability is embodying the same conceptual basis.

And even if one might argue – in response to claims that this might spark a new ‘trend’ – that it is exaggerated or premature to compare such a scenario with femicide, one is still setting a snowball rolling. Although one knows where one starts off with a snowball, it is impossible to forecast what it will look like miles down the hill, or what it will eventually carry with it along its path.

9.2.2.3 UK – Evaluation concerning allowing Autism Screening

While the health authorities in Western Australia, under the regulation and supervision of the RTC, have adopted the policy of considering autism screening applications on a case-by-case basis, Britain’s Human Fertilisation and Embryology Authority was reported to be

weighing up whether to allow access to autism screening as a general practice.⁴³

It was reported that in this regard, the criterion to be eligible to access such services would be that of 'families at high risk' of having an autistic child,⁴⁴ echoing the terminology used regarding the process in Western Australia. Such families that would be considered were further defined as, for example, families who already have two boys 'with severe autism',⁴⁵ again mirroring the sex factor from the Western Australian model, while aligning this process with identifying a much-maligned disability.

Once again, this process differs from prenatal testing in the womb, since it is PGD on the same lines as in Western Australia, so the same arguments about it not leading to termination, but to prevention/ circumvention, can be raised. In response to this, however, the points raised earlier in this regard still stand.

However, the concerns raised earlier about how this facility will be used, both by the medical profession, as well as by parents, echo once again in this case.

The use of terminology such as 'high risk' and 'severe autism' definitely do not help allay fears apprehensive parents, especially first-time parents, might have, especially when lacking awareness of or access to resources showing the other 'face' of autism, and how positive adjustments, accommodations and supports can help their child grow happily and live a full life, a process which would also be manageable for them, rather than being simply faced with the horrors of having to raise a 'severely' disabled child, affecting the quality of life of both the child and of them, or of having to go to extra lengths to 'normalise' this child if it is born.

Further to this, the inclusion of the sex factor into the equation is both problematic and misleading for the reasons outlined earlier, and adding the factor of having had other autistic children as a criterion simply adds to parents' fears in deciding whether to conceive, continue with a pregnancy or carry it to term, in the absence of positive alternative scenarios mentioned earlier, and in the face of a fear campaign.

⁴³ O' Leary, op. cit.

⁴⁴ Ibid.

⁴⁵ Ibid.

9.2.3 International/ European Legislation pertinent to this Scenario

The following table aims to put the scenario just described into perspective, by placing it against relevant sections from three international/ supranational legal texts:

<u>EU CHARTER OF FUNDAMENTAL RIGHTS⁴⁶</u>
Article 3: <i>“In the fields of medicine and biology (...) the prohibition of eugenic practices, in particular those aiming at the selection of persons, must be respected”.</i>
<u>UN DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS⁴⁷</u>
Article 1: <i>“The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.”</i>
Article 2 (a): <i>“Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics.”</i>
<u>COUNCIL OF EUROPE CONVENTION ON HUMAN RIGHTS AND BIOMEDICINE⁴⁸</u>
Article 12: Predictive Genetic Tests – <i>“Tests (...) may be performed only for health purposes or for scientific research linked to health purposes”</i>

⁴⁶ Charter of Fundamental Rights of the European Union, O.J. C 326/02 (Oct. 26, 2012), at 391-407.
⁴⁷ UN Universal Declaration on the Human Genome and Human Rights, UNESCO Gen. Conf. Res. 29 C/Res.16, reprinted in Records of the General Conference, UNESCO, 29th Sess., 29 C/Resolution 19, at 41 (1997) (adopted by the UN General Assembly, G.A. res. 152, U.N. GAOR, 53rd Sess., U.N. Doc. A/RES/53/152 (1999)) (Nov. 11, 1997).
⁴⁸ Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, (ETS No. 164), entered into force Dec. 1, 1999.

9.3 Disability-Specific Abortion Legislation

As stated earlier in this thesis, while the merits and demerits of the wider abortion debate are not a matter this thesis will be concerned with, the issue of disability-specific legal provisions on abortion are definitely matters of relevance.

The listing of specific circumstances affecting the foetus, and the earmarking of such as giving the green light for an abortion to be performed, particularly in jurisdictions with restrictive abortion legislation, where abortions are allowed as exceptions to the rule,⁴⁹ send the message that such particular foetuses are 'abortion-eligible' due to particular qualities.

In the case of specific medical grounds, such as a strict physical survival-couched definition of fatal foetal abnormality, issues of ethics and morality alone, rather than also issues of discrimination, could be safely said to be possibly raised.

However, earmarking a foetus identified pre-natally as disabled as 'abortion-eligible' could very well also raise the ground of discrimination. This point has been raised by disability law academics such as Gerard Quinn and Theresia Degener, who stated that "[t]he relative invisibility of people with disabilities can have a dramatic impact on their enjoyment of civil rights. The right to life has been violated through abortion on the basis of disability."⁵⁰

⁴⁹ For example, the Polish Act of 7th January, 1993 on Family-Planning, Human Embryo Protection and Conditions of Legal Pregnancy Termination (Ustawa z dnia 7 stycznia 1993 r. o planowaniu rodziny, ochronie płodu ludzkiego i warunkach dopuszczalności przerywania ciąży (z 1993 r., Dz.U. Nr 17, poz. 78; z 1995 r., Nr 66, poz. 334, z 1996 r., Nr 139, poz. 646, z 1997 r. Nr 141, poz. 943, Nr 157, poz. 1040 i z 1999 r. Nr 5, poz. 32)), unofficial translation commissioned by the Polish Federation for Women and Family Planning, available online at <http://www.federa.org.pl/english/AbortionLaw1993.doc>, states in Article 4a.1. which covers termination of pregnancies, specifying that these can only be performed by a doctor, that one of circumstances in which such termination can take place, as per sub-article 2), is when "pre-natal examinations or other medical conditions indicate that there is a high likelihood of a severe and irreparable handicap of the foetus or an incurable illness threatening its life." However, the Polish government has mooted amendments to legislation, following the recent collapse of a civic initiative aiming at a near-total abortion ban, to instead specifically ban abortion in the case of disabilities, as reported in 'Polnisches Parlament kippt völliges Abtreibungsverbot', DiePresse.com, 6 October 2016, accessed online at http://diepresse.com/home/panorama/welt/5097208/Polnisches-Parlament-kippt-volliges-Abtreibungsverbot?_vl_backlink=/home/index.do.

⁵⁰ Gerard Quinn and Theresia Degener, *The moral authority for change: human rights values and the worldwide process of disability reform*, in Gerard Quinn and Theresia Degener (eds.) (2nd ed.), *Human Rights and Disability*, Disability Studies Series, Eötvös Loránd University - Bárczi Gusztáv Faculty of Special Education, 2009, electronic publication accessed at <http://mek.oszk.hu/09400/09466/09466.pdf>, at 26.

Similarly, authors like Troy Duster, cited earlier, have insisted that such legislation is nothing more than a ‘back door to eugenics,’ with autistic activists having started initiatives such as the Autism Genocide Clock in light of this.

The issue has likewise been raised by the UN CRPD Committee itself, of which Degener is also a member, as will be described further later in this Section.

9.3.1 *Review by the CRPD Committee*

A particular case in point in Europe is that of Spain. The 2010 Spanish Law on the Voluntary Termination of Pregnancy⁵¹ also addresses specifically the issues of risk to the mother's life, as well as possible clinical diagnoses attributed to the foetus, that would see the statutory term allowed by law for voluntary terminations extended. However, the wording of the provisions covering the latter point have brought the Spanish Government within the UN CRPD Committee's line of fire.

In the List of Issues submitted to the Spanish Government, the Committee has asked said Government to provide information on this law, and on "in particular the longer time limits allowed for terminating pregnancies when the foetus has a disability."⁵² The Government was further asked whether it considered such to be in line with article 4, paragraph 1 (d), of the UN CRPD.⁵³

The provisions in question were sub-articles b)⁵⁴ and c)⁵⁵ of Article 15 of the Law. The former extended the statutory time limit of 14 weeks to 22 weeks, in the case of there

⁵¹ Ley Orgánica 2/2010, de 3 de marzo, de salud sexual y reproductiva y de la interrupción voluntaria del embarazo.

⁵² *List of issues to be taken up in connection with the consideration of the initial report of Spain (CRPD/C/ESP/1), concerning articles 1 to 33 of the Convention on the Rights of Persons with Disabilities*, UN Document CRPD/C/ESP/Q/1, 20 June 2011, at para. 4.

⁵³ Ibid.

⁵⁴ The original Spanish text of this sub-article reads as follows:

“Que no se superen las veintidós semanas de gestación y siempre que exista riesgo de graves anomalías en el feto y así conste en un dictamen emitido con anterioridad a la intervención por dos médicos especialistas distintos del que la practique o dirija.”

⁵⁵ The original Spanish text of this sub-article reads as follows:

“Cuando se detecten anomalías fetales incompatibles con la vida y así conste en un dictamen emitido con anterioridad por un médico o médica especialista, distinto del que practique la intervención, o cuando se detecte en el feto una enfermedad extremadamente grave e incurable en el momento del diagnóstico y así lo confirme un comité clínico.”

'existing a risk of grave anomalies in the foetus,' as certified by 2 independent medical professionals. The latter waived time limits totally, in case of the 'detection [of] fetal anomalies incompatible with life' by an independent medical professional, or in case of the 'detection in the foetus [of] an extremely grave and incurable infirmity at the moment of diagnosis' confirmed by a clinical committee.

In response to the question posed in the List of Issues, the Spanish Government first asserted that the Law did not regulate any terminations of pregnancy with regard to disabilities,⁵⁶ but only 'so-called fetal unviability' (specifying that such had to be incompatible with life) and extremely grave and incurable infirmities of the foetus.⁵⁷

It further stressed that this legislation was compatible with Article 4 of the UN CRPD covering General Obligations,⁵⁸ since the issue of disability in this regard was nothing more than a vestige of a failed Japanese proposal, during the drafting of the Convention, and covering Article 10 - Right to Life. Such proposal would have explicitly extended to the unborn child, hypothetically disabled, all the rights envisioned in the Convention. However, once such proposal had been defeated, the resulting situation was that the option was left up to every individual state party, as to decide whether or not to extend such rights in such situations.⁵⁹

And while noting that the Human Rights Committee had stated that "the right to life should not be interpreted restrictively,"⁶⁰ the Spanish Government emphasised that it is also true that international norms, jurisprudence and practice leave the question of the point of commencement of life, and of the entitlement to such, to be decided by every individual state party.⁶¹

⁵⁶ *Respuestas del Gobierno de España a la lista de cuestiones (CRPD/C/ESP/Q/1) que deben abordarse al examinar el informe inicial de España (CRPD/C/ESP/1)* (Response by Spain to the CRPD Committee's List of Issues), UN Document CRPD/C/ESP/Q/1/Add.1, 27 July 2011, at 13.

⁵⁷ Ibid.

⁵⁸ Ibid., at 15.

⁵⁹ Ibid.

⁶⁰ Human Rights Committee, *General Comment 6, Article 6 (Sixteenth session, 1982)*, Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, U.N. Doc. HRI/GEN/1/Rev.1 at 6 (1994), as cited by the Spanish Government.

⁶¹ Response by Spain to the CRPD Committee's List of Issues, op. cit. at para. 15.

However, the Spanish Government's assertions are contradicted by its assertion shortly afterwards, in the same document, that in cases under Article 15 b), covering the risk of grave anomalies in the foetus, the mother would also be informed in writing of the rights, social benefits and state supports available towards the promotion of autonomy of persons with any disability, as well as of the network of organisations providing social assistance to such persons.⁶²

Having considered the Spanish Government's response, as well as its oral submissions before the CRPD Committee, as well as those of civil society, the Committee stated, in its Concluding Observations, that it "recommend[ed] that the State party abolish the distinction made in Act 2/2010 in the period allowed under law within which a pregnancy can be terminated based solely on disability."⁶³

The Committee had made similar observations, when delivering its Concluding Observations concerning Austria. Here, it had similarly "recommend[ed] that the State party abolish any distinction in the period allowed under law within which a pregnancy can be terminated based solely on disability[.]"⁶⁴ stating that, while said Committee "recognise[d] women's right to reproductive autonomy," it noted that under Austrian law, it was legal for a foetus to be aborted up to the onset of birth if "serious damage to the health of the foetus [could] be expected."⁶⁵

The Committee stated its concerned that there appeared to be a link between this provision and the fact that, according to OECD statistics, births of children with Down's syndrome in Austria fell by 60% between 1995 and 2006, also noting that discussions on this matter were underway. However, the legislation in question has so far not been amended in any manner.⁶⁶

And although not highlighted by the CRPD Committee as yet, a similar situation currently prevails in Israel, as to an incompatibility on similar grounds, since present Israeli

⁶² Ibid., at 17.

⁶³ Concluding observations of the Committee on the Rights of Persons with Disabilities – Spain, *op. cit.*, at 18.

⁶⁴ Concluding observations of the Committee on the Rights of Persons with Disabilities – Austria, *op. cit.*, at 15.

⁶⁵ Ibid., at 14.

⁶⁶ Ibid.

legislation mentions 'mental birth defects' as an explicit ground allowing termination.⁶⁷ Furthermore, Sagit Mor also observes that a number of wrongful birth suits have been brought in recent years,⁶⁸ especially after abortion requests had been rejected by Israel's system of Abortion Committees. The Commission for the Equal Rights of Persons with Disabilities have said that they will look into the relevant provisions of the law.⁶⁹

Thus, it was very clear to the Committee, as it is similarly clear to anyone performing a simple reading of the texts in question, that the Spanish Government was doing its best to skirt the issue of disability-related grounds present in the legislation. It was doing this by presenting the scenarios under discussion as specifically medical issues, on the same lines as the provision relating to a mother's health and life in Article 15 a)⁷⁰ was medical.

In the same breath, it emphasised that no rights were attached to disabled fetuses, outlining its reasoning for such, while having previously stated that this was not a disability-related issue at all. The ambiguity is further compounded by the specific explanation concerning provision of disability-specific materials to mothers concerning termination under Article 15 b).

Other than these considerations, that can be gleaned from a reading of said texts at face value, serious concerns can be raised about how to interpret the particular categories defined by the law. In particular, while the term 'foetal anomalies incompatible with life' could be understood to equate to fatal foetal abnormalities, the terms 'risk of grave anomalies in the foetus' and 'detection in the foetus [of] an extremely grave and incurable infirmity' are much wider, and much more open to interpretation.

⁶⁷ Criminal Law Amendment (Interruption of Pregnancy) Act of 1977, as subsequently amended. Although amended in 2014, to virtually allow abortion on demand for women between 20 and 33 years old, the original structure of the Act, and the relevant qualifiers, still remain in place for women falling outside of the eligible categories.

⁶⁸ Sagit Mor, 'The dialectics of wrongful life and wrongful birth claims in Israel: A disability critique', in Austin Sarat (ed.), *Studies in Law, Politics, and Society*, Vol. 63, Emerald Group Publishing, 2014, at 113.

⁶⁹ Interview with the Office of the Israeli Commissioner for Equal Rights of People with Disabilities, Ahiya Kamara – Commissioner, Gaby Admon-Rick and Another, Jerusalem, July 2015.

⁷⁰ The original Spanish text of this sub-article reads as follows:

"Que no se superen las veintidós semanas de gestación y siempre que exista grave riesgo para la vida o la salud de la embarazada y así conste en un dictamen emitido con anterioridad a la intervención por un médico o médica especialista distinto del que la practique o dirija. En caso de urgencia por riesgo vital para la gestante podrá prescindirse del dictamen."

The general impression created by the law is one which intends to address the issue of fatal foetal abnormalities and related matters, however, the fact that, for example, Article 15 b) is currently used as the provision allowing abortions in cases of pre-natally identified Down's Syndrome,⁷¹ and the possible different interpretations as to what constitute 'grave anomalies,' 'extremely grave infirmities' and 'incurable infirmities,' especially for a person viewing disabilities from a much more medicalised point of view, considerably muddy the waters in this area. The Spanish Government's conflicting explanations on the matter far from help make issues clearer in this regard.

The European level lacks a strong body of case law that has moved away from a functional limitational notion of disability, as has been discussed in Section 5.3, due to the fact that the relevant litigation focuses on issues such as damages and compensation, hence the use of medicalised notions, even if an assessment of disabilities themselves are moving more towards the social model in more recent cases. And on the national level, no single jurisdiction has yet shown a paradigm shift in this direction in its body of case law, not least a shift strong enough for disability-specific provisions in a state's abortion law to be challenged on such grounds.

With such unclear and wide interpretations of such terms, there is nothing preventing these criteria to be applied to pre-natally identified autistic fetuses, should initiatives discussed in Section 9.2 above gain further traction, and edge closer towards the mainstream in medical practice.

Thus, the Spanish Government's assertion that Article 15 deals simply with medical instances, and not disability-related instances, looks to fall flat on its face. This unless, as discussed above, one agrees to the notion of medicalising disabilities, which violates the spirit and letter of the UN CRPD, as well as the obligations Spain has committed itself to implement under said Convention, through its ratification of such.

⁷¹ 95% of Spanish Down's Syndrome Children Aborted After Prenatal Testing, LifeSiteNews.com, 31 July 2008, accessed online at <http://www.lifesitenews.com/news/95-of-spanish-downs-syndrome-children-aborted-after-prenatal-testing/>.

9.3.2 Initiatives at CRPD-Compliant Law Reform

In 2012, the new Popular Party government had embarked on reforming the abortion law. This initiative⁷² led to protests, due to a planned reversion to abortions being allowed as exceptions to the rule under the Criminal Code, culminating in Parliament only passing a very watered-down version of said amending Act, regulating abortions by minors.⁷³ However, the original Bill as envisaged, controversy aside, would have, among other things, also clarified the situation substantially concerning disability-specific abortions.

This would have been due to the fact that, while exceptions were again explained as medical grounds, the other ground proposed, aside from grave danger to the physical or psychological health of the mother,⁷⁴ was that of 'existence in the foetus of any anomaly incompatible with life.'⁷⁵ This term was also further explained in the text of the proposed provision, to the effect that it referred to 'that which predictably and usually, at the time of

⁷² The Bill through which such initiative aimed to be undertaken was entitled 'Anteproyecto de Ley Organica Para la Proteccion de La Vida del Concebido y de Los Derechos de La Mujer Embarazada.'

⁷³ After the failure of the reform Bill, the aspects of such relating to abortions performed on minors were enacted through a new law, Ley Orgánica 11/2015, de 21 de septiembre, para reforzar la protección de las menores y mujeres con capacidad modificada judicialmente en la interrupción voluntaria del embarazo.

⁷⁴ The proposed amendment under the Bill, to Article 145 bis 1a) Criminal Code - Ley Organica 10/1995, de 23 de noviembre, del Código Penal, read as follows in the original Spanish text:

"Que sea necesario, por no poder solucionarse el conflicto, desde el ámbito medico, de ninguna otra forma, para evitar un grave peligro para la vida o la salud física o psíquica de la embarazada, siempre que se practique dentro de las veintidos primeras semanas de gestacion. A estos efectos, se entenderá que existe grave peligro para la vida o la salud de la mujer cuando el embarazo produzca un menoscabo importante a su salud, con permanencia o duracion en el tiempo, segun los conocimientos de la ciencia medica en ese momento, y así se constate en un informe motivado y emitido con anterioridad por dos medicos de la especialidad correspondiente a la patología que genera el grave peligro para la mujer, distintos de aquel que practique el aborto o bajo cuya direccion este tenga lugar y que no desarrollen su actividad profesional en el centro o establecimiento en el que se lleve a cabo."

⁷⁵ The proposed amendment under the Bill, to Article 145 bis 1a) Criminal Code, read as follows in the original Spanish text:

"No será punible el aborto, aunque se superen las veintidos semanas de gestacion, siempre que no se hubiese detectado o podido detectar anteriormente, con un diagnostico certero, la anomalía incompatible con la vida del feto y así conste en el informe emitido con anterioridad, conforme a lo exigido en este apartado, o cuando exista riesgo vital para la mujer que no sea posible evitar, dentro de lo clínicamente exigible, mediante la proteccion de la vida del concebido a traves de la induccion del parto."

The Bill also made provision for reducing the amount of certifying medical professionals from two to one, in case such fatal foetal abnormality was the cause of the mother's grave threat to physical or psychological health under the proposed amendment to Article 145 bis 1a) Criminal Code cited in Footnote 74 above, the proposed proviso reading as follows in the original Spanish text:

"En el caso de que el grave peligro para la salud psíquica de la mujer tenga su origen en la existencia en el feto de alguna anomalía incompatible con la vida, el informe exigido en el párrafo anterior será emitido por un solo medico."

diagnosis, is associated with the death of the foetus or of the newborn in the neonatal period, although in exceptional conditions survival may be greater.¹⁷⁶

A clear definition in this regard is essential in order to emphasise the medical nature of the conditions the relevant provisions of law would seek to address, and also firmly exclude any disability-specific abortion provisions in the process.

For example, three attempts have so far been made to amend the Irish Protection of Life During Pregnancy Act 2013,⁷⁷ by introducing provisions in the Act allowing for abortions to be performed in cases of diagnosed fatal foetal abnormality. However, the first two bills in this regard, introduced by Claire Daly TD⁷⁸ and Mick Wallace TD⁷⁹ respectively, stated that fatal foetal abnormality "means a medical condition suffered by a foetus such that it is incompatible with life outside the womb[.]"⁸⁰ Such terminology, especially the use of the term 'incompatible with life,' opens up the same interpretational minefield that is currently an issue with the present Spanish legislation in force.

A much clearer situation, that would be akin to the one envisaged in the Spanish Bill, was more recently put forward in the Bill presented by Michael McNamara TD,⁸¹ which defines fatal foetal abnormality instead as

⁷⁶ This definition was laid out as follows in the proposed amendment under the Bill to Article 145 bis 1a) Criminal Code, the original Spanish text reading as follows:

"se entenderá por anomalía fetal incompatible con la vida aquella que previsible y habitualmente, en el momento del diagnóstico, se asocie con la muerte del feto o del recién nacido durante el período neonatal, aunque en condiciones excepcionales la supervivencia pueda ser mayor."

⁷⁷ Act No. 35 of 2013. This act also sought to clarify the instances in which an exception to Ireland's prohibition on abortion was to be made, particularly following earlier determinations by the Supreme Court that the constitutional prohibition on abortion, enshrined in the Eight Amendment to the Constitution of 1983, could also be interpreted as allowing abortions in certain cases, in *Attorney General v. X* [1992] 1 IR 1, and later in *Miss D v the Health Service Executive, District Judge, Attorney General and Ireland* (as quoted in Barbara Hewson, 'Ireland's Miss D: a 'bizarre dispute'', *Abortion Review*, available online at <http://www.abortionreview.org/index.php/site/article/186/>), where such interpretation was also extended to a girl pregnant with a foetus that was anencephalic, also opening the debate on abortions in the case of fatal foetal abnormalities, although the case in this instance concerned the permission to travel abroad for an abortion.

⁷⁸ Protection of Life in Pregnancy (Amendment) (Fatal Foetal Abnormalities) Bill 2013, Bill No. 115 of 2013 (Clare Daly Bill).

⁷⁹ Protection of Life in Pregnancy (Amendment) (Fatal Foetal Abnormalities) (No. 2) Bill 2013, Bill No. 122 of 2013 (Mick Wallace Bill).

⁸⁰ Clare Daly Bill at s. 1 (2); Mick Wallace Bill at s. 1 (2).

⁸¹ Protection of Life During Pregnancy (Amendment) (Fatal Foetal Abnormalities) Bill 2015, Bill No. 20 of 2015 (Michael McNamara Bill).

"(i) a medical condition, or medical conditions, suffered by a foetus which results in that foetus having no prospect of being born alive, or

(ii) a medical condition listed in Schedule A (as inserted by the Schedule to the *Protection of Life During Pregnancy (Amendment) (Fatal Foetal Abnormalities) Act 2015*);"⁸²

with the Schedule proposed in the Bill listing Anencephaly as the first and only condition proposed,⁸³ while allowing for the addition of further such conditions.

Therefore, by enunciating this ground as referring to a condition in which physical expiration was envisaged *in utero* or in the early stages of life, barring minor exceptional circumstances, specific provision for disability-specific abortions would have been done away with, also making Spain's abortion legislation CRPD-compliant, although the other proposed amendments would have opened it to barrages directed by other human rights bodies, such as the CEDAW Committee.

The discussion, this observation equally applying to the most recent Irish Bill, was now about pure projected survival of a human being, no longer allowing a window for a discussion instead on projected qualified of life of a human being, which was and is still the case under the current legislation in force.

It is worth mentioning, at this stage, the peculiar conundrum presented by Hungarian law in such scenarios. Deformity making post-natal life of the foetus impossible was listed as one of the grounds allowing abortion in the relevant 1992 Act.⁸⁴ However, this same Act also made provision for protection of the life of the foetus,⁸⁵ and stated that abortion was not to be considered a family planning mechanism.⁸⁶ The quandary was further deepened

⁸² Ibid., at s. 2 (a).

⁸³ Ibid., at s. 9 and Schedule.

⁸⁴ Act LXXIX of 1992 on the protection of foetal life, at 6(1)(b). as cited in United Nations, Hungary – ABORTION POLICY, accessed online at <http://www.un.org/esa/population/publications/abortion/doc/hungary.doc>.

⁸⁵ Ibid., at art. 1,2.

⁸⁶ Ibid., at Preamble.

by the provision in the new Hungarian Constitution of 2012, protecting the right to life of the foetus.⁸⁷

The situation in Spain, therefore, remains unchanged, and the Government's plans are unclear, with a representative of the Health Ministry, when asked about the status quo and plans to come in line with the CRPD,⁸⁸ answering that the Spanish Government is aware of the CRPD Committee's Concluding Observations, and takes note of this in its work in implementing the UN CRPD.

⁸⁷ Hungarian Constitution of 2012, at art. II.

⁸⁸ Question asked by the author to Begoña Gosálbez Raull, representative of the Spanish Ministry of Health, Social Services and Equality, following a panel discussion on a 'Human rights approach to disability,' at the *2016 Work Forum on the Implementation of the UN Convention on the Rights of Persons with Disabilities in the EU and the Member States*, organised by the European Commission - DG Employment, Social Affairs and Inclusion and the European Disability Forum, Brussels, 10 June 2016.

Chapter 10: The Post-Natal Sphere – Cure, Remission or Normalisation

After having analysed topics in the pre-natal field in the previous Chapter, this Chapter will continue in the same vein, analysing a number of topics in the post-natal field. This is being done in order to be able to subsequently conduct an analysis as to the possible genocidal nature of acts and omissions highlighted when tackling the different topics under discussion.

The Chapter will first look into the issue of cures, tackling the components of research into cures, euthanasia as a possible extreme ‘solution’ to solving the ‘problem’ at hand, as well as specific therapies. In this latter field, both behavioural therapies applied with a specific aim, as well as science and pseudo-science based ‘curative’ therapies, will be analysed. The choice of touted cures or therapies in this category was based on their stated aim to provide a cure for autism, remission of autistic symptoms, or normalisation/indistinguishability in the patient, in comparison to the non-autistic ‘norm’.

The role of the media and of personalities in this regard is also tackled, while autistic persons’ rights not to be abused, both physically and pharmaceutically, are dealt with as part of the discussion, citing legal instruments, as well as advocacy at EU and UN levels. The issue of sterilisation, viewed as abuse, within the context of a person’s right to bodily integrity, will also be addressed as a possible area of concern in this regard. Such concern would stem from perceptions, even if benevolent, of the dominant social group, also as to issues of capacity and competence, as also discussed earlier in Section 5.2.4 of this thesis.

10.1 Introduction

As detailed earlier, initial research into autism, especially from a more medicalised point of view, had viewed the phenomenon as a medical condition requiring a medical approach.

Nowadays, although revised, such medical descriptions, having medical codes in international manuals, still exist. And while some believe the way to remove them from that list should mirror homosexuality’s DSM exit – through declassification, others still believe this should rather mirror smallpox’s exit – through eradication.

Autism Speaks, one of the largest NGOs in the public eye, especially in the United States, started off life, as earlier outlined, as Cure Autism Now (CAN). Another vocal NGO in the United States is TACA (Talk About Curing Autism). As detailed elsewhere in this thesis, a cure for autism is seemingly becoming a more remote possibility, due to the complex nature of autism. However, neither researchers, nor parents and guardians, seem to want to give up on the fight.

And with a willing industry to support such research and cure propagation, even if in the form of snake oil, this issue seems to be far from a closed chapter at this point, bringing with it a number of linked and serious right violations.

10.2 Research into a Cure

First and foremost, one can speak of a research into a cure. Any research, described in Section 9.2 of this thesis, that either has the specific aim of excluding autism from future births, or else the stated aim of ‘turning off’ instances of autism that present themselves, fall within such category.

This does not extend to research that leads to exclusion of conception or implantation, or to termination of pregnancy, since a ‘cure’ in this regard can be seen as any method that would alter the biological course of a pregnancy or possible pregnancy, leading to a demonstrable change in a subject in the aftermath of a live birth.

Together with this, the issue of channelling funds into research towards a cure, rather than towards identification and development of supports and services for autistic persons, is also taking its toll. It has been pointed out by different studies that not investing money into such process at an earlier stage, will invariably lead to societies having to foot the bill at a later stage.

This was discussed when tackling issues such as the medicalisation of approaches towards autistic adults, issues of institutionalisation as opposed to efforts to integrate such persons into society as well as into the job market, and also the overarching matter of the costs to the state of maintaining the status quo. Such an approach to spending, rather than focusing on a more holistic, socially-oriented approach, was spurred on by driving factors emanating

from the pressure placed by the UK National Autistic Society (NAS) and affiliated groups in pushing forward their argument with legislators in this country.¹

This also culminated in a report commissioned by the Shirley Foundation, and prepared by the Institute of Psychiatry at the Maudsley, entitled 'Economic Consequences of Autism in the UK',² on similar lines to a report published in the United States and authored by researchers at Harvard University.³

The latter report was also instrumental in lobbying US Congress in re-authorising the initial Combating Autism Act in 2011, as well as continuing funding and initiatives in this regard through further policy and legislative enactments.⁴ The same report was also made reference to by the petitioners in *Auton*,⁵ in arguing that the Canadian state would have to pay more for the children in question years down the line, if it did not provide funding at an earlier stage.

The situation in this regard is shifting in certain countries, while it remains at an impasse in others. Professor Tony Charman, psychiatrist and academic at King's College London, speaking as lead researcher on the EU-AIMS project⁶ in September 2016, outlined that currently, in the UK, £42 billion a year is spent on supports and services, with next to nothing being spent on research into autism's aetiology. This is in contrast with the prevailing situation in the United States, where currently, 98% of annual autism-related spending goes towards researching aetiology and possible cures.⁷

¹ Interview with Amanda Batten, Policy Officer, National Autistic Society, London, 27 February 2014.

² Martin Knapp, Renée Romeo and Jennifer Beecham, London, 13 October 2007.

³ Tara A. Lavelle, Milton C. Weinstein, Joseph P. Newhouse, Kerim Munir, Karen A. Kuhlthau, Lisa A. Prosser, Economic Burden of Childhood Autism Spectrum Disorders', *Pediatrics*, Volume 133, Issue 3, March 2014, at 520.

⁴ Interview with Norrah Whitney, Founder of FEAT (Families for Early Autism Treatment) Ontario and Co-Petitioner in *Auton*, on behalf of her son Lucas, Toronto, July 2013.

⁵ *CONNOR AUTON, an Infant by his Guardian Ad Litem, MICHELLE AUTON, and the said MICHELLE AUTON in her personal capacity, MICHELLE TAMIR, an Infant, by her Guardian Ad Litem SABRINA FREEMAN, and the said SABRINA FREEMAN in her personal capacity, JORDAN LEFAIVRE, an Infant by his Guardian Ad Litem, LEIGHTON LEFAIVRE, and the said LEIGHTON LEFAIVRE in his personal capacity, RUSSELL GORDON PEARCE, an Infant, by his Guardian Ad Litem, JANET GORDON PEARCE, and the said JANET GORDON PEARCE in her personal capacity v. THE ATTORNEY GENERAL OF BRITISH COLUMBIA and THE MEDICAL SERVICES COMMISSION OF BRITISH COLUMBIA*, Supreme Court of Canada, per McLachlin CJ and Major, Bastarache, Binnie, LeBel, Deschamps and Fish JJ, 9 June 2004, Docket: 29508 [2004] 3 SCR 657, 2004 SCC 78 (*Auton et al. v. Attorney General of British Columbia*).

⁶ See Section 10.6.2 of this thesis for a further discussion of this initiative.

⁷ Tony Charman, Panel Presentation during the 'ASDEU and EU-AIMS Research Projects: Results

This approach could be seen as having brought full circle a process that looked in the totally opposite direction in the first half of the century when, as discussed earlier in this thesis, financial implications were used, both on the European continent, most notably in Nazi Germany,⁸ as well as in the United States and through the subsequent eugenics programmes instituted there,⁹ as justifying disabled persons as being a burden on the state, and their subsequent incarceration, sterilisation and eventual annihilation a necessary good on society through the most Kantian of approaches.

10.3 The Issue of Euthanasia

Although this Chapter aims to cover the issues of cures, remission or normalisation, one cannot ignore the possibility of the use of euthanasia being used, as a post-natal mechanism, as an 'extreme' form of solution to the 'problem' of autism.

In the Netherlands, conditions and process of termination are regulated by the so-called 'Groningen Protocol',¹⁰ addressed to medical professionals, whereby the life of infants under 12 can be terminated by a physician, following the granting of relevant consent in the conditions described.

Debates as to what would fulfil the criterion of 'hopeless and unbearable suffering for the child', particularly that this is left in the hands of the parents, raises similar concerns to those discussed in Section 9.3 of this thesis. Such debates could be extended also as regards the possibility of such Protocol being used in the case of autistic children, although no such case has been reported so far.

In the Netherlands, the conditions of the Groningen Protocol have not been codified into Dutch law, while adult euthanasia, where similar concerns have also been raised by disability advocates, is regulated by the Termination of Life on Request and Assisted

and Future Impact' Panel, XI Autism-Europe International Congress, Edinburgh, 15 September 2016.

⁸ Robert Proctor, *Racial Hygiene: Medicine under the Nazis*, Harvard University Press, Cambridge (Massachusetts), 1988, at 96.

⁹ See, for example, Margaret Sanger, *The Pivot of Civilization*, Brentano's Press, New York City (New York), 1922.

¹⁰ As reported in A.A. Verhagen, J.J. Sol, O.F. Brouwer and P.J. Sauer, '[Deliberate termination of life in newborns in The Netherlands; review of all 22 reported cases between 1997 and 2004]', *Ned Tijdschr Geneeskde*, Volume 149, Issue 4, Jan. 2005, at 183.

Suicide (Review Procedures) Act.¹¹ This legislation allows for adults to directly request such a procedure, should they be able to give valid consent, and if their desire to so request the procedure would have subsisted over a period of time, among other conditions.¹² In the case of children, the law only extends this option to 16 – 18 year olds, and to 12 – 15 year olds following the additional consent of parents or guardians.¹³

Similar concerns have also been raised in the case of adult euthanasia, which a number of disability advocates, particularly autistic self-advocates, oppose vocally, including through dedicated campaigns such as the online resource ‘Not Dead Yet’.¹⁴

They argue that adults with disabilities, including autistic adults, could be pressured by their family or society into choosing this route if available, being made to feel they are a burden on society or on their families, for example.¹⁵ Such opposition was voiced both to established laws, such as that in the state of Oregon in the United States,¹⁶ as well as the eventually defeated proposed legislation in Scotland.¹⁷

10.4 Specific Therapies

In this regard, two factors must be taken into account. First of all, rights violations to be examined shortly shall be considered in instances of a ‘forced cure’, and not of a ‘cure’

¹¹ Effective 1 April 2002, as cited in André Janssen, ‘The New Regulation of Voluntary Euthanasia and Medically Assisted Suicide in the Netherlands’, *International Journal of Law, Policy and the Family*, Vol. 16, Issue 2, 2002, at 260.

¹² Ibid.

¹³ Ibid.

¹⁴ Further information is available on the website of ‘Not Dead Yet’, the grouping of disability activists opposed to the legalisation of assisted suicide, at <http://notdeadyet.org/>.

¹⁵ See, for example, ‘Autistic Self Advocacy Network Joins Disability Rights Amicus Brief Opposing Physician-Assisted Suicide in New York’, 15 January 2016, accessed online at <http://autisticadvocacy.org/2016/01/autistic-self-advocacy-network-joins-disability-rights-amicus-brief-opposing-physician-assisted-suicide-in-new-york/>, in connection with ASAN’s amicus brief in the case of *Myers v. Shneiderman*.

¹⁶ See, for example, ‘ASAN Testimony on Assisted Suicide’, 16 July 2015, <http://autisticadvocacy.org/2015/07/asan-testimony-on-assisted-suicide/>, in which Sam Crane, ASAN Director of Public Policy, also writing as a Board Member of Not Dead Yet, stated several reasons in opposing the Oregon Death with Dignity law, arguing “[I]et’s focus on aid in living, not ‘aid in dying.’”

¹⁷ Stephen Drake, ‘Scotland: Disability Community Protesting Assisted Suicide Bill’, notdeadyet.org, 28 September 2010, accessed online at <http://notdeadyet.org/2010/09/scotland-disability-community.html>.

requested and accepted by a patient who has capacity, understanding and free will as to the choice in question.

However, it must be noted that such a scenario would constitute a minority of cases, as such criteria could only be more safely applied to adults, free from comorbidities such as those of a psychosocial nature, and not under any form of guardianship or supervised legal capacity arrangements. The area of therapies is most usually territory reserved for children, mostly vulnerable children, in the field of autism.

The second factor to be taken into account is the fact that, as described in Sections 2.4 and 3.3, certain outward symptoms would need to be addressed, as would challenges in communicating with the ‘outside world’ in a ‘different vernacular’. Therefore, any reduction, mitigation or extinguishing of symptoms, as part of the reason a therapy is applied, can be considered a partial or complete aim at a cure if the targetting of such symptoms is performed as an end in itself, and not as a means to an end – because the symptoms are considered ‘the wrong’ response, or ‘socially unacceptable.’

It is the intent of such therapies to focus on the ‘cosmetic’ over the functional elements, that would render the use and application of such therapies vehicles towards a cure.

10.4.1 Certain Applications of Behavioural Therapies

Here, one could also include certain forms of therapies, described in Sections 2.4 and 3.3 of this thesis. Although these therapies themselves describe themselves as behavioural therapies, it is the stated aim of a specific therapy, or else the stated intention of the person applying the therapy, the person receiving the therapy, or the persons requesting the therapy, that would determine the aim to be attributed for each and every specific instance of use of that therapy method.

Therefore, an intent to ‘reduce’ the outward symptoms of autism or ‘mitigate’ them, can be said to constitute attempt at a partial cure, while intent to ‘extinguish’ autistic symptoms or lead to ‘indistinguishability’ from non-autistic peers can be said to be aiming at a more complete cure.

The Canadian litigation in *Auton v. British Columbia*, discussed further in Sections 1.1.3 and 3.3 of this thesis, is again being made reference to here, as is the Irish litigation in *O' Cuanachain v. Minister for Education*,¹⁸ further discussed in Section 3.3.1.1 of this thesis. The latter is being made reference to notwithstanding the fact that such litigation argued for a right to ABA funding by framing the therapy as a form of special education, rather than as a therapeutic behavioural intervention.

The issue of the use of restraints and seclusion in certain applications of behavioural therapy is also being referred back to here. Particularly emphasis is also being made on the use of aversives in application of such therapies, such as in the case of electro-shock 'therapy' administered at the Judge Rotenberg Center in Massachusetts, as well as relevant efforts to bring an end to such practices.

10.4.2 Science-based and Pseudo-science-based 'Curative' Therapies

Aside from research and use of therapies, a number of medical or pseudo-medical procedures have also been advocated over the years, claiming to be able to cure autism, or provide relief from the symptoms of autism – be the 'sufferer' the patient, or the parents or guardians of the patient.

Many of these procedures take the form of interventions that are dangerous in their own right, particularly because they are termed experimental by the medical community, or are otherwise unlicensed or banned by such. They usually involve application by practitioners in the alternative medicine field, or persons 'licensed' following a 3-day seminar, administering possibly life-threatening procedures, sometimes also using noxious substances, the maladministration or very administration of which is dangerous and possibly lethal to any person ingesting such.

Apart from possible legal sanctions that might be faced by practitioners or parents and guardians administering such procedures, attempts at such lead to possible rights violations

¹⁸ *Sean O' Cuanachain (a minor suing by his father and next friend, Cian O' Cuanachain) v. The Minister for Education and Science, the Minister for Health and Children, The Health Service Executive, Ireland and the Attorney General*, High Court of Ireland, per Pearl J, 16 May 2007, [2007] IEHC 170. The case was subsequently appealed by plaintiff to the Supreme Court of Ireland, but eventually settled in 2010.

in two fields – breaches of rights targetting a person’s individuality and personhood, but also breaches of rights concerning the dangerous and abusive practices linked to such ‘cure’ attempts and the administration of procedures and/ or substances within such attempts.

As to therapies with a curative ethos that are of a medical or pseudo-medical nature, rather than of a behavioural nature, a number of examples have sprouted over recent years, of which the following have done much to steal the limelight from others.

In this regard, it would be good to cite the words of the US FDA, which in 2014 stated, in a public service announcement, that “[t]here is no cure for autism. So, products or treatments claiming to ‘cure’ autism do not work as claimed. The same is true of many products claiming to ‘treat’ autism. Some may carry significant health risks.”¹⁹

Likewise, in a joint statement on the occasion of World Autism Awareness Day 2015, the UN Special Rapporteur on the Right to Health, Dainius Pūras, and the UN Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas Aguilar, stressed that

“[a]utistic persons are particularly exposed to [...] medical practices which are unacceptable from a human rights point of view. Such practices – justified many times as treatment [...] – violate their basic rights, undermine their dignity, and go against scientific evidence. Autistic children and adults face the proliferation of medicalized approaches [...]. This may be particularly harmful and lead to the deterioration of their condition. All too often, such practices amount to ill-treatment or torture.

¹⁹ US Food and Drug Administration (FDA), 'Beware of False or Misleading Claims for Treating Autism', April 2014, as cited in Erich Kofmel, *Review of Thailand: Medical Experiments on Thai Autistic Children*, Written submission to the 15th session of the Committee on the Rights of Persons with Disabilities, Autistic Minority International, Geneva, 4 March 2016, accessed online at https://www.google.ie/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKewiAuqD0hoXQAhUELcAKHUpSBOwQFggcMAA&url=http%3A%2F%2Fbinternet.ohchr.org%2FTreaties%2FCRPD%2FShared%2520Documents%2FTHA%2FINT_CRPD_CSS_THA_23257_E.doc&usg=AFQjCNG61dbEDT7vb8beWLA0ZPLxJiUD3A., at 2.

[...] We call for caution about enthusiastic attempts to find [...] ways to 'cure' autism through sophisticated but not necessarily ethical research. Autism as a condition is a critical challenge for modern health systems, in which we need to ensure that the practice and science of medicine is never again used to cause the suffering of people.”²⁰

Summing up the matter, Andrew Baumann, President and CEO of New York Families for Autistic Children, stated that “[p]arents are willing to try just about anything”, adding that “[y]ou can’t cure something [when] you don’t know what the cause is”.²¹

10.4.2.1 ‘Le Packing’

The example of ‘packing,’ the method rooted in psychoanalysis, by which a subject is wrapped in wet blankets, and forced to be ‘reborn,’ in order to be able to initiate a new bonding experience with the mother, has already been described in Section 2.2.2 of this thesis. Apart from psychological damage, such method can also lead to permanent physical harm, or even death.

10.4.2.2 Stem Cell Therapy

The concept of stem cell therapies has been touted by some, not least due to a possible link posited by researchers as to the linkages between autism and the autoimmune system.²² However, such therapies have been found to be experimental at best, with evidence as to

²⁰ Catalina Devandas Aguilar and Dainius Pūras, ‘Discrimination against autistic persons, the rule rather than the exception – UN rights experts’, Office of the UN Office of the High Commissioner for Human Rights (OHCHR), Geneva, 1 April 2015, and accessed online at [http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15787&LangID=E%20\(English\)](http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15787&LangID=E%20(English)), as cited in Kofmel, op. cit., at 2.

²¹ Mackenzie Dawson, ‘The miracle that cured my son’s autism was in our kitchen’, *The New York Post*, 17 June 2015, accessed online at <http://nypost.com/2015/06/17/is-diet-the-key-to-curing-autism/>.

²² See, for example, C Onore, M Careaga and P Ashwood, ‘The role of immune dysfunction in the pathophysiology of autism’, *Brain, Behavior and Immunity*, 28 August 2011; AC Brown, L Mehl-Madrona, ‘Autoimmune and gastrointestinal dysfunctions: does a subset of children with autism reveal a broader connection? *Expert Review of Gastroenterology & Hepatology*, Vol. 5, Issue 4, August 2011, at 465. However, other studies such as MW Abdallah, N Larsen, J Grove, B Nørgaard-Pedersen, P Thorsen, EL Mortensen and DM Hougaard, ‘Amniotic fluid chemokines and autism spectrum disorders: an exploratory study utilizing a Danish Historic Birth Cohort’, *Brain, Behavior and Immunity*, Vol. 26, Issue 1, January 2012, at 179, also carried by the US National Institute of Health at <https://www.ncbi.nlm.nih.gov/pubmed/21933705>, are inconclusive as to such possible link.

their efficiency being anecdotal.²³ This is particularly because the efficiency of such methods relies on 'results' being measured from a change in behavioural approach,²⁴ rather than through observing actual physical and brain changes in the patient. Also, a number of dangers have been associated with such methods.²⁵

The relevant methodology involves the harvesting of stem cells from aborted fetuses,²⁶ or of umbilical cord stem cells, usually from 'healthy,' non-autistic siblings, or from patients themselves following collection of such following birth.²⁷ Such cells are then 'infused' into the autistic sibling, through methods such as via subcutaneous IV drip, or even direct injections to the brain, in a bid to correct the patient's developmental 'shortcomings.'²⁸

Certain countries such as Ukraine, where the medical regulatory framework can be said to be shakier when compared to the ideal gold standard, have licensed clinics offering such therapies,²⁹ notwithstanding the fact that there is only anecdotal evidence as to the effectiveness of such methods.

²³ Ibid. Furthermore, the Canadian Stem Cell Foundation, on the 'Autism' page of the 'Diseases' section of its website, while discussing stem cell clinical trials, accessed online at <http://stemcellfoundation.ca/en/diseases/autism/>, states that "[c]urrently, there are no Health Canada or U.S. FDA approved stem cell therapies for treating autism."

And Ukrainian 'service provider' EmCell, which became known to the author through Google Ad advertising while carrying out an online search for autism-related information, while extolling the virtues of their 'treatment', state on the 'Autism Treatment' section of their website at http://www.emcell.com/en/list_of_diseases/autism_treatment.htm, that "the degree of these improvements varies from child to child".

²⁴ As reported on the 'Autism Treatment' section of EmCell's website, op. cit.

²⁵ See, for example, Xuejun Kong, Xiaochun Wang and William Stone, Prospects of Stem Cell Therapy for Autism Spectrum Disorders, *North American Journal of Medicine and Science*, Vol. 4, Issue 3, 2011, at 134.

²⁶ As in the case of EmCell, 'Autism Treatment', op. cit.

²⁷ See, for example, the Cord Blood Banking blog on the Autism Speaks website, accessed online at <https://www.autismspeaks.org/blog/2013/01/04/cord-blood-banking>.

²⁸ See, for example, Kong et., op. cit. However, doctors disagree as to at which sites the stem cell injections are to take place, thus also increasing possible risks to the patients, as outlined in this discussion of stem cell therapy protocols used in India, described in 'Doctors divided over effectiveness of stem cell treatment for autism', *The Times of India*, 2 August 2015, accessed online at <http://timesofindia.indiatimes.com/city/mumbai/Doctors-divided-over-effectiveness-of-stem-cell-treatment-for-autism/articleshow/48313253.cms>.

²⁹ While major Western health regulation authorities such as the US FDA and Health Canada, as mentioned in Footnote 23 above, still consider such therapies experimental, Ukrainian authorities, conversely, already both authorise, as well as specifically patent autism treatments based on foetally-acquired stem cells, as detailed on 'About EmCell' section of EmCell's website, accessed online at http://www.emcell.com/en/about_emcell.htm. In this regard, EmCell state that:

"Starting from 1994, we operated under a general license for medical practice. In 2011, a new regulation required all clinics working with stem cells to apply for a special license, the only one

Also, the way such therapies are ‘marketed’ is equally a cause for concern. Many times, certain adverts ‘pop up’ through online advertising services such as Google Ads,³⁰ in much the same way as ‘get-rich-quick’ schemes would pop up to internet users browsing particular leisure-related sites. The reputability of the treatments in question, as well as of the operators behind them and the ethical standards they can be held to, could be called into question due to such product placement techniques.

There would be a further ethical concern, due to the fact that such ‘treatments’ usually ‘pop up’ following online tracking of a user’s internet search behaviour, particularly the customising of online advertising in virtue of search terms such as ‘autism’ and ‘autism treatment’ or ‘autism cure’ having been entered by said user.

This method is easily verifiable, and also points to the worrying way in which vulnerable and at times desperate parents, many times young first-time parents, often lacking knowledge and a support framework underlying possible autism diagnoses and management, could be exploited in this regard, for thing more financial gain by such schemes’ operators.

10.4.2.3 Chelation Therapy

As to chelation therapy, such involves a painful and dangerous process, whereby heavy metals are ‘purified’ from a patient’s body, in order to eliminate environmentally-induced factors, such as toxins, which are believed to affect a person’s health, development and

allowing legal manipulations with stem cells. EmCell was also the first in Ukraine to receive the state license for fetal cell bank operation.

EmCell holds two Ukrainian patents for the "Method of Treatment of Autism and Autism Spectrum Disorders with Medicinal Preparation from Cells Harvested from Fetal Material" (Patent #107,271) and the "Method of Treatment for Autism and Autism Spectrum Disorders with Medicinal Preparation from Fetal Material and Cells Harvested from It" (Patent #85,144)"

³⁰ As described by the author in Footnote 23 above in the case of EmCell. Similar instances encountered by the author in this regard have also included:

Cure for autism - Stem cell treatment for autism
 Ad www.startstemcells.com/autism-clinic
 Natural way to treat autism.

Stem Cells for Autism
 Ad www.puhuahospital.com/autism
 Safe and effective treatment for Autism -Stem Cell Therapy

behaviour.³¹ Although controlled chelation therapy can be beneficial in the case of certain medical conditions, in specified doses and regulated sessions following an approved protocol,³² this kind of therapy has not been shown to be effective in the case of autism.³³

Particularly, this is due to the fact that, while environmental factors have been shown to exacerbate symptoms related to or comorbid with an autism diagnosis,³⁴ they have neither been shown to cause autism, nor have they been shown to be responsible exclusively for certain autism symptoms which such therapy seeks to cancel out when so applied.³⁵ Also, misdiagnosis of autistic-like symptoms which do not constitute an autism diagnosis can be an additional problem, when claiming that such therapies ‘cure autism.’³⁶

The way in which these therapies have been documented to have been applied in the case of autism have been through aggressive zeal,³⁷ treating the autism like a cancer, through the false belief of the aetiology of said autism, and applying aggressive protocols, going far outside the boundaries warranted in the case of other applications of such therapies, that have been proven to be both harmful and life-threatening to patients, especially child patients,³⁸ when so applied. Destroying a cause that is not a cause, or a ‘disease’ without targetting its causative root, is bad science at its best.

³¹ See, for example, Nina Mikirova, Joseph Casciari, Ronald Hunninghake and Neil Riordan, ‘EDTA chelation therapy in the treatment of toxic metals exposure,’ *Spatula DD*, Vol. 1, Issue 2, 2011, at 81.

³² Chelation has been proved to be effective in, for example, the case of heavy metal poisoning, as reported in JS Flora Swaran and Vidhu Pachauri, ‘Chelation in Metal Intoxication,’ *International Journal of Environmental Research and Public Health*, Vol. 7, Issue 7, July 2010, at 2745, and; in the case of atherosclerosis, as reported in MV Villaruz, A Dans and F Tan, ‘Chelation therapy for atherosclerotic cardiovascular disease,’ *Cochrane Database of Systematic Reviews*, Vol. 4, 2000, at CD002785.

³³ Tonya N. Davis, Mark O’Reilly, Soyeon Kangb, Russell Lange, Mandy Rispolid, Jeff Sigafosse, Giulio Lancionif, Daelynn Copelanda, Shanna Attaia and Austin Mulloy, ‘Chelation treatment for autism spectrum disorders: A systematic review,’ *Research in Autism Spectrum Disorders*, Vol. 7, Issue 1, 2013, at 49.

³⁴ *Draft Baseline Report on Neurodevelopmental disorders in the framework of the European Environment and Health Strategy*, Technical Working Group on priority diseases – subgroup neurodevelopmental disorders, COM(2003) 338 final, Brussels, 5 December 2003, archived version available online at http://web.archive.org/web/20091222090158/http://ec.europa.eu/environment/health/pdf/neurodevelopmental_disorders.pdf.

³⁵ Ibid.

³⁶ See Section 10.5 of this thesis for a further discussion.

³⁷ Paul A. Offit, *Autism’s False Prophets: Bad Science, Risky Medicine and the Search For a Cure*, Columbia University Press, New York/ Chichester, 2008, at 85-87.

³⁸ See, for example, Jay L. Hoecker, ‘Is chelation therapy an effective autism treatment?’, *Diseases and Conditions, Autism Spectrum Disorder*, Mayo Clinic website, accessed online at: <http://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/basics/definition/con-20021148>.

However, a good number of parent activists, especially in countries such as the United States, still cling on to this therapy as one of the main desperate lines of hope being marketed³⁹ – with the fallacy of looking at the behaviour and not the cause, lying at the root of many problems underlying autism rights nowadays. This allows for a continued supply of such ‘services’ to willing takers, while certain areas of the medical and academic community still advocate for such methods, one such academic citing the ‘improvement’ so observed as being central to its legitimacy.⁴⁰

10.4.2.4 Hyperbaric Oxygen Therapy

Vulnerability is likewise an issue not just within certain social groups in Western countries, be it parents, young parents, parents with lack of access to information and services, or parents without a certain educational background. In certain developing countries, the possibility of pseudo-science being picked up on and mainstreamed is becoming reality in countries such as Thailand.

Here, the use of Hyperbaric Oxygen Therapy (HBOT) is being used as treatment for autism.⁴¹ Once again focusing on mitigating the behavioural aspects of autism, the relevant benefits are presumed to be derived through patients breathing pure oxygen over multiple sessions administered in purpose-built chambers.⁴² While such therapy has been proven medically useful in situations such as decompression for deep-sea divers,⁴³ the same has not been proved in the case of autism.⁴⁴

However, the medical community has pointed out, aside from detailing that such therapy is not effective for autism, general risks of injury and possible side-effects, particularly in children, as well as the possibility of death.⁴⁵ Notwithstanding, an incorrect understanding

³⁹ Offit, op. cit., at 121.

⁴⁰ Interview with Mary Holland, Professor of Law and Anti-Vaccine Autism Activist, Founder and Director of the Elizabeth Birt Center for Autism Law and Advocacy (EBCALA) at New York University, New York, May 2011.

⁴¹ Kofmel, op. cit.

⁴² Ibid., at 2.

⁴³ Ibid.

⁴⁴ Ibid.

⁴⁵ 'Complications of Hyperbaric Oxygen Treatment', as outlined in the 'Diseases and Conditions' section, Health Library, Johns Hopkins Medicine website, accessed online at http://www.hopkinsmedicine.org/healthlibrary/conditions/physical_medicine_and_rehabilitation/complications_of_hyperbaric_oxygen_treatment_134,148/.

of autism and the approach to it, in countries such as Thailand, have seen the continued use of such therapies accepted in the mainstream, and administered as 'first-line' treatment in reputable hospitals around the country.⁴⁶

There have been at least two medical studies about its efficacy in the Thai context. The first⁴⁷ is authored by the Director of the 500+ bed Vachira Phuket Hospital. The study finds HBOT to be an "effective method", with "improvements" having been observed. However, the same concerns here as those raised in Section 2.4.1 of this thesis were observed, with one parent stating that "my daughter has stopped walking on tiptoes and stopped flicking her hand. She has already started to speak".⁴⁸ It is clear here that the end aims of this therapy was simply to end 'stimming' behaviours⁴⁹ and develop verbal communication, raising the relevant concerns of therapies having such goals as ends in themselves.

During the second study,⁵⁰ one boy suffered a febrile convulsion during early treatment, while a further fourteen children experienced ear barotrauma. Furthermore, the study concluded that "HBOT conferred no benefit above that owing to a participation (or placebo) effect."⁵¹

Such an incorrect approach, and allowing such approaches to snowball, will only lead to propagation of abusive treatment of autistic persons, and of rights violations related to such, also in terms of international instruments which such governments, the Thai government in this case, have ratified and are bound by.

⁴⁶ Kofmel, *op. cit.*, at 3, states that "'the use of HBOT in Thailand is widespread. While in other countries this treatment is offered by small and often shady businesses or clinics, in Thailand it is major hospitals that apply it to autistic children'".

⁴⁷ *Ibid.*, at 3.

⁴⁸ *Ibid.*

⁴⁹ 'Stimming', or self—stimulatory behaviours, are behaviours are used as a form of sensory stimulation by autistic persons, see, for example, Stephen M Edelson, 'Self-Stimulatory Behavior', Autism Research Institute, accessed online at https://www.autism.com/symptoms_self-stim, for further insights into this topic. Although having a medicalised slant, this resource gives a good overview of the range and background of such behaviours.

⁵⁰ *Ibid.*, at 3-4.

⁵¹ *Ibid.*, at 4.

10.4.2.5 Bleach Enemas/ MMS

Similarly to chelation therapy, the rationale behind bleach enemas posited that toxins in the patient's body had to be released, through the administration of enemas containing chlorine dioxide, that would send the body into a high fever, which would subsequently lead to the body expelling matter and purging, progressively, the 'sufferer' of said toxins.⁵² Once again, no medical evidence exists to prove that such a therapy is effective in the least. Rather, the noxious effects of administering such a procedure have been documented.⁵³

Once again, the behavioural results of such 'treatment' are emphasised by its supporters, who view their children's weakening and breaking of will as to 'challenging behaviours,' following the repeated administration of bleach enemas, as 'progress,'⁵⁴ and who comment on mailing lists, and celebrate their children's first induced fever, hoping to follow in the footsteps of the results achieved by other parents.⁵⁵

In the case of a specific method of administration of such bleach enemas though, known as the Miracle Mineral Solution (MMS),⁵⁶ the method has been surrounded by a group with almost cult-like trappings. The Genesis II Church of Health and Healing claims to have developed such method,⁵⁷ listing it as one of its Sacraments, boasting of its efficacy, while holding regular seminars, in which new practitioners are trained in relevant methods, receiving their 'certification' following a 3-day course, also being made 'Ministers' within said Church as part of the process.⁵⁸

⁵² 'Basic Science of MMS', a description of the relevant 'science' behind and related protocols as to MMS, online at http://mmswiki.is/index.php?title=Basic_Science_of_MMS, accessed through a link on the Genesis II Church of Health and Healing's main website at <http://genesis2church.is/>.

⁵³ See, for example, 'FDA Warns Consumers of Serious Harm from Drinking Miracle Mineral Solution (MMS): Product contains industrial strength bleach', News Release issued by the US Food and Drug Administration (FDA), 30 July 2010, accessed online at <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm220747.htm>.

⁵⁴ See, for example, 'MMS and Autism' section, on the MMS Testimonials Database within the website of the Genesis II Church of Health and Healing, accessed online at <http://mmstestimonials.is/all-mms-testimonials>.

⁵⁵ Ibid.

⁵⁶ 'Basic Science of MMS', op.cit.

⁵⁷ Ibid.

⁵⁸ 'Become a Health Minister' section on the Genesis II Church of Health and Healing, accessed online at <http://genesis2church.is/become-a-health-minister>.

The activities of said Church have been particularly protested against in different locations such as, for example, around the time it held one such training in Ireland,⁵⁹ which had to be organised under covert circumstances due to the media blaze. Activists drew attention to the matter, which also made it to the national media,⁶⁰ starting petitions to ban the group and practice, and also have them investigated by authorities.⁶¹ Ireland's Health Minister was also urged to ban the practice in 2015.⁶² Subsequent action was also taken by authorities and by Gardaí in connection with incidents linked to this matter.⁶³

10.4.2.6 Nutritional and Chemical Supplements

Finally, many nutritional supplements are advertised,⁶⁴ and linked to online search results, as described earlier, trying to target vulnerable persons, particularly parents, into believing

⁵⁹ As cited in the Event Invitation posted on the Church's official Facebook page, accessed online at <https://www.facebook.com/GenesisIIChurch/posts/548316321933239>.

⁶⁰ See, for example, 'Irish patients warned 'miracle cure' from US church is bleach', *The Irish Independent*, 11 July 2014, accessed online at <http://www.independent.ie/irish-news/irish-patients-warned-miracle-cure-from-us-church-is-bleach-30423760.html>; James Brennan, "'Autism Cure' – Former scientologists are selling bleach called MMS to cure any ailment", *TheLiberal.ie*, 17 April 2015, accessed online at <http://theliberal.ie/autism-cure-former-scientologists-are-selling-bleach-called-mms-to-cure-any-ailment/>; the episode of the programme *Prime Time* dedicated to the MMS/CD Protocol by national Broadcaster RTÉ, on 9 April 2015, full episode accessed online at https://youtu.be/_8LbfYAphF8, following the activism of self-advocate Fiona O' Leary on the matter.

⁶¹ See, for example, 'Irish Government and Authorities: Stop the Use of CD and mms as a Treatment for Autism in Ireland, and Child Abuse of Autistic Children and Adults', Petition by Emma Spence at [change.org](https://www.change.org), accessed online at <https://www.change.org/p/irish-government-and-authorities-stop-the-use-of-cd-and-mms-as-a-treatment-for-autism-in-ireland-end-child-abuse-of-autistic-children-and-adults>; 'Autistic Rights Together: Criminalise the Bleach Treatment for Autism - Stop the Abuse', Petition by Claire Rooney at [change.org](https://www.change.org), accessed online at <https://www.change.org/p/autistic-rights-together-criminalise-the-bleach-treatment-for-autism-stop-the-abuse>; a dedicated Facebook page at <https://www.facebook.com/AutisticsandAspiesAgainstCDautismandMMS>; a dedicated Facebook page at <http://facebook.com/bleaching4jail> and twitter account at @sayno2quackery were also set up, along with the twitter hash-tag #bleaching4jail, by Irish activists.

⁶² As reported in 'Harris urged to criminalise controversial bleach 'cure' for autism', *The Irish Examiner*, 23 August 2016, accessed online <http://www.irishexaminer.com/breakingnews/ireland/harris-urged-to-criminalise-controversial-bleach-cure-for-autism-750984.html>.

⁶³ See, for example, 'Gardaí interview parents who used controversial bleach treatment on autistic children', *The Irish Independent*, 13 April 2015, accessed online at <http://www.independent.ie/irish-news/health/gardai-interview-parents-who-used-controversial-bleach-treatment-on-autistic-children-31137515.html>; 'Genesis II Church 'bishop' fined €4,000 for making and marketing 'autism cure'', *thejournal.ie*, Sunday 30 October 2016, accessed online at <http://www.thejournal.ie/genesis-ii-bishop-mms-autism-cure-3051148-Oct2016/>.

⁶⁴ See for example, supplements being sold on the 'Supplements' page in the 'Vitamins, Minerals, Amino Acids, Enzymes, Probiotics, Oils & More' section of the Autism Coach website, accessed online at <http://autismcoach.com/supplements/>; and the 'Our Kids...' website, which claims to sell "The Purest Nutritional Supplements in the World!" for autism, accessed online at <https://www.ourkidsasd.com/>.

that they would cure autism – once again, focus on the behavioural, symptomatic manifestations of autism.⁶⁵

In this regard, similar to the mechanism with other described methods, certain supplements and vitamins might improve functioning or symptom intensity, however, not eliminate symptoms, and not cure the underlying autism – and again, such preparations may be addressing autistic-like symptoms in incorrectly-diagnosed persons, and not cases of autism and ‘real’ autistic symptoms.

Linking in with this, the recent Australian ‘breakthrough’ research on nose sprays said to improve autistic symptoms in patients, described earlier in this thesis,⁶⁶ are of similar concern for the exact same reasons – that of dealing with autistic behaviours, while totally neglecting the underlying causes of such.

Worrying trends are that such methods are not simply being peddled across darker lurches of the internet, but also through respectable-looking medical establishments, in countries lacking stronger regulatory frameworks, and also making use of legal loopholes and sales tricks, in order to prey on the vulnerable using totally legitimate means.

In Romania, a European Union members state, whereby any medical preparations are also subject to oversight and approval by the European Medicines Agency (EMA),⁶⁷ parents have spoken of the services of a clinic being advertised, offering to diagnose autism

⁶⁵ For accounts of parents using and supporting such supplements, see, for example, ‘Supplements’ in ‘Healing Autism & ADHD: A Mom’s View on Biomedical Intervention’, accessed online at <https://healingautismandadhd.wordpress.com/supplements/>; ‘Healing with Supplements’, on the Autism Road to Recovery Blog, 5 April 2012, accessed online at <http://autismroadtorecovery.blogspot.ie/2012/04/healing-with-supplements.html>.

⁶⁶ See Section 2.3.2 of this thesis for a further discussion.

⁶⁷ As per Directive 2001/83/EC of the European Parliament and of the Council of 6 November 2001 on the Community code relating to medicinal products for human use, OJ L 311, 28.11.2001, at 67, any therapeutic medication marketed and distributed within the European Union must obtain prior clearance from the EMA. However, such clearance is not required in the case of supplements that would otherwise classify as ‘homeopathic medicines’ which only require a simplified approval procedure, also in terms of the additional provisions of Council Directive 92/73/EEC of 22 September 1992 widening the scope of Directives 65/65/EEC and 75/319/EEC on the approximation of provisions laid down by Law, Regulation or Administrative Action relating to medicinal products and laying down additional provisions on homeopathic medicinal products, OJ L 297, 13.10.1992, 8–11. This has led certain producers and distributors of products discussed within this Section of the thesis to offer their products as such to potential consumers, together with employing backhand marketing techniques to push forward such products, as described in this Section.

through blood tests, and to provide further advice on results being obtained.⁶⁸ The blood tests themselves are sent abroad, to be performed in specialised laboratories there, adding to the veneer of cutting-edge practice being put across.

However, on results being returned to the laboratory, parents are presented with a written report on the relevant blood work, with the following pages simply allowing parents to sign up for the purchase of 'supplements' targetting the autism.⁶⁹

The parent in question was able to figure out the actual cost, and actual ineffectiveness and possible harmfulness of the active ingredients in said supplements, through internet searches and consulting with his spouse who was a qualified medical doctor.⁷⁰ However, many more parents, even with a certain level of education, but lacking certain specific skills, would have and possibly still are falling prey to such schemes.

10.5 The Role of the Media and Personalities

In this regard, the mass media can play a major role in influencing the debate, especially as regards sections of the population without access to the right knowledge or support services, or else having more rudimentary education backgrounds. In this regard, one could mention the case of model Jenny McCarthy, who put her face to the cause of autism research and treatment, after claiming that her son had been diagnosed with autism.⁷¹

One of her famous claims – which underlies the worrying reality being lived through by many parents today – was that of having earned a 'PhD in "Google Research"',⁷² in trying to figure out what autism is, where it came from, and how it could be cured. Such 'research'

⁶⁸ Meeting with Marin Mugur, Parent of an Autistic Child, on the side-lines of the XI Autism-Europe International Congress, Edinburgh, September 2016.

⁶⁹ Ibid.

⁷⁰ Ibid.

⁷¹ As further discussed by McCarthy in *Louder Than Words: A Mother's Journey in Healing Autism*, Dutton, New York, 2007. The Foreword to the book, written by David Feinberg, Medical Director at UCLA's Resnick Neuropsychiatric Hospital, includes two sections entitled 'What is Normal?' and 'How are Children with Autism Different?'.

⁷² Ibid.

led her to associate with questionable charities such as Talk About Curing Autism (TACA),⁷³ as well as applying attempted cures, such as chelation therapy, on her son.⁷⁴

A few years later, McCarthy made the ground-breaking claim that her son had been 'cured of autism'.⁷⁵ In the wake of this, media coverage surfaced, stating that McCarthy had eventually changed her position on vaccines causing autism, and that her child was not autistic due to the fact that he had, in fact, been wrongly diagnosed with autism, instead of with Landau-Kleffner Syndrome, all along. In the latter condition, some of the behavioural symptoms exhibited are similar to or mimic autistic symptoms, but with a totally different and also specific aetiology, and cure.⁷⁶

While McCarthy publicly stated that she had been misrepresented, she affirmed this on her Twitter feed by stating that "[s]tories circulating online, claiming that I said my son Evan may not have autism after all, are blatantly inaccurate and completely ridiculous."⁷⁷ Notwithstanding the inaccuracies she set out to rectify, this flew in the face of her earlier

⁷³ See, for example, this article by TACA Founder Lisa Ackerman, 'TACA & Jenny McCarthy', authored on 5 October 2008 and accessed online at <http://www.tacanow.org/about-taca/taca-jenny-mccarthy-2/>.

⁷⁴ As also promoted through 'What is Chelation and How Can it Help My Child with Autism?', accessed online at <http://www.generationrescue.org/recovery/biomedical-treatment/treatments-to-explore/>, on the 'Treatments to Explore' section of the website of Generation Rescue, the controversial charity with strong links to McCarthy and disgraced anti-vaccines proponent Andrew Wakefield, seeking a cure for autism. In line with the organisation's 'Hope for Recovery' motto, this page states, in its introductory blurb, that "Conventional medicine treats the symptoms of autism. Biomedical treatment addresses the root cause."

⁷⁵ Lisa Belkin, *The False Prophets of Autism*, Motherlode: Living the Family Dynamic, Parenting Blogs at the *New York Times*, 2 February 2010, accessed online at http://parenting.blogs.nytimes.com/2010/02/02/the-false-prophets-of-autism/?_r=0. Belkin speaks of, for example, how her son "is no longer in the world of autism".

⁷⁶ The WHO's *International Statistical Classification of Diseases and Related Health Problems* (10th Revision) (ICD-10), World Health Organisation, Geneva, 1992, at F80.3, specifies Landau-Kleffner Syndrome as being 'Acquired aphasia with epilepsy'. It further describes it as "A disorder in which the child, having previously made normal progress in language development, loses both receptive and expressive language skills but retains general intelligence; the onset of the disorder is accompanied by paroxysmal abnormalities on the EEG, and in the majority of cases also by epileptic seizures. Usually the onset is between the ages of three and seven years, with skills being lost over days or weeks. The temporal association between the onset of seizures and loss of language is variable, with one preceding the other (either way round) by a few months to two years. An inflammatory encephalitic process has been suggested as a possible cause of this disorder. About two-thirds of patients are left with a more or less severe receptive language deficit."

⁷⁷ Cavan Sieczkowski, Jenny McCarthy Slams Rumors Claiming Her Son Does Not Have Autism, 'Parents' section, *Huffington Post Online*, 6 January 2014 (Updated 23 January 2014), accessed online at http://www.huffingtonpost.com/2014/01/06/jenny-mccarthy-son-rumors-autism_n_4548244.html.

affirmations that her son had been cured of autism, including on respected prime-time media such as on the *Larry King Live* talk show.⁷⁸

Although the question of McCarthy's son's diagnosis was laid to rest for the time being, the abuse he endured was still perpetrated. And the number of parents who followed McCarthy's lead, as a prominent figure in the entertainment media, and took her advice as to diagnosis, aetiology – and most importantly, cure and relevant methods – were still a sizeable amount. These were parents to whom McCarthy, through her standing, and to whom also the media around her, are still responsible.

They are responsible for having propagated the wrong information, for possibly years of their lives these children may have lost, and for a licence for abuse. This firstly with regard to parents seeing their children as sick and as needing a cure, rather than as developmentally different and requiring a holistic approach, including relevant person-centred interventions, and adequate support services.

Secondly, also with regard to parents using abusive, damaging methods with possible life-long consequences on their children, looking for the same results this star achieved, and also leading them to waste their money on snake oil, rather than on real supports and services for their children and families.

10.6 The Right Not To Be Abused – International Instruments

10.6.1 Physical and Mental Abuse

The MI Principles exacted, when laying down standards of care, that every patient was to be protected from harm and acts causing mental distress or physical discomfort, including abuse by other patients, staff or others.⁷⁹ The Declaration on Mentally Retarded Persons asserted a right to protection from abuse and degrading treatment for 'mentally retarded'

⁷⁸ Ibid.

⁷⁹ Principles for the Protection of Persons with Mental Illnesses and the Improvement of Mental Health Care, G.A. res. 46/119, 46 U.N. GAOR Supp. (No. 49) at 189, U.N. Doc. A/46/49 (1991) (hereinafter 'MI Principles'), at Principle 8(2).

persons, and also prohibited exploitation.⁸⁰

The Autism-Europe Charter of Rights provides both for the freedom from abusive physical treatment or neglect,⁸¹ as well as pharmaceutical abuse or misuse.⁸² Both the abusive treatment and the neglect of autistic persons are areas covered by practically every international and European regional instrument in force.

The Declaration on the Rights of Disabled Persons spoke of protection against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature,⁸³ while the UN CRPD also required freedom from torture, cruel and inhuman treatment as well as punishment for disabled persons, as well as freedom from degrading punishment.⁸⁴ It further required that effective legislative, administrative, judicial and other measures be taken by contracting States Parties to prevent such acts.⁸⁵

The CRPD later also speaks of a right to respect for one's physical and mental integrity on an equal basis with other persons,⁸⁶ this is couched in general terms and, therefore, applies also to instances in which one is deprived of one's liberty.

Freedom from violence was also asserted specifically with respect to abuse and exploitation,⁸⁷ over and above the instrument's general prohibition.⁸⁸ Contracting States Parties are required, towards this end, to take all appropriate legislative, administrative, social, educational and other measures to ensure these aims, both within and outside the house, and gender-based aspects of such acts are also specifically mentioned.⁸⁹

Contracting States Parties are further obliged to take all appropriate measures promoting

⁸⁰ Declaration on Mentally Retarded Persons, at art. 6.

⁸¹ Autism-Europe Charter of Rights, at art. 17.

⁸² *Ibid.*, at art. 18.

⁸³ Disability Declaration, *op. cit.*, at art. 10.

⁸⁴ UN CRPD, *op. cit.*, at art. 15.

⁸⁵ *Ibid.*, at art. 15(2).

⁸⁶ *Ibid.*, at art. 17.

⁸⁷ *Ibid.*, at art. 16 (1).

⁸⁸ *Ibid.*

⁸⁹ *Ibid.* In this regard, art. 16 (2) further specifies that Contracting States Parties are also required to provide gender- and age-sensitive assistance and support measures to persons with disabilities, their families and caregivers, especially information and education on avoiding, identifying and reporting instances of the offences under discussion, with related protection measures being in addition also disability-sensitive. Art. 16(3) also provides for all facilities and programmes in this regard to be monitored by independent authorities.

the physical, cognitive and psychological recovery, rehabilitation and social reintegration of victims of the offences under discussion, including through the provision of protection services, and offered in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person, also taking into account gender- and age-specific needs.⁹⁰

Such measures must also be backed up by legislation, including women- and child-focused legislation, and policies meant to ensure that such offences are identified, investigated and, where appropriate, prosecuted.⁹¹

Protection from abusive physical, as well as mental treatment, is also mandated by the UN CRPD when highlighting disabled persons' right to respect for their physical and mental integrity, on an equal basis with others.⁹²

Finally, the EP Autism Rights Declaration specifically mentions the right of autistic people to freedom from fear, threat and from abusive treatment,⁹³ while the ECHR declares that no one shall be subjected to torture or to inhuman or degrading treatment or punishment,⁹⁴ and further that no one shall be held in slavery or servitude,⁹⁵ or required to perform forced or compulsory labour.⁹⁶

10.6.2 Freedom from Pharmaceutical Abuse

As to freedom from pharmaceutical abuse or misuse specifically, the MI Principles state that medication is to meet the best health needs of the patient and should be given to him and her only for therapeutic or diagnostic purposes, never being administered as a punishment or for the convenience of others.⁹⁷ This is amply demonstrated in popular

⁹⁰ Ibid., at art. 16(4).

⁹¹ Ibid., at art. 16(5).

⁹² Ibid., at art. 17.

⁹³ EP Autism Rights Declaration, op. cit., at art. 2(d).

⁹⁴ ECHR, op. cit., at art. 3.

⁹⁵ Ibid., at art. 4(1). This could be the case concerning instances of non-pharmaceutical treatments or therapies deemed to be 'experimental'. Bartlett et. Citation as to how this comes into play. Peter Bartlett, Oliver Lewis and Oliver Thorold, in 'Mental Disability and the European Convention on Human Rights', Martinus Nijhoff Publishers, Leiden/ Boston, 2007, mention that the ECHR provisions relating to slavery and servitude (art. 4(1)) can also be seen as having special significance in this regard.

⁹⁶ Ibid., at art. 4(2); Bartlett et., op. cit., also mention that the ECHR provisions relating to forced or compulsory labour (art. 4(2)) could be seen as having special significance in this regard, for the reasons mentioned in the previous footnote.

⁹⁷ MI Principles, op. cit., at Principle 10(1).

culture through the film adaption of the book 'One Flew Over the Cuckoo's Nest',⁹⁸ in which an 'unruly' patient is lobotomised due to his being the head nurse's nemesis.

Furthermore, only medications of known or demonstrated efficacy are to be administered,⁹⁹ except in the case of clinical trials and experimental treatment. In such cases, medication is only to be administered with the patient's informed consent, or the approval of a competent, independent review body specifically constituted for this purpose should this not be possible.¹⁰⁰

Such course of action should always unfold saving the right of the patient, his or her personal representative or any interested person, to appeal to a judicial or other independent authority concerning any treatment given.¹⁰¹ The ECHR provisions relating to slavery, servitude¹⁰² and forced or compulsory labour¹⁰³ can also be seen as having special significance in this regard.

In this regard, one could comment about a particular area of pharmaceutical research linked to autism, the EU-funded European Autism Interventions – A Multicentre Study for Developing New Medications (EU-AIMS) programme.¹⁰⁴ The European Union contributes towards this initiative through provision of funding to the Innovative Medicines Initiative (IMI), a public-private partnership with the pharmaceutical industry association EFPIA.¹⁰⁵

One can recognise the fact that certain autistic persons can benefit from the use of medication in connection with the intensity of certain aspects of their autism, such as obsessional behaviour, or of comorbid conditions such as anxiety,¹⁰⁶ and that subsequently, such an initiative could lead to outcomes beneficial to the lives of autistic persons, and also

⁹⁸ Miloš Forman, *One Flew Over the Cuckoo's Nest*, United Artists, Century City (California), 1975.

⁹⁹ MI Principles, op. cit., at Principle 10(1).

¹⁰⁰ Ibid., at Principle 11(1).

¹⁰¹ Ibid., at Principle 11(16).

¹⁰² ECHR, op. cit., at art. 4(1).

¹⁰³ Ibid., at art. 4(2).

¹⁰⁴ Further details on the initiative available at the EU-AIMS website, online at <http://www.eu-aims.eu>.

¹⁰⁵ Funding Mechanisms sections of EU-AIMS website, online at <http://www.eu-aims.eu/funding-mechanisms/>.

¹⁰⁶ See, for example, Anastasios Galanopoulos, Dene Robertson, Debbie Spain and Clodagh Murphy, *Your Autism* (Supplement on Mental Health), Vol. 8, Issue 4, Winter 2014.

conducive to the aims of CRPD in the field of health.¹⁰⁷ It is also the single largest grant made in the field of autism in the world so far.

However, once again, it is important that this initiative, even though of a strictly medical nature, is approached with the autistic person at its centre, and terminology such as that stating that the grant is the largest so far for the study of ‘any mental health disorder in Europe’¹⁰⁸ should be avoided.

Advocacy groups have raised concerns about the current state of play in this regard,¹⁰⁹ due to the consultation of only particular stakeholders in the field of autism, such as controversial parent advocacy organisation Autism Speaks, and not enough consultation of autistic persons, self-advocates and their groups,¹¹⁰ in breach of the principle of ‘Nothing About Us Without Us’ underlying the CRPD.

Failure to rectify such a course can lead to the CRPD being breached as regards to autistic persons’ rights to freedom from torture or cruel, inhuman or degrading treatment,¹¹¹ freedom from exploitation, violence and abuse¹¹² and to protection the integrity of the person.¹¹³

In particular, the issue of children must also be dealt with very carefully, also in light of the CRPD article dealing with children with disabilities.¹¹⁴

10.6.3 Recent Movements at European Level

On the same topic, the EP Autism Rights Declaration similarly speaks in general terms,

¹⁰⁷ UN CRPD, op. cit., at art. 25.

¹⁰⁸ EU-AIMS website, op. cit., at <http://www.eu-aims.eu/>.

¹⁰⁹ See, for example, Alistair de Gaetano (lead author), *Review of the European Union: About Autism, Without Autistics*, joint written submission to the 14th session of the UN Committee on the Rights of Persons with Disabilities by Autistic Minority International, Enthinderungsselbsthilfe von Autisten für Autisten (und Angehörige) (Germany), Alliance Autiste (France) and Autism Women Matter (United Kingdom), Geneva, 3 August 2015, available online at http://tbinternet.ohchr.org/Treaties/CRPD/.../EUR/INT_CRPD_CSS_EUR_21278_E.doc.

¹¹⁰ EU-AIMS website, op. cit., at <http://www.eu-aims.eu/>.

¹¹¹ UN CRPD, op. cit., at art. 15.

¹¹² Ibid., at art. 16.

¹¹³ Ibid., at art. 17.

¹¹⁴ Ibid., at art. 7.

which can also be seen as encompassing deprivation of one's liberty, when declaring that autistic persons have the right to freedom from fear, threat and from abusive treatment.¹¹⁵

It was further agreed, at a consultation meeting for civil society summoned by the European Commission's DG-Employment and Social Affairs in October 2015, mentioned in Section 5.2.4.1 of this thesis, that the EU should promote the exchange of good practices on prevention of forced treatment.

In this regard, it was specific that attention should be paid to forms of therapies that can amount to degrading treatment, especially as regards persons with mental or psychosocial disabilities.¹¹⁶ In this regard, instances of forced sterilisation and abortion for persons with disabilities in particular Member States should be addressed.¹¹⁷

10.6.3.1 Lacking Guarantees: Autism, Detention and Sterilisation?

Although this is not a specifically documented instance in the case of autism nowadays, wrong perceptions and lack of understanding of autism might very well allow this to happen in certain jurisdictions, even if veiled under genuine concerns in terms of 'best interests' and issues of legal capacity.

Perhaps the largest affront to one's physical integrity in the sexual sphere, forced sterilisation is nowadays expressly prohibited by a number of relevant international statutes. The MI Principles, though not mentioning the issue of sterilisation directly, cover it through its requirements of the consent of patients or their caregivers to treatment.¹¹⁸ They specifically outline that "*Sterilization shall never be carried out as a treatment for mental illness*",¹¹⁹ as well as the rights of patients or their caregivers to be notified about the

¹¹⁵ EP Autism Rights Declaration, op. cit., at art. 2(d).

¹¹⁶ Final Minutes, Meeting with NGOs on the follow-up to the UN concluding observations on the EU's initial report on the Convention on the Rights of Persons with Disabilities, Brussels, 26 October 2016.

¹¹⁷ Ibid.

¹¹⁸ MI Principles, op. cit., at Principle 11.

¹¹⁹ Ibid, at Principle 11(12). It is also interesting to note that this principle has also been transposed into the Kosovo Charter of Rights for Mental Health Patients promulgated by the nascent Kosovar state in art. 19, and available online through the World Health Organisation's Kosovo mission at http://whokosovo.exclusion.net/pdf/charter_rights_patients.pdf. Although enforceability of such a provision will also depend on changing regional mentalities, as in other parts of Europe, as well as being influenced by the fact that Kosovar citizens cannot at this point in time petition regional institutions like the ECtHR, and that Kosovar institutions are not formally bound by their decisions

treatments being received and also about all treatment options prior to this.¹²⁰ Its provisions on physical abuse and degrading treatment¹²¹ can also be interpreted as prohibiting such a course of action.

The UN CRPD's provisions on respect for home and the family also state that persons with disabilities, including children, should retain their fertility on an equal basis with others.¹²² The Council of Europe further recommends that the use of a treatment for mental disorder with the aim of producing irreversible physical effects should be exceptional,¹²³ and even in such cases would require free, informed and specific consent in writing, as well as that meticulous rules be followed and the procedure recorded in a register. It also forbids such non-elective procedures from being performed when a person is involuntarily committed.¹²⁴

Nonetheless, the United Kingdom, for example, is still treading a very thin line in this area. The nature of the possibility of such procedures being rooted in grounds of public policy rather than medical necessity, as argued earlier, can be seen through a Swedish Government Commission report about the practice that lasted until 1975 in Sweden.¹²⁵ In that country, women with intellectual disabilities, even when they had the capacity to decide on medical treatment, were nonetheless compulsorily sterilised, against their will, on the basis of their intellectual disability.

As to the United Kingdom, notwithstanding the instruments just mentioned, and also in view of certain reservations it has lodged to such, still continues with the practice of forced sterilisation when the courts decide, on a case-by-case basis, that the procedure is in the

due to not partaking in their membership, it can nonetheless be seen as a bold first step on which future ones can be built.

¹²⁰ MI Principles, op. cit., at Principle 11(2).

¹²¹ Ibid., at Principle 1(3).

¹²² UN CRPD, op. cit., at art. 23(1)(c).

¹²³ Council of Europe Recommendation Rec(2004)10 of the Committee of Ministers to member states concerning the protection of the human rights and dignity of persons with mental disorder (Adopted by the Committee of Ministers on 22 September 2004 at the 896th meeting of the Ministers' Deputies), Art. 28(2). The United Kingdom government adopted this Recommendation with reservations to a number of articles, including to Article 28, due to its position on sterilisation that will be discussed.

¹²⁴ Ibid.

¹²⁵ Swedish Government Commission Report, 2000:20 *Steriliseringsfrågan i Sverige 1935-1975: Historisk belysning – Kartläggning*, Intervjuer, SOU 2000:22, 'Från politik till praktik. De svenska steriliseringslagarna, 1935-1975', as quoted in Bartlett et al., op. cit., at 193.

patient's 'best interests'.¹²⁶ This happened, very notably in cases such as *F v. West Berkshire Health Authority*,¹²⁷ as well as later cases like *Re W (Mental Patient)*.¹²⁸

Robert Nelson, counsel for plaintiff in *F*, which made it all the way to the House of Lords,¹²⁹ and whereby the adult plaintiff was being represented by her parents as her legal guardians, very genuinely spoke of the necessity of the surgery, which said parents successfully petitioned the Court to allow, due to its necessity, being in the best interests of the lady in question, and specifically for her own protection due to her mental disorder.¹³⁰

Counsel was acting in line with what he perceived to be the best course of action, in line with medical information available to him, as well as related perceptions. As to the procedure itself, this was not shackled by the described supranational prohibitions under English law, and so was legal if a Court so decided.

Nelson also asked, after having discussed the *F* matter, about what constitutes autism, and what the main points were as to identifying and addressing autism.¹³¹ This scenario, while benign, serves to illustrate a point. Presented with the relevant information, a person such as Nelson, a Knight of the Realm, distinguished barrister and former High Court judge, would be better placed to make the right call if approached by petitioners seeking sterilisation for their autistic offspring. However, with the wrong information available, and within the context of hostile perceptions concerning autism, *F* could easily happen again, this time in a different scenario.

Since *F* and *Re W*, the United Kingdom developed a specific Practice Note with regard to

¹²⁶ Bartlett et al., op. cit., at 193.

¹²⁷ *F v. West Berkshire Health Authority* [1989] 2 All ER 545, [1990] 2 AC 1, [1989] 2 WLR 938, as quoted in Bartlett et al., op. cit., at 193. In this case, the mother of a 36-year old woman stated as having the mental age of a child sought a declaration authorising the sterilisation of her daughter, with the subject-matter in question closely resembling that in *Buck v. Bell*, discussed earlier at Section 2.3.1 of this thesis.

¹²⁸ *Re W (Mental Patient) (Sterilisation)* [1993] 1 FLR 381, as quoted in Bartlett et al., op. cit., at 193. The facts in this case, concerning a young woman described as mentally handicapped and suffering from severe epilepsy, are similar to those in *F v. West Berkshire Health Authority* mentioned in Footnote 127 above.

¹²⁹ Per Lord Bridge of Harwich, Lord Brandon of Oakbrook, Lord Griffiths, Lord Goff of Chieveley and Lord Jauncey of Tullichettle, 17 July 1990, [1991] UKHL 1.

¹³⁰ Interview with Robert Nelson, Counsel for Plaintiff in *F v. West Berkshire Health Authority*, Crown Office Chambers, London, February 2011.

¹³¹ Ibid.

sterilisation,¹³² and applying to such cases, which has now been superseded by a new Code of Practice¹³³ since the coming into force of the Mental Capacity Act in 2005.¹³⁴ Nonetheless, this still, however, makes similar provisions concerning sterilisation.

There are reasons as to why instruments such as the CRPD, as well as the Council of Europe's Recommendations, seek to prohibit sterilisation in many circumstances. However, in a scenario such as the United Kingdom's, where the different jurisdictions within it are not bound by further top-down supranational restrictions, and where the door is open to various possibilities in areas such as sterilisation, autistic persons too are a very possible target.

In such scenarios, one must not rely simply on common sense, but go further in working on awareness and perceptions, as also discussed earlier in this thesis.

¹³² Practice Note (Official Solicitor: Declaratory Proceedings: Medical and Welfare Decisions for Adults who Lack Capacity) [2001] 2 FLR 158, appendix I, as quoted in Bartlett et al., *op. cit.*, at 193.

¹³³ Code of Practice issued by the Lord Chancellor in accordance with sections 42 and 43 of the Mental Capacity Act 2005, published by The Stationery Office on behalf of the Department for Constitutional Affairs, London, 23 April 2007, available online at <http://www.justice.gov.uk/docs/mca-cp.pdf>.

¹³⁴ Mental Capacity Act 2005, c. 9.

Chapter 11: The Word on the Street – Awareness or Acceptance?

11.1 Introduction

Analysis in this Chapter shall be carried out using the same rationale and methodologies, and in the same vein, as in the previous two Chapters.

It will discuss the use of medicalised language, and approaches to delivering awareness and knowledge to the general public on the topic of autism. Concerns around skewed or absent awareness efforts, and their effects on societal perceptions through the dissemination of wrong knowledge, or of a lack of knowledge being disseminated, will be tackled.

The Chapter will also discuss how such an approach puts the brakes on the journey towards awareness, acceptance and inclusion, rather leading to a situation in which the status quo is enforced, or possibly even regression would occur as to autistic persons' rights situation.

This topic was raised also by UN Special Rapporteur on the Right to Health, Dainius Pūras, and the UN Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas Aguilar, through a declaration issued on the occasion of World Autism Awareness Day 2015.¹

The opening line of such declaration read:

“As part of human diversity, autistic persons should be embraced, celebrated and respected. However, discrimination against autistic children and adults is more the rule rather than the exception.”²

Examples covering EU legal texts, as well as the EU's legal basis for autism initiatives will be discussed, as will different scenarios, in which either the status quo remained untouched

¹ Office of the Un High Commissioner for Human Rights (OHCHR), ‘Discrimination against autistic persons, the rule rather than the exception – UN rights experts’, Geneva, 2 April 2015, accessed online at <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15787>.

² Ibid.

or regression was a possibility, or else movements were observed away from medicalisation in view of attempts at reform. As to these scenarios, the implementation of the DSM-5's new autism criteria will be discussed, and reference will be made to the situation in Canada, the United States, Northern Ireland and Malta.

11.2 Use of Medicalised Language – The EU Situation

11.2.1 EU Legal Basis for Autism Initiatives

While the European Union has undertaken a number of initiatives in the field of autism, a number of which have also been commended, there is no unifying thread underlying the European Union's approach to autism rights and autistic persons. Furthermore, the current legislative framework empowering Union action in the field is still rooted in the Medical Model of Disability, one of the key concept that the drafters of the CRPD sought to move beyond.

The legal basis for European Union action on autism is Article 168 (1) of the Treaty on Functioning of the European Union, which authorises Union action on Public Health. All European Union-launched or funded initiatives in the field of autism to date have been authorised in virtue of this Article.

Apart from the above, it is worth noting the areas covered by the authorisation this Article grants the Union in conducting actions on Public Health:

- the fight against the major health scourges;
- promoting research into their causes, their transmission and their prevention;
- health information (incl. epidemiology) and education;
- monitoring, early warning of and combatting serious cross-border threats to health.

It should be clear from a simple reading of the above Article's wording, that such provisions, dating back to the original EC Treaty, no longer sit well with the spirit and letter of the European Union's obligations under the CRPD, particularly also in the field of autism.

11.2.2 Medicalised Language in EU Initiatives

However, the current website of the European Union's Directorate-General (DG) for Health and Food Safety simply, at present, lists 'Autistic Spectrum Disorders' under the 'Diseases' section of 'Major and Chronic Diseases' on its website for the public, simply providing a collection of outdated and broken links³ – a clear disservice, if not a violation, in terms of the CRPD concerning awareness-raising,⁴ as well as concerning access to information.⁵

Particularly, remaining areas of concern with the above initiatives are the still-present prevalence of the medical model of disability in defining and dealing with autism in such initiatives, as well as the use of preventive language such as 'epidemiology'.⁶

Furthermore, the final intended aim of data gleaned from such initiatives, and also the way in which such data will and/ or might be used, and the absence of or presence of weak or improper rules and guidelines regulating such use, is also of concern, as mentioned in Section 9.2 of this thesis.

³ Current EU Autism Information Portal available online at http://ec.europa.eu/health/major_chronic_diseases/diseases/autistic/index_en.htm.

⁴ Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, U.N. GAOR, 61st Sess., U.N. Doc. A/Res/61/106 (Dec. 13, 2006) (hereinafter 'UN CRPD'), at art. 8.

⁵ Ibid., at art. 21.

⁶ In this regard, see Footnote 112 in Section 7.4.4 concerning the discussion around the United Nations' Agenda 2030 document.

See, also, for example, Antoni Montserrat, *Some elements about the prevalence of Autism Spectrum Disorders (ASD) in the European Union*, European Commission Directorate-General Health and Consumer Protection (Directorate C – Public Health and Risk Assessment), Luxembourg, 2005, available online at http://ec.europa.eu/health/ph_information/dissemination/diseases/autism_1.pdf; *Draft Baseline Report on Neurodevelopmental disorders in the framework of the European Environment and Health Strategy*, Technical Working Group on priority diseases – subgroup neurodevelopmental disorders, COM(2003) 338 final, Brussels, 5 December 2003, archived version available online at http://web.archive.org/web/20091222090158/http://ec.europa.eu/environment/health/pdf/neurodevelopmental_disorders.pdf.

This is both within the terms of reference of these specific initiatives, as well as through a wider framework on a Union—wide level. Special attention is to be given to the Harmonised Early-Detection Tool that was being developed as part of the now-stalled European Autism Information System (EAIS).⁷

Also, the grouping together of autism and cerebral palsy, in the framework of the European network of surveillance on risk factors for autism and cerebral palsy (ENSACP) project,⁸ within said EAIS, could lead to the wrong conclusions being drawn, particularly concerning the specific nature and needs attached to autism and autistic persons.

11.2.3 Conclusion

While legislative efforts such as the Framework Directive on Employment Equality, and a European Parliament declaration on the rights of autistic persons⁹ way back in 1996 – a politically-correct watered-down version of the more extensive Autism-Europe Charter of Rights¹⁰ – as well as a multitude of initiatives in the field of autism, also described in Section 11.2.2 of this thesis, are a promising start, there remains the need to develop a coherent underlying framework covering the Union's mandate in the field of autism,

This should be in line with the reality of autism, as well as the principles embodied in the CRPD. There should be a clear shift from the medical model of disability to the social model of disability, and a shift from health-based mandates to rights-based mandates where appropriate.

For this reason, it is imperative that the European Union initiate a public dialogue, particularly with stakeholders, and involving as far as possible disability self-advocates and their organisations, while making its best efforts to include those active in the field of autism and autistic rights where these areas are being dealt with specifically.

⁷ Further details on the initiative available online at http://ec.europa.eu/health/ph_information/dissemination/diseases/docs/autism1.pdf.

⁸ Ibid.

⁹ Declaration on the rights of people with autism', adopted as a Written Declaration by the European Parliament on 9 May 1996, available online at <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=OJ:C:1996:152:FULL&from=EN>, at 87.

¹⁰ Charter of Rights, presented and adopted at the 4th Autism-Europe Congress (hereinafter Autism-Europe Charter of Rights), The Hague, 10 May 1992, available online at <http://www.autismeurope.org/files/files/charter-for-persons-with-autism.pdf>.

This exercise should lead to the necessary legislative and policy reforms being eventually launched and implemented by the European Union, in order to bring the basis of its mandate in the field of disability, and also specifically in the field of autism, as well as its subsequent legislation, policy and actions in these fields, in line with both the spirit and the letter of the CRPD, and the provisions contained therein.

An EU Autism Strategy, on the lines of those adopted by countries such as the United Kingdom and Hungary,¹¹ and which is countries like Malta¹² and Ireland¹³ have in the pipeline, is also a medium-term goal that self-advocates have been pushing for, with the process in relation to this conducted in the spirit of the principle of ‘Nothing About Us Without Us’.

This exercise was attempted through an initiative by a group of MEPs, including Maltese MEP Miriam Dalli, with whom the author is in contact, who submitted a Written Declaration to the European Parliament in April 2015, calling for a European Autism Strategy.¹⁴

¹¹ UK Department of Health, ‘Think Autism’ – National Autism Strategy 2014, all related documents available online at <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>.

¹² The Persons within the Autism Spectrum (Empowerment) Act, Cap. 557 of the Laws of Malta, mandates the Autism Advisory Council set up in terms of the Act, to draft a national autism strategy styled the ‘Autism State Support Plan’, within one year of entry into force of the Act, in virtue of art. 10(1)(a) of the Act.

¹³ A Private Member’s Bill was tabled in the Dáil Éireann by TD Michael McCarthy in 2012. Titled the Autism Bill 2012, Bill 90 of 2012, it called for the establishment and oversight of a National Autism Strategy for Ireland. However, the legislative procedure in this regard has remained stalled, not least to recent political developments in the Irish context, diverting possible efforts away from autism-related initiatives.

However, an Autism Coalition was formed in Ireland in 2016, spearheaded by self-advocacy organisation AsIAM, as well as autistic-friendly employer Specialisterne and Inclusion Ireland, who are pushing for an approach that would see autism-specific strategy being written into the Irish national disability strategy as a first step, upon which further steps could be built.

The author was informed of these developments by Adam Harris, Founder and CEO of AsIAM, in October 2016, when asked to assist the Coalition, in preparing a brief of the situation concerning law and policy in other jurisdictions, to be used in the Coalition’s lobbying efforts with authorities, with further information being obtained at a meeting with Coalition representatives attended later that month.

¹⁴ Nicola Caputo (S&D), Enrico Gasbarra (S&D), Miriam Dalli (S&D), Marian-Jean Marinescu (PPE), Ivan Jakovčić (ALDE), Renata Briano (S&D), Péter Niedermüller (S&D), Maite Pagazaurtundúa Ruiz (ALDE), Daniel Buda (PPE), Barbara Kappel (NI), Lampros Fountoulis (NI), Milan Zver (PPE), Ivo Vajgl (ALDE), Tibor Szanyi (S&D), Kostas Chrysogonos (GUE/NGL), Rosa Estaràs Ferragut (PPE), Biljana Borzan (S&D), Marek Plura (PPE), José Blanco López (S&D), Ivan Štefanec (PPE), Dubravka Šuica (PPE), Eleftherios Synadinos (NI), Demetris Papadakis (S&D), Igor Šoltes (Verts/ALE), Eduard Kukan (PPE), Eva Kaili (S&D), Momchil Nekov (S&D), Marlene Mizzi (S&D), Laurențiu Rebega (S&D), Mara Bizzotto (NI), Georgios Epitideios (NI), WRITTEN

Following on from this, Autism-Europe, together with MEP Dalli, as well as European Parliament Disability Intergroup co-chair Marek Plura and MEP Nicola Caputo, convened a conference at the Europe Parliament to further discuss the topic in August 2015.¹⁵ However, the tone of this conference was seen as medicalised by many,¹⁶ due to over-representation by medical professionals and behavioural therapy practitioners, with a focus on medical aspects and the use of behavioural therapy.

The conference was also one of the factors that inspired Autism-Europe to work towards reforming its structures, in order to be more inclusive towards self-advocates, and autistic persons in general.¹⁷

DECLARATION 0018/2015, submitted under Rule 136 of the Rules of Procedure, on autism, 27 April 2015.

¹⁵ Moving forward for the adoption of a European Strategy for Autism in Europe, European Parliament, Brussels, 29 September 2015. Further information on the conference is available through the *Conference Report*, accessed at <http://www.autismeurope.org/files/files/ep-report-website-1-1.pdf>.

¹⁶ For example, this resulted in complaints being received by Autism-Europe and by the MEPs involved, concerning both the content of the conference, as well as of the Written Declaration, as mentioned in *Conversations with Aurélie Baranger*, op. cit., as well as with self-advocates who wished to remain anonymous.

To this end, Autism-Europe drafted a response in May 2016 to the persons and organisations involved, which also stated the following:

“Regarding the EP written declaration, we fully understand your comments, we are aware that the text is not perfect. AE was consulted by MEPS drafting the document, but we had unfortunately limited time/scope for providing our feedback.

We are also aware that the text lacks nuances and that the wording is not always adequate, but please note that the length of a written declaration is subjected to a strict limit of 200 words. We also wish that some other elements, such as references to the UNCRPD, could have been inserted.

However, such a declaration is meant to give an impetus to the European commission and the member states, but it is not enforceable per se. Our objective in supporting the written declaration was to raise awareness and open way for more actions and support for autism in Europe, and the written declaration also reasserts the importance of having life-long support services for adults. However, it is a call for action, but it is not a legislative document.”

Autism-Europe then proceeds to highlight that one of its objectives is to advance the social model of disability, mentioning past position papers and awareness efforts it undertook, as well as its close cooperation with autistic persons, for example through the Congress Scientific Committee, in terms of the then-upcoming XI Autism-Europe International Congress, held in Edinburgh in September 2016, and also inviting those concerned to take part in the consultation Autism-Europe was undertaking in connection with the ASDEU project.

The email aims by affirming that:

“Enhancing the participation of self-advocates in Autism-Europe is a priority, and I hope we can initiate cooperation with all of you.”

¹⁷ See, for example, Autism-Europe’s consultations with the Autism Society of America (ASA) towards this aim, further discussed in Footnote 39 at Section 6.3.3.1 of this thesis. The topic was also raised by Autism-Europe Director Aurélie Baranger, in answering a question from the audience, following her presentation during the ‘ASDEU and EU-AIMS Research Projects: Results and Future Impact’ Panel, at the XI Autism-Europe International Congress, Edinburgh, 15 September 2016.

Further efforts were made by MEP Dalli, both to bring together all different stakeholders following this initial foray, and find more common ground as to a European Autism Strategy, as well as in lobbying the European Commission, in line with the stated aim of the initial European Parliament session.

However, the European Commission replied to MEP Dalli in early 2016, that a European Autism Strategy was not one of its priorities,¹⁸ and that it would not pursue such a strategy further, adding that it would focus instead on further implementing its Disability Strategy 2010 -2020¹⁹ – which the Commission had earlier stated that it was not considering amending or updating in any way, prior to its term of expiration.²⁰

The European Union was similarly reticent of giving further priority to disabilities, let alone autism, when refusing a request to have disabilities declared as one of the priorities of the European Council during the Maltese EU Presidency in 2017, following a formal request by the Maltese negotiators at the behest of the Parliamentary Secretariat for the Rights of Persons with Disabilities and Active Ageing.²¹

Nonetheless, both MEP Dalli, as well as the Parliamentary Secretary for the Rights of Persons with Disabilities and Active Ageing,²² are both still committed to this concept, which this thesis once again affirms would give a principal boost to autism rights within the European Union.

11.3 The DSM-5 Revisions – Perpetuating the Medical Model?

While the change might seem a brave step, the challenges it provokes are akin to a double-edged sword: traditionalists argue that the removal of established categories will lead to an exclusion of diagnoses for certain categories of previously ‘diagnosable’ individuals²³ who

¹⁸ Conversations with Aurélie Baranger, Director of Autism-Europe, Brussels, March 2016.

¹⁹ Ibid.

²⁰ As mentioned in discussions where the author was present, during a Strategic Dialogue Meeting on the EU Pillar of Social Rights, organised by the European Commission’s DG-Employment, Social Affairs and Inclusion, in Brussels on 10 December 2015.

²¹ During a meeting with Hon. Justyne Caruana, Maltese Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing, within the Ministry for the Family and Social Solidarity, Valletta, May 2016, following a similar suggestion made by the author.

²² Meeting with Hon. Justyne Caruana, Valletta, September 2016.

²³ Fred Volkmar, comment made during ‘Setting the Scene – The Background to DSM-5’ presentation

would ‘fall off the radar’, as well as exclusion of relevant services, both for them, as well as for previously-diagnosed individuals whose needs will now be assessed according to the new criteria.²⁴

On the other hand, reformers have lauded the emphasis on an autism spectrum, for the first time in such a key document in modern medical literature,²⁵ as well as the emphasis on particular aspects such as sensory issues,²⁶ however, changes have been made hastily, and the resulting arrangement is far from watertight,²⁷ and open to interpretation, attacks, and manipulation by the insurance industry.

11.3.1 Window-Dressing Gone Wrong

The main issue at stake that emerges from the DSM revisions is the continued adherence of the mainstream medical and services community to a medicalised view of autism, viewing different expressions along the autism spectrum as ‘strains’²⁸ of a ‘disease’, much as one would list different sub-types of cancer.

While the shift to an autism spectrum overview is a positive step, in asserting what autism is, who is autistic, and what rights such persons have, one has to prepare both the medical and services community, as well as the wider public – especially parents of newly-diagnosed children lacking any knowledge of autism – for this paradigm shift in perception, and what it means.

at ‘Challenging DSM-5’ international conference, organised by Aspire: Asperger Syndrome Association of Ireland, at Trinity College Dublin, 8 November, 2013.

²⁴ Ibid.

²⁵ Dena Gassner, speaking during the Panel of People on the Spectrum of Autism Town Hall Meeting, 44th National Conference of the Autism Society of America, Pittsburgh, 13 July 2013.

²⁶ Stephen Shore, comments made during the Panel of People on the Spectrum of Autism Town Hall Meeting, 44th National Conference of the Autism Society of America, Pittsburgh, 13 July 2013; Stephen Shore, comments made during ‘Perspectives and Approaches to Diagnosis’, presentation at ‘Challenging DSM-5’ Conference, op. cit.

²⁷ Gassner, op. cit.

²⁸ Shore, comments made during the Panel of People on the Spectrum of Autism Town Hall Meeting, 44th National Conference of the Autism Society of America, op. cit; Shore, comments made during ‘Perspectives and Approaches to Diagnosis’, presentation at ‘Challenging DSM-5’ Conference, op. cit.

11.3.2 *What the Neurodiversity Community wanted*

In insisting on an autism spectrum, the neurodiversity community wanted to highlight the broad continuum of characteristics that make up autism, and the different ways in which such conditions can be manifested, while remaining just different expressions of the same subject-matter.²⁹

It does not matter whether a person is non-verbal or highly articulate, whether the person exhibits multiple stereotypical/ 'challenging' behaviours or acts 'normal' – the traditional medicalised artificial divide between 'low functioning' and 'high functioning' autism³⁰ – that person still views the world in a certain way, processes things in a certain way, and responds in a certain way – the person may exhibit signs of distress/ satisfaction in their own particular way, in response to particular stressors related to issues such as environmental adaption and change, and mainly to sensory input.³¹

11.3.3 *What the DSM Committee Wanted*

The DSM committee took a 'sexy' page out of the neurodiversity community's book, and stuck it into the DSM-5 without proper (consultation and) explanation.

The emphasis before the DSM-5 was on increasing efforts in the areas of identification and 'treatment' of 'lower functioning' autism – the 'epidemic' that was not being given enough attention,³² especially when put in the same basket as 'higher functioning' autism, which, certain activists claimed, 'was not what they called autism'³³ – and who were especially irked at neurodiversity groups, who they saw as pushing a false misconception of autism, based on the perception and 'condition' of the movement's activists, who they did not see as speaking for the rest of the autism community.³⁴

²⁹ Interview with Ari Ne'eman, Founder and President – ASAN (Autistic Self-Advocacy Network), New York, May 2011.

³⁰ Ibid.

³¹ Ibid.

³² Terminology used by organisations such as Autism Speaks, and further mentioned in Section 1.1.3 of this thesis.

³³ Interview with Jean and Michael Lewis, activists and former Presidents of the Autism Society of Canada and the Autism Society of British Columbia, and co-petitioners in *Auton v. British Columbia* on behalf of their son Aaron, West Vancouver, May 2011.

³⁴ Ibid.

11.3.4 What Really Happened...

With the DSM-5, these activists got what they wanted, while the DSM Committee also tried to placate the neurodiversity movement, which had made its submissions and attended hearings, by including the autism spectrum. They just did things the wrong way – the current arrangement, though containing positive elements, is hastily pasted together and unworkable – without further efforts to reinforce the current DSM text.

While traditionalists see it as unworkable mainly because of the deletion of the Asperger Syndrome and PDD-NOS categories – and hence a step backwards³⁵ – it should be considered as a scenario, although still of concern, that leaves the window ajar for a step forward – but once the hard work of redefining the way the professional and lay community at large sees and understands autism.

The changes may have been made to strike a balance. They may have even been made in order to placate the insurance industry in the United States – as the DSM is primarily intended for US use in the first place – as some have noted.³⁶

However, this does not dim the fact that, while messy, the current DSM text provides a good window of opportunity to make changes to perception and practice regarding autism, with the right efforts in the right direction. This is where the rights of autistic persons will be served better in the long run, and this is where the legislator comes in, by drafting and enforcing legislation and policy intended towards this aim.

11.4 The Importance of Awareness: EU Awareness Frozen In Time

There have been a number of European Union-led or supported initiatives over the last years, that were also not mentioned in its Initial CRPD State Report, but which have dealt specifically with autism and the situation of autistic persons. Although a number of these

³⁵ Michael Fitzgerald, comment made during ‘DSM-5 – Implications for Professional Practice and Research’ presentation at ‘Challenging DSM-5’ international conference, op. cit.

³⁶ Stephen Shore, comment made during ‘Perspectives and Approaches to Diagnosis’, presentation at ‘Challenging DSM-5’ international conference, op. cit.

initiatives commenced before the European Union's ratification of the CRPD, they were still useful initiatives for laying the ground upon which next steps could be built.

Unfortunately, there has been no follow-up or further steps in many of these areas, leaving the current European Union position concerning autism 'frozen in time'. These initiatives could be built upon positively, should there be a paradigm shift in approach described elsewhere in this report.

The initiatives in question are listed below:

a) European Commission Reports

- i) Reference to Autism in EU Public Health Work Plans³⁷
- ii) Report on Prevalence of Autism Spectrum Disorders (ASD) in the EU³⁸
- iii) Report on ASD and environmental factors³⁹

b) Other Research Initiatives

- i) Research on discrimination against people with ASDs⁴⁰

³⁷ European Commission DG Health and Food Safety, website on Public Health – Health Programme – Key Documents, available online at http://ec.europa.eu/health/programme/key_documents/index_en.htm#anchor5.

³⁸ Antoni Montserrat, *Some elements about the prevalence of Autism Spectrum Disorders (ASD) in the European Union*, European Commission Directorate-General Health and Consumer Protection (Directorate C – Public Health and Risk Assessment), Luxembourg, 2005, available online at http://ec.europa.eu/health/ph_information/dissemination/diseases/autism_1.pdf.

³⁹ *Draft Baseline Report on Neurodevelopmental disorders in the framework of the European Environment and Health Strategy*, Technical Working Group on priority diseases – subgroup neurodevelopmental disorders, COM(2003) 338 final, Brussels, 5 December 2003, archived version available online at http://web.archive.org/web/20091222090158/http://ec.europa.eu/environment/health/pdf/neurodevelopmental_disorders.pdf.

⁴⁰ Autism-Europe, EU-wide Autism-Europe Survey into the Discrimination of Persons with Autism Spectrum Disorders (ASD) in the context of Education and Health, archived version of questionnaires available online at <http://web.archive.org/web/20090803115952/http://www.autismeurope.org/portal/Default.aspx?tabid=480>.

- ii) The European Autism Information System (EAIS),⁴¹ aiming to rectify Unreliable/ Inconsistent Information, focus on the Need for Early and Intensive Education, and develop an Information System, through Development of a European Autism Alliance (EAA), conducting a study on Characteristics of ASDs in Europe, Implementation of a pilot study, a Harmonised early-detection tool, and the European network of surveillance on risk factors for autism and cerebral palsy (ENSACP) project

All of these initiatives would fall within the European Union's CRPD obligations in terms of statistics and data collection⁴² and national implementation and monitoring,⁴³ while covering principally the provisions addressing awareness-raising,⁴⁴ equality and non-discrimination,⁴⁵ education⁴⁶ and health,⁴⁷ as well as the specific categories of persons covered by the provisions on women with disabilities⁴⁸ and children with disabilities.⁴⁹

While commending the number of initiatives undertaken, and the positive outcomes or potential for such outcomes that emanate from such initiatives, one should once again insist on mindfulness being retained at all times of the fact that all of the above initiatives can act as a double-edged sword, in the same way, but not always to the same extent, as with the genetic research initiative described in the previous section.

11.5 *Beyond Medicalisation?*

11.5.1 *The United States and Canada*

The United States, the first country in the world to pass autism-specific legislation, termed its first contribution in this regard the Combating Autism Act.⁵⁰ As would be already

⁴¹ Further details on the initiative available online at http://ec.europa.eu/health/ph_information/dissemination/diseases/docs/autism1.pdf.

⁴² UN CRPD, at art. 31.

⁴³ Ibid., at art. 33.

⁴⁴ Ibid., at art. 8.

⁴⁵ Ibid., at art. 5.

⁴⁶ Ibid., at art. 24.

⁴⁷ Ibid., at art. 25.

⁴⁸ Ibid., at art. 6.

⁴⁹ Ibid., at art. 7.

⁵⁰ Pub. Law No. 109-416.

evident from the Act's title, the main concerns regarding this legislation were that it was too rooted in medical model of disability, or else in a 'pro-cure' approach.

In line with the stated aim of the title of the legislation, the Act aimed to keep epidemiological studies overseen by the US Centre for Disease Control (CDC) up to date,⁵¹ in line with concerns raised by the apparent increase in autistic births reflected in the latest CDC statistics on autism.⁵² Such legislation had a ring of populism to it since, as has been discussed, such an increase is due less to genetics than it is to proper advances in medical science, and consequentially a rapid increase in autism diagnoses, across the whole of the autism spectrum.⁵³

Self-advocates in particular pushed for a number of changes, when the Act came up for re-authorisation in 2011. Although the re-authorisation was a far cry from what was on the wish-list of groups such as ASAN, tackled in Section 6.3.3.2, and similar autistic rights advocates, further advocacy on their part seemed to slowly start turning the tide.

This was not least in the outward makeover of the second re-authorisation of the Act, which now bore a different title without the same medical ring to it, that of the 'Autism CARES (Collaboration, Accountability, Research, Education and Support) Act'.⁵⁴ However, substantively, a number of new additions were made to the Act, in view of such lobbying, such as in the fields of employment opportunities,⁵⁵ and of transitioning for young adults.⁵⁶

⁵¹ Section 3 of the Act amended Title III of the Public Health Service Act (42 U.S.C. 241 et seq.), in order to include the requirement to report data to the US Center for Disease Control and Prevention (CDC), as part of a Surveillance and Research Programme with regard to Autism.

⁵² As per statistics reflected in, for example, Melody Stevens, Anita Washington, Catherine Rice, Walter Jenner, Jennifer Ottolino, Kristen Clancy and Julia Whitney, *Prevalence of the Autism Spectrum Disorders (ASDs) in Multiple Areas of the United States, 2000 and 2002*, Community Report from the Autism and Developmental Disabilities Monitoring (ADDM) Network, Centers for Disease Control and Prevention (CDC), US Department of Health and Human Services, accessed at <http://www.cdc.gov/ncbddd/autism/documents/autismcommunityreport.pdf>.

⁵³ Gassner, op. cit.

⁵⁴ Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2014 or Autism CARES Act of 2014, H.R. 4631, Pub.L. 113–157.

⁵⁵ Ibid., at 6(b)(2)(D)(ii).

⁵⁶ Ibid., at 6(b)(2)(C)(ii), (iii).

This ushered in a tone similar to that of more neutrally-labelled legislation in the United Kingdom and upcoming legislation in Ireland,⁵⁷ although the content of all three instruments is or will be markedly different at this point in time.

This contrasted with the situation north of the border, in that the Canadian Parliament has been so far reticent to pass legislation with respect to autism, other than an Act calling for World Autism Awareness Day to be respected.⁵⁸

However, this Act can be seen as nothing more than lip-service to a concept which is neither much understood yet in Canada, nor linked to any concerted strategy as to how to translate such awareness into something effective. Efforts at specific autism legislation, as well as legislation attempting to enact a national autism strategy, have all fallen flat on their faces,⁵⁹ with the perennial struggle remaining centred around ABA/ IBI state funding, in the vein of *Auton* and successor litigation such as *Ward*.

11.5.2 Northern Ireland: A Novel Approach

Following on the heels of the 2009 Autism Act applicable to England, Northern Ireland was the second jurisdiction within the United Kingdom to pass autism-specific legislation in 2011.⁶⁰

At a first glance, the Act seems to be a collection of non-justiciable strategy and policy priorities, much in the same vein as with the Act covering England, only that such priorities are stated to also apply to children. While the Act similarly mandates the creation of an autism strategy for Northern Ireland⁶¹ - even if the setting up of the office of Autism Commissioner envisaged in the Bill did not materialise in the final Act, due to financial

⁵⁷ The Autism Act 2009, c.15, covers autism policy in England, while the Autism Act (Northern Ireland) 2011, c. 27 serves the same aim in that territory, and the Autism (Scotland) Bill 2010, SP-44, was tabled before the Scottish Parliament in 2010.

In Ireland, Bill No. 90 of 2012 is titled the Autism Bill.

⁵⁸ S-210: An Act respecting World Autism Awareness Day, op. cit.

⁵⁹ The main legislative efforts, introduced and re-introduced in successive Canadian legislatures, have been Bill C-304: An Act to provide for a National Strategy for the Treatment of Autism and to amend the Canada Health Act, and; Bill C-218: An Act to Amend the Canada Health Act (Autism Spectrum Disorder).

⁶⁰ Autism Act (Northern Ireland) 2011, c. 27.

⁶¹ Ibid., at 2.

considerations⁶² - the Bill⁶³ in virtue of which the Act came into force did also bring in a novel, and also justiciable approach, from a rights perspective.

The Bill also proposed amendments to the UK Disability Discrimination Act (DDA) of 1995, as applicable to Northern Ireland, which were subsequently carried. These amendments added a third category to the existing categories of physical and mental disabilities under the original Act,⁶⁴ making Northern Ireland only the second jurisdiction in the world, after Israel,⁶⁵ to recognise the category of social disabilities in its law.

This consequently also allowed for justiciable disability claims to be brought on the basis of such newly-amended legislation. Having such category, although also a form of labelling, albeit necessary, can make it easier for plaintiffs to assert their rights to supports and services, as well as reasonable accommodations, by being able to quote a more specific provision of law.

This can similarly be used to couch more specific disability discrimination claims. While beneficial to plaintiffs seeking relief, it will likewise serve to guide courts and tribunals more specifically in their work. It also ensures further CRPD compliance for the United Kingdom in respect of Northern Ireland, not least in terms of provisions relating to equality and non-discrimination,⁶⁶ as well as provision of reasonable accommodation.⁶⁷

⁶² This office was proposed in the All-Party Group on Autism of the Northern Ireland Legislative Assembly, but the relevant provision did not make the final Autism Bill (Northern Ireland) of 2010, Bill 2/10, due to financial considerations raised during the ensuing debate in the Group, as reported on the Assembly's website at <http://www.niassembly.gov.uk/visit-and-learning/autism-and-the-assembly/autism-legislation/autism-bill-as-introduced-explanatory-and-financial-memorandum/>.

⁶³ Autism Bill (Northern Ireland), *op. cit.*

⁶⁴ The ensuing Autism Act (Northern Ireland) amended paragraph 4(1) of Schedule 1 of the DDA as applicable to Northern Ireland, which lists the qualifying impairments in terms of the Act, adding the following 2 categories:

- (i) taking part in normal social interaction; or
- (j) forming social relationships

Thus, the less-than-elegantly worded, but nonetheless functional concept of social impairments was brought within the justiciability of the DDA as applicable to Northern Ireland, as laid out in the Explanatory Memorandum to the Bill.

⁶⁵ The Israeli National Insurance Law of 1968, as subsequently amended, specifies a category of 'special impairments' in its Definitions, within which autistic children qualify as of being 91 days of age or older. Autism was included in this category following a concerted grassroots lobbying effort of legislators, further described in Section 12.3.2 of this thesis.

⁶⁶ UN CRPD, art. 5.

⁶⁷ UN CRPD, arts. 5(3), 14(2), 24(2)(c), 24(5).

Such a provision could also be one of the aspects considered by the Autism Coalition in Ireland, which is pushing for further strategy and possible legislation there, as mentioned earlier in Section 11.2.3, with the experience of the North able to be applied south of Newry, possibly in terms of current North-South consultation and cooperation mechanisms.

11.5.3 Malta: Awareness versus Acceptance

Perhaps the most ground-breaking point made so far by Malta's autism law is that which ensued from the proposal made by self-advocates in terms of the article of the Persons within the Autism Spectrum (Empowerment) Bill which spoke of working to increase autism awareness.⁶⁸

Self-advocates argued, in this regard, that these initiatives should raise autism acceptance, not merely awareness.⁶⁹

The proposal was taken on board by Government, and an amendment mandating also 'autism acceptance within society' introduced to the Bill at Committee stage, such amendment being carried unanimously.⁷⁰

This followed an emotional speech by Parliamentary Secretary for the Rights of Persons with Disability Justyne Caruana, during the first session of the Second Reading debates on the Bill at the Parliament plenum, a few hours after such amendment had been proposed to Government, whereby she outlined such concept and exhorted Parliament to take it on board.⁷¹ This was the final result, as Parliament adopted the final text of the Bill unanimously at the Bill's Third Reading.

The Maltese government's stated rationale behind and commitment towards this principle was also raised two months later at the United Nations. Here, during the side-event on

⁶⁸ Persons within the Autism Spectrum (Empowerment) Bill, art. 10(1)(h).

⁶⁹ The author drafted and also passed on, after requesting such from a number of self-advocates active in different jurisdictions, a number of proposals concerning such Bill, to the Hon. Justyne Caruana, Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing, within the Ministry for the Family and Social Solidarity, after having secured a meeting with her in April 2016.

⁷⁰ The amendment is reflected in the final text of the Persons within the Autism Spectrum (Empowerment) Act, at art. 10(1)(h).

⁷¹ Justyne Caruana, Minutes of Parliamentary Debates, Second Reading Debates, Persons within the Autism Spectrum (Empowerment) Bill, Bill No. 136 of 2015, 4 April 2016.

autism chaired by Malta at 9th Conference of States Parties to the UN CRPD (COSP), the Parliamentary Secretary emphasised the belief that being on the Autism Spectrum is, in the end, one of the many neurological expressions of human diversity.

Here, the Government sought to put its stated policy into practice, by being responsible for a ‘world first,’ the first time where, at an international forum, a UN member state government has hosted a panel about autism, where each and every single invited panellist was on the autism spectrum.⁷²

The Parliamentary Secretary further added that, as with every diverse element in life, there are challenges and there are strong positive characteristics associated with such. However, autism was still, in Malta, being viewed as a childhood malady, a tragedy befalling families, a phenomenon to be viewed simply from a deficit model, without looking at the very core of the matter – that here, we were also talking about human beings.⁷³

It was for this reason that Malta not only mandated necessary autism awareness within its law, but also went further and mandated autism acceptance, for the very reasons just stated.

In this regard, during the Second Reading debates leading up to the adoption of Malta’s autism law by Parliament, speakers from both sides of the House expressed these sentiments.

Tying in with the Parliamentary Secretary’s comments, Opposition MP Claudio Grech quoted a recent article from *The Economist*, stating that we run the risk of letting Beautiful Minds go wasted if we ignored autistic persons. He mentioned that dealing with the

⁷² Government of Malta and Autistic Self-Advocacy Network (ASAN), ‘Building an Inclusive Rights Agenda for Autistic Adults’, Side-Event hosted by the Government of Malta at the 9th Conference of States Parties to the United Nations Convention on the Rights of Persons with Disabilities (COSP 9), United Nations General Assembly Building, 15 June 2016, as also reported in a Press Release issued by the Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing, PR161396, Department of Information, Valletta, 17 June 2016.

⁷³ As also cited in ‘Building an Inclusive Rights Agenda for Autistic Adults: COSP9 side event held by the Government of Malta in collaboration with Autistic Self-Advocacy Network’, Press Release Issued by the Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing, op. cit.

challenges that autism presents is important, the teaching of necessary skills and self-care, to persons who view the world in a different manner, coming to mind as a first point.⁷⁴

In her winding up of the Second Reading debates, the Parliamentary Secretary acknowledged the Hon. Grech's comments, adding that although the Maltese law deals with this matter, it also deals with strengths – with empowerment – with awareness, but also with acceptance.⁷⁵

⁷⁴ See Minutes of Parliamentary Debates, Second Reading Debates, Persons within the Autism Spectrum (Empowerment) Bill, Bill No. 136 of 2015, 26 April 2016.

⁷⁵ Ibid.

PART IV: CONCLUSION

Chapter 12: Conclusions & Recommendations

12.1 Introduction

Following the analyses in the previous Chapters as to possible rights breaches as applicable to autistic persons as a group, this thesis will now proceed to testing such instances of breaches against the criteria for genocide, in terms of the way the concept was outlined in Chapters 7 and 8, and using the methodology described in the Introduction to Chapter 9.

This will be done in light of the blueprint laid out in earlier Chapters, identifying autistic persons as a distinct social group, the rights breaches in respect of whom stem from jaded societal perceptions as to this group. As argued earlier in this thesis, this happening in the same manner as did rights breaches in the case of other social groups, and stemming from the lack of or incomplete shift towards a journey leading to acceptance and inclusion.

The thesis shall first carry out such an analysis, as to the main themes discussed in Chapters 9, 10 and 11, with reference also to similar underlying themes spread throughout the thesis. It will then proceed, after having taken stock of the overarching resulting picture, to discuss possible ways of breaking the deadlock that has led and is still leading to such breaches, some of which fall within the realm of genocidal crimes.

This will be done by identifying and discussing the main problems causing such, as well as discussing methods, by also referring to real-life examples, in which such deadlock can be broken. It will also outline possibilities as to a structure being put in place, to bring all stakeholders around the table, in order to implement a scenario in which all such stakeholders move towards acceptance and inclusion.

This would have the final goal of resulting in an emancipation in autism rights, that would move further towards a model in which all partners are equal partners in achieving autistic justice.

12.2 Possible Genocidal Nature of Actions and Omissions

12.2.1 The Pre-Natal Sphere – Prevention and Termination

As to the rights breaches discussed in Chapter 9, the following elements of Article 2 of the Genocide Convention could be said to be recurring themes:

Article 2(a) – Killing members of the group: This criterion would be fulfilled, depending on the stance one takes on abortion, or on the legal stance outlined in the legislation of particular jurisdictions.¹ This would be the case, both in cases of termination of pregnancy following pre-natal determination of a disability, in the specific instance autism, as well as when refusing to implant embryos identified as carrying, or at risk of carrying characteristics linked to a disability, in the specific instance autism.

Article 2(d) – Imposing measures intended to prevent births within the group: This criterion would be fulfilled, when specifically referring to initiatives outlining ‘risk factors’ for possible live births with autism, and legal labelling of such in abortion laws. This would also be the case, in the case of offering of methods for pre-natal screening of such, and of opportunities of terminating a pregnancy or not proceeding with embryonic implantation in such cases, both in law and in practice.

Within such measures, there also fall initiatives of spreading a medicalised and ‘broken’ image of autistic persons, as well as relevant campaigns with the aim of fostering awareness and knowledge of how to prevent and reduce such incidences, as well as creating a climate of fear in the medical world around this topic.

As to elements Article 3 in these instances, one could point to the following:

¹ For example, Ireland, where the Eight Amendment to the Constitution amended Article 40 to include the provision, in Article 40 (3) 3°, to the effect that “[t]he State acknowledges the right to life of the unborn and [...] guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate that right[.]” and; Malta, which in Sub-title VII: Of Abortion, Of the Administration or Supplying of Substances Poisonous or Injurious to Health, and of the Spreading of Disease of its Criminal Code, Cap. 9 of the Laws of Malta, although not enunciating a right to life of the unborn foetus in explicit terms as the Irish Constitution does, still criminalises the actions of “[w]hosoever, by any food, drink, medicine, or by violence, or by any other means whatsoever,” causes the miscarriage of “any woman with child,” whether such miscarriage is procured by the woman herself, or by a third party.

Article 3(a) – Genocide: This criterion would be fulfilled in terms of Article 2(a), should one consider the pre-natal termination or non-continuation of possible life as tantamount to killing, since both the *actus reus* and *mens rea* would be fulfilled. As to Article 2(b), this criterion would be fulfilled, due to the prevailing status quo allowing for termination of pregnancies or non-implantation of embryos, in the case of detection of disabilities, as well as related promotion of options and facilities in this regard.

However, in the case of autism, the facilities available for such screening, as outlined in Section 9.2 of this thesis, are still very rudimentary in the few places where they are available. Therefore, notwithstanding the nature of legislation currently in place allowing for termination or non-implantation in the case of disabilities, as well as notwithstanding the availability of awareness and facilities that could lead to such termination and non-implantation, the fact currently remains that it is still scientifically near-impossible to screen for autism pre-natally.

And although such facilities are available in a limited number of places, as discussed, the minimal footprint of such facilities in terms of geographical reach and possible volume of terminations or non-implantation, does not warrant a conclusion of Article 3(a) being currently satisfied, specifically in terms of autism.

However, a continued push towards researching the genetic aetiology of autism, together with the existence of relevant facilities that one could adapt to also screen for autism should relevant discoveries be made, and the existence of relevant legislation, all lay the ground for this conclusion to be overturned, in case of such discoveries being made. This is in line with the situation prevalent with other disabilities such as Down's Syndrome, as discussed in Section 9.3.1 of this thesis.

Article 3(b) – Conspiracy to commit genocide: This criterion would be fulfilled in the case of autism, in line of the argumentation as to Article 3(a), this being the case through the relevant initiatives described, aiming to take the relevant actions under the said two categories further, for example, through the efforts such as the Autism Genome Project, and similar initiatives discussed.

Article 3(c) – Direct and public incitement to commit genocide: In line with the discussion concerning Article 3(a), one could not say that the specific intent as to the necessary *mens rea* would be fulfilled in this regard, since there is not, as yet, a mainstream scientific test yet available to pre-natally screen for autism.

However, the *actus reus* of direct and public incitement is being carried out, such as through awareness campaigns aimed at prevention and reduction of disabilities, as well as through autism-specific awareness and information campaigns that put forward incorrect information or lack information.

This is equally being carried out through the spreading and perpetuating of a climate of fear, through the use of preventive or derogatory language, such as references to the ‘autism epidemic’. Such instances of ‘awareness’ gone wrong could easily also fulfil the specific intent required for the *mens rea* in such instances, should a mainstream pre-natal screening method be devised for autism, and the tone of such campaigns becomes more specific.

Article 3(d) – Attempt to commit genocide: This criterion would be fulfilled through the concerted and repeated efforts of states and supranational bodies towards implementing the stated aims of the initiatives discussed when tackling Article 3(a).

Even if the aetiology of autism has not yet been specifically established, and even if a mainstream scientific test for pre-natal detection of autism is not yet available, the efforts of such states and supranational bodies in pushing towards such, which one could describe as a case of ‘we can’t get it right yet’, definitely fulfil the specific intent criterion required for *mens rea*, aside from also fulfilling the *actus reus* criterion.

Article 3(e) – Complicity in genocide: This criterion would not be fulfilled specifically as to autism, in line of the discussion concerning Article 3(a), due to the absence, as yet, of a mainstream scientific pre-natal screening method for autism.

However, should the current status quo described when discussing Article 3(a) persist, in the case of such test being placed into the mainstream, then persistence in relevant actions by states and supranational bodies would fulfil the necessary *actus reus* towards such complicity, and the drive towards prevention of autism the necessary *mens rea* towards

such. The *actus reus* criterion would be further fulfilled should one equate resulting termination of pregnancies or non-implantation of embryos with killing.

In all such cases, such criterion would be fulfilled both in a horizontal manner, through both supranational and bilateral state action, as well as in a vertical manner, through states acting in collusion with other entities, or by allowing actions or omissions by non-state actors within their jurisdiction.

12.2.2 The Post-Natal Sphere – Cure, Remission or Normalisation

12.2.2.1 Researching an Aetiology/ Cure

As to research, should such have the stated aim of eventual prevention of autism, or termination of pregnancy or non-implantation of embryos in terms of pre-natal screening developed in terms of such, then such research would lead to the rights breaches, and possible genocidal crimes, discussed in Section 12.2.1 above.

Should such research have the stated aim of finding a cure, then such research would lead to the rights breaches, and possible genocidal crimes, discussed in Sections 12.2.2.3 and 12.2.2.4 below.

12.2.2.2 Euthanasia

As to possible instances of euthanasia in the case of autism, as outlined in Section 10.3, the criteria for Article 2(a), as to physically killing members of the group, as well as 2(c), as to deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part, would be fulfilled. However, there have not been any documented cases of such happening yet in the case of autism, in jurisdictions allowing such procedure for either children or adults.

Therefore, none of the criteria concerning Article 3 would be applicable in this instance with regard to autism, although Article 3(a), and possibly other sub-articles, depending on whether a ‘campaign’ to this effect were to be launched, could become applicable in the relevant scenario. At this point, this thesis simply wants to point this area out as a possible

area of concern, to be followed appropriately in order to prevent possible rights breaches for autistic persons as a group.

12.2.2.3 'Curative' Therapies

As to the rights breaches discussed in Section 10.4.2, the following elements of Article 2 of the Genocide Convention could be said to be recurring themes:

Article 2(a) – Killing members of the group: This criterion cannot be said to be fulfilled in this regard, because although deaths have resulted from the administration or maladministration of certain 'curative' protocols, such as packing and administration of bleach enemas, neither the necessary *actus reus* nor the necessary *mens rea* would not subsist.

Criteria for the necessary *actus reus* would not be fulfilled, due to the limited number of reported cases, with regard to the total autistic population, and the total number of publicised deaths from such procedures. The *mens rea* would not be fulfilled, since there was no specific intent to kill said persons through such procedures, but rather the specific intent was to 'cure' them, with the deaths an unwanted consequence of said procedures.

Article 2(b) – Causing serious bodily or mental harm to members of the group: This criterion could be said to be fulfilled in the cases under discussion. As was described earlier in Sections 1.1.3 and 3.3 of this thesis, there exists a disagreement between certain 'pro-cure' activists and other activists, including most self-advocates, as to what constitutes rights and breach of rights.

However, while one might opine that the aim of persons administering such 'curative' therapies to patients, especially if such patients are below the age of consent, or cannot otherwise exercise a right to consent, due to legal or functional matters, does not have the specific intent of causing serious harm to said patients, the term 'serious harm' is open to definition in such cases.

While a parent, for example, may consider a bleach enema to be a positive, curative intervention, an autistic self-advocate, or even a medical doctor, would probably consider such to be an abusive instance of 'serious harm'.

Thus, in light of the overwhelming consensus that a ‘curative’ therapy is a way of causing serious harm, and in light of the overwhelming amount available within the mainstream in this regard pointing to such, then the element of specific intent required for *mens rea* in this regard would subsist, since the person applying such therapy, or giving the instruction or consent for it to go ahead, would have the specific intent of applying such therapy, and hence such serious harm to the patient.

This would be coupled with the *actus reus* of the actual administration of the therapy itself. As to the specific elements of the serious harm in question, these would be due to the psychological abuse and scars carried by the patients, in the shorter and longer terms, as well as possible physical effects and scars resulting from such ‘treatments’, such as possible complications resulting from administration or maladministration of HBOT, or through the administration of nutritional or chemical supplements.

Article 2(c) – Deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part: This criterion would be fulfilled, since the specific aim of administering ‘curative’ therapies is to cure autism, whatever one’s view about autism would be, even if there is no specific intent on the part of the persons administering or giving instructions for said therapies to be administered, as to the elimination of the autistic person’s personhood and/ or identity through such attempt at a cure.

Thus, such intent fulfils the element of specific intent required for *mens rea*, with the actual administration of said ‘curative’ therapies fulfilling the *actus reus* requirement in this regard.

As to elements Article 3 in these instances, one could point to the following:

Article 3(a) – Genocide: While the specific intent for genocide is present in terms of the Article 2(b) and 2(c) criteria discussed, the scale and intensity of the use of such ‘curative’ therapies does not fulfil the requirements of a concerted, wholesale effort that could be termed as genocide in respect to autistic persons as a group.

This is due to the fact that these are ‘fringe’ therapies, with only limited application, and widely discredited not only by autistic self-advocates and disability rights advocates in

general, but also by staunch ‘pro-cure’ groups as well as by the mainstream medical community.

Article 3(b) – Conspiracy to commit genocide: The facts that such methods are neither widely offered, supported or publicised by different states or supranational bodies, due to the reasons outlined in discussing Article 3(a), provide for neither the *actus reus* to be fulfilled, nor the specific intent required for *mens rea*.

However, specific states such as Thailand, where the use of HBOT is widespread as a touted ‘cure’ for autism, and also widely supported and publicised, would mean fulfilment of both the *actus reus*, as well as the specific intent necessary for *mens rea*, in such states. States failing to speak up in this regard would likewise fulfil these criteria.

Article 3(c) – Direct and public incitement to commit genocide: This criterion would not be applicable in such cases, for the same reasons outlined when discussing Article 3(b).

However, it would be applicable in the case of certain states offering, promoting or supporting certain ‘curative’ therapies, as with the case of Thailand outlined when discussing Article 3(b).

Article 3(d) – Attempt to commit genocide: This criterion would similarly not be applicable in such cases, for the same reasons outlined when discussing Articles 3(b) and 3(c), although it would similarly be applicable in the case of certain states offering, promoting or supporting certain ‘curative’ therapies, as similarly discussed therein. One could argue that this would be a case of such state not being able to ‘get it right yet’.

Article 3(e) – Complicity in genocide: This criterion would similarly not be applicable in such cases, for the same reasons outlined when discussing Articles 3(b), 3(c) and 3(d).

It would similarly be applicable in the case of certain states or supranational bodies offering, promoting or supporting certain ‘curative’ therapies, as similarly discussed therein, in which case such complicity could be both horizontal, in the case of supranational bodies being involved, or of bilateral state cooperation, as well as vertical, where a state

acts in collusion, or by allowing actions or omissions by non-state actors within its jurisdiction.

12.2.2.4 Certain Applications of Behavioural Therapies

As to the rights breaches discussed in Section 10.4.1, the following elements of Article 2 of the Genocide Convention could be said to be recurring themes:

Article 2(b) – Causing serious bodily or mental harm to members of the group: The same criteria as for ‘curative’ therapies would make this criterion applicable, in terms of the definition of ‘serious harm’ resulting from particular applications and intentions of outcomes for the therapies under discussion. The discussion as to ‘serious harm’ in this specific area emanates from the discussions as to the right to therapy and the wider rights picture, conducted at Sections 1.1 and 3.3 of this thesis.

As to the specific elements of ‘serious harm’, in this regard these would be overwhelmingly the psychological abuse and scars, in both the short and longer terms, as outlined in discussions in Sections 2.4.1 and 3.3.2 of this thesis, as well as possible physical scars resulting from restraints, seclusion and the use of therapies incorporating elements such as electric shocks, as further discussed in Section 2.4.1 of this thesis.

Article 2(b) – Deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part: This criterion is fulfilled in this regard, for the same reasons it was fulfilled when discussing ‘curative’ therapies, the necessary specific intent for the *mens rea* in this case being fulfilled through the intent to normalise patients or make them indistinguishable from their peers, as opposed to the intent to seeking an overt cure when discussing ‘curative’ therapies.

As with the discussion about the latter therapies, the reason for seeking such normalisation or indistinguishability is irrelevant to this analysis, since it, in itself, fulfils the specific *mens rea* for such criterion, with the application of said behavioural therapies, according to a specific protocol, and with the relevant specific desired outcomes, constituting the necessary *actus reus*.

Article 2(d) – Imposing measures intended to prevent births within the group: This criterion can be considered in terms of possible sterilisation of autistic persons, when discussing abuse of such persons.

However, there is no data available to suggest that such sterilisations are routinely applied to autistic persons, or that such are being applied with a particular intensity or concerted effort.

Thus, neither the necessary *actus reus* nor the necessary *mens rea* are fulfilled in this regard, although it is important to highlight the possibility of rights breaches of autistic persons happening when such procedure is still available and the possibility of its application exists, and to address such rights concern accordingly.

As to elements Article 3 in these instances, one could point to the following:

Article 3(a) – Genocide: While the specific intent for genocide is present in terms of the Article 2(b) and 2(c) criteria discussed, the scale and intensity of the use of such behavioural therapies, in the manner and for the outcomes discussed, does tally in terms of concern with both a widespread effort, as well as an intense and concerted effort, in different jurisdictions, and also with the backing of supranational institutions.

While certain organs of such institutions, such as the UN Special Rapporteur on Disability Rights, have rejected such an approach, others, such as the World Health Organisation, still embrace such an approach. And while the policy in certain countries like Malta, is to move away from such an approach, certain world players such as the United States still look towards this approach, and gear policy in this direction.

For these reasons, one can say, in comparison with the analysis made with regard to rape when such reaches alarming levels, as discussed in Section 7.4.2 of this thesis, that the necessary specific intent required for the *mens rea* is thus present in this regard, as is the *actus reus* through the continued application of such therapies, in the specified form, and for the goal of the specified outcomes.

Article 3(b) – Conspiracy to commit genocide: The fact that such methods are widely offered, supported and publicised by different states and supranational bodies, due to the

reasons outlined in discussing Article 3(a), provide for both the *actus reus* to be fulfilled, as well as the specific intent required for *mens rea*.

This is furthered through both overt support, as well as through silence when such events are unfolding, and such conspiracy is applicable in both a horizontal and a vertical manner.

Article 3(c) – Direct and public incitement to commit genocide: This criterion would be applicable in such cases, for the same reasons outlined when discussing Article 3(b). This is due to states and supranational institutions offering, promoting or supporting such applications of the therapies under discussion.

Once again, this is furthered through both overt support, as well as through silence when such events are unfolding. It is equally furthered through withholding support or availability of positive and non-harmful therapies, and access to information, or otherwise promoting or allowing for promotion of the image that children ‘fixed’ in a certain way are the only ‘good’ kids, and that anything not in line with this is ‘bad and evil’.

Article 3(d) – Attempt to commit genocide: This criterion would similarly be applicable in such cases, for the same reasons outlined when discussing Articles 3(b) and 3(c), due to states and supranational bodies offering, promoting or supporting such applications of the therapies under discussion.

One could argue that in this case, attempts are a case of the state or supranational body ‘not being able to get it right yet’.

Article 3(e) – Complicity in genocide: This criterion would similarly be applicable in such cases, for the same reasons outlined when discussing Articles 3(b), 3(c) and 3(d).

This would again be applicable due to states or supranational bodies offering, promoting or supporting such applications of the therapies under discussion, as similarly discussed therein, in which case such complicity could be both horizontal and vertical, for the same reasons outlined when discussing the applicability of this sub-article in relation to ‘curative’ therapies.

12.2.3 *The Word on the Street – Awareness or Acceptance?*

As to the rights breaches discussed in Chapter 11, as well as also, in this instance, the wider discussion running through the thesis as to the nature, and to the provision or otherwise, of awareness and information relating to autism, the following elements of Article 2 of the Genocide Convention could be said to be recurring themes:

Article 2(a) – Killing members of the group: Wholesale murder of autistic persons, as a result of the state of awareness and the information being diffused, is not a phenomenon recorded in any jurisdiction as yet, although it has contributed towards the killing of certain autistic persons by their caregivers, such as in the United States, as mentioned in Footnote 10 in Section 9.2 of this thesis.

Hence, neither the necessary *actus reus*, nor the necessary *mens rea*, are present in this regard.

Article 2(b) – Causing serious bodily or mental harm to members of the group: This criterion is fulfilled in a two-fold manner.

First of all, it is caused by the psychological effects on autistic persons of information and awareness campaigns, particularly those containing preventive or derogatory language, supranationally and in a number of jurisdictions. Lack of information and awareness is considered to be equally damaging, as also earlier discussed.

It is equally caused by the resulting discrimination against them that ensues, also criticised by the UN Special Rapporteur for the Rights of Persons with Disabilities as mentioned in Section 11.1 of this thesis.

While the relevant acts or omissions constitute the *actus reus*, the specific intent necessary for the *mens rea* is derived from the definition of ‘serious harm’, as outlined when discussing ‘curative’ therapies and certain applications of behavioural therapies in the previous sections.

The *actus reus* in question has led to anger and hurt on the part of many autistic persons, resulting in exclusion from society and from collaborative rights enforcement processes,

as described elsewhere in this thesis, such as in Section 3.3 and further on in these Conclusions.

The fulfilment of this criterion is equally due to turning societal attitudes against autistic persons, or maintaining the status quo, in line with the theme of perception running throughout this thesis. This instead of fostering understanding and correct awareness, that would build towards societal acceptance and inclusion. Once again, the same reasoning is being applied in terms of existence of both the *actus reus* as well as the *mens rea* necessary.

Article 2(c) – Deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part: This criterion is fulfilled by an overall maintenance of the status quo as to the situations described as fulfilling the criterion of Article 2(b), with shifts towards acceptance and inclusion being slow, and only few and far between in a number of jurisdictions.

This constitutes the *actus reus*, while the specific intent required for the *mens rea* is fulfilled by persisting in a course of action or inaction. This could either be not taking action due to the belief that matters are good, believing that a seriously harmful ‘course of inaction’ is good. Otherwise, it is fulfilled by persisting in courses of action fuelled by the perception that the course being charted, even though such is a harmful course of action, is right, hence the specific intent for carrying out such actions.

As to elements Article 3 in these instances, one could point to the following:

Article 3(a) – Genocide: Although exceptions to the rule have been noted in this regard, on the part of both organs of certain supranational bodies, as well as on the part of certain states, concerted efforts towards devising, allowing and promoting information and awareness campaigns that use preventive and derogatory language are still the order of the day, supranationally and in many states.

This is coupled with inaction towards any awareness or information dissemination, actions and omissions being on a concerted and intense scale. This is due to the fact that, many times, this is the result of relevant stakeholders not consulting the autistic community in order to obtain a correct picture of autism, or simply due to inaction by different states or supranational bodies, as well as their relevant organs, many a time.

Even when taking into account efforts, although as yet sporadic, undertaken by different jurisdictions towards shifting perspectives, even minor ‘cosmetic’ ones such as the change of title of the United States’ autism-specific federal legislation, the overall scenario remains unchanged.

Thus, the criterion of *actus reus* could be said to be satisfied in this regard, with the seriously harmful courses of action or inaction being taken by states and supranational bodies fulfilling the specific intent necessary in the *mens rea* component.

Article 3(b) – Conspiracy to commit genocide: In line with the comments about Article 3(a), this criterion would also subsist.

One could mention efforts such as researching a cure, and states or supranational bodies supporting or being silent about groups pushing a cure operating within their jurisdiction, as instances contributing towards the necessary *actus reus*, with the specific intent required for the *mens rea* being present as per the discussion with respect to Article 3(a).

This would make such states or supranational bodies part of said conspiracy, by acting in a vertical manner. While stating this, one must never discount the possibility of the tide turning, and an eventual shift towards acceptance and inclusion instead.

One could point to certain events such as the recent decision by Autism Speaks, the largest global player in the ‘pro-cure’ camp, to drop finding a cure for autism from the organisation’s stated aims within its statutes, as mentioned in Section 6.3.3.1 of this thesis. However, such changes remain slow and sporadic, and the overall picture remains unchanged for the time being.

Article 3(c) – Direct and public incitement to commit genocide: This criterion is fulfilled through the actions of such states and supranational bodies in promoting hateful or misleading language, as discussed earlier, or promoting or allowing for the promotion of societal standards as to how children are broken or otherwise, and what it would take for them to be fixed, as discussed in Section 12.2.2.4 above.

Such actions would constitute the necessary *actus reus*, while the specific intent required for the *mens rea* would be fulfilled, as per the discussion with respect to Article 3(a).

Article 3(d) – Attempt to commit genocide: This criterion would be applicable, in terms of the discussions with respect to Articles 3(a), 3(b) and 3(c), with necessary and continuing attempts in this regard constituting the necessary *actus reus*, and the specific intent required for the *mens rea* would be fulfilled, as per the discussion with respect to Article 3(a).

One could argue that continuous and repeated efforts in this regard could be described as a case of the relevant states or supranational bodies ‘not being able to get it right yet’.

Article 3(e) – Complicity in genocide: This criterion would be fulfilled, in terms of the discussions about Articles 3(b), 3(c) and 3(d) above, due to both horizontal initiatives, at supranational and bilateral level, as well as vertical initiatives, such as the EU being in collusion or allowing actions or omissions by member states and non-state actors within its jurisdiction, as well as by individual states doing the same.

Such actions would constitute the *actus reus* necessary for complicity, in terms of the substantive discussions carried out in Articles 3(b), 3(c) and 3(d), while the specific intent required for the *mens rea* would be fulfilled, as per the discussion with respect to Article 3(a).

12.2.4 Notes of Genocide – And the Way Forward?

While the resulting picture from the analysis conducted does not point to an outright genocide, it still paints a stark picture and prognosis. Because although talk of a genocide might not go down well with the established mainstream, talk of rights breaches is more likely to find a sympathetic ear, and the analysis conducted above points to the gravity of rights breaches in a number of areas, as to autistic persons as a group.

Society nowadays has placed a major focus on the concepts of prevention, cure and normalisation, and of chasing the ‘autism epidemic’. It has been noted that it can be said that genocidal crimes are being carried out, through action or omission, by both states and supranational bodies, in the areas of prevention, therapies with sole scope of normalisation

to the exclusion of everything else, and the creation of a siege mentality with regard to autism.

This is actually diverting both funds and efforts away from the real problems surrounding autism. Problems rooted in perception, as to an understanding of what autism really is, and an understanding by society of why things are going the way they are. This, after looking at both hard science, as well as social patterns past and present, would allow for a clearer, franker discussion about the real needs of autistic persons, their families and communities.

And such will hopefully lead to discussions involving all sides, including autistic persons, within the principle of 'Nothing About Us, Without Us', enshrined in the CRPD, in order to take stock of the situation, and move forward following a practical, rights-based approach.

While screams of genocide might be a wake-up call, the important take home point at this instance is the fact that societal perceptions are grossly discriminating against a large social group, that of autistic persons, and that this has already happened in the past in the case of other social groups, with deleterious consequences. Therefore, what needs to be done at this point is to wake up to the real problems, and then chart a way forward, towards a solution that works for all sides.

Because at this point, if one were to ask the question 'Is It Illegal to Be Autistic?' – the answer would be 'It is Not, but it is definitely also not State-Sanctioned'.

12.3 Ending the Madness: The Need to Talk to the Other Side

The main issue with pushing forward at the moment is that, in present-day society, sections of society and 'affiliated' activists are at two opposing ends. Due to this, the only way to move forward is to build a bridge, in order to be able to arrive at middle ground.

In this respect, the thesis shall recapitulate how things failed in such a setup in Canada, and then discuss possible ways forward, insisting on a cohesive approach, discussing the grassroots model adopted in the UK, and other countries to a lesser extent, in this regard, and then emphasising the need of coordination by the state and oversight by an independent

regulator in order to bring all sides together, also outlining the upcoming Maltese model in this regard.

Throughout this discussion, current roadblocks with groups on both sides of the divide will be tackled, as well as solutions to such offered. The thesis concludes by outlining how such a cohesive, all-party approach must push forward towards creating an environment in which not only are autistic rights help, but rather, all partners around the table are equal partners in creating autistic justice.

12.3.1 The Canadian Fracas

Tensions between advocates and self-advocates have always been historically present, although these have abated in certain other movements, such as in the case of deaf and blind activists. However, in the sensitive scenario of intellectual and developmental disabilities, the least the Canadian government could have done – in the same vein as its southern neighbour, the United States – was to reach out and listen.

There were genuine, desperate parents on the one side, who were clinging on to every hope offered to them by the therapeutic community. While the therapies in question could be criticised for their goal of normalisation or indistinguishability of the therapy subjects, and of the methods used in such therapies, most parents, these parents definitely included, have the best interests of their children at heart in choosing any therapy.

It was definitely not the case that these parents hated these children so much that they wanted to go the whole nine yards and normalise them. It was what they felt would work best for their children, and in light of the information and research available to them, and within the constraints imposed by the Canadian service provision industry and Canadian society, it was the best that they could find.

None of the plaintiffs were either medical or care service professionals. They were parents, with formation in different professional fields, working hard to save up enough money to provide for their families, and especially for their children, on the one hand. On the other, they were doing this while also spending an enormous amount of time in a voluntary environment, learning how to make the lives of their children and their family environment

better. They were also working to share this knowledge with other similar families, and advocating with authorities and other different stakeholders in order to achieve these aims, sometimes facing humiliation or even arrest.

On the other hand, self-advocates were always members of a very excluded, vulnerable group, not having been given access to necessary basic rights and validation of their identity and personhood, by parents and peers, but mainly by authorities, the educational system, and further on in the world of work.

This was due to a society that was not properly sensitised about disabilities, and especially about I/DDs and autism, a society without the necessary structures, information and resources or mechanisms in place. This is a fundamental necessity, in order for society to be more inclusive for these persons, and for these persons to be able to access their rights at a par with other persons in their same situation, but with such other persons being neither disabled nor autistic.

These are the persons, from a place of pain and anger, who are fighting for their rights, and who are also fighting in order that other persons like them, especially when growing up, which was the worst part of their life, do not experience anything that constitutes abuse. Such persons have all experienced abuse, restraints, seclusions and the like, in one form or another.

So it is natural for these persons to see red, when faced with the prospect that children of a certain age are to be faced with normalisation therapies, that have at their basis the stifling of an autistic child's identity, and the goal of compliance within a reward or punishment structure.

However, the two different poles that activists on both sides find themselves on, does not allow for an open and frank discussion, that would allow both sides to see each other's point of view. The parents are coming from a place of anger and desperation, while the self-advocates are coming from a place of anger and pain.

If the parents could see the points made by the self-advocates, and be able to apply them in choosing intervention strategies for their children and families, that would be

implemented by specific service providers, and regulated by the state, they would definitely choose this, if it were a better option for their children.

And self-advocates would be more than happy to contribute to healthy, nurturing alternatives, should there be the necessary conditions present to allow them to reach through. To the parents, but most importantly to service providers and state regulators. This would be done through a defined intermediary, but also through the necessary supports, accommodations and conditions being provided for such persons in being able to participate in this process.

12.3.2 The United Kingdom (England) – A Concerted Approach

The path to the UK Autism Act, as applicable to England, is a useful example in which to observe the dynamics of building a cohesive setup, in order to push forward a common agenda towards the emancipation of autism rights. The dynamics of coordination, and of different parties coming around the same table in achieving this goal, as well as the roadblocks encountered, and issues to be addressed in similar exercises, will be discussed.

The example here was not a top-down, state-coordinated approach, but rather a bottom-up initiative, coordinated at grassroots level by the UK National Autistic Society (NAS), and introduced in Parliament by way of a Private Member's Bill.

12.3.2.1 Towards the Autism Act: A Grassroots Approach

The roots of the current legislative framework in the UK can be traced back to grassroots activism, albeit mostly initiated by parent-based groups. The National Autistic Society (NAS) of the UK is the oldest specific-purpose autism association in Europe, and one of the oldest in the world, distinct in the sense that it functions as an umbrella organisation for several different autism-related groups, many with differing takes on the topic and different goals. It functions much like the Autism Society of America nowadays, rather than as a streamlined top-down organisation consisting of different regional and local branches.

The main point, however, is that the NAS' efforts were always drawn from the grassroots, rather than through a centralised overseeing structure. And it was the sum of the unified lobbying of all these different strands, necessitating the striking of compromise in many positions taken by the NAS on a national level, that lobbied UK lawmakers into pushing forward the Autism Bill in the 2000s.²

Even the introduction of the Bill in the UK Parliament was not the result of an initiative undertaken by government after representations or pressure by the NAS, but was the result of a Private Members' Bill.³ This was introduced by Conservative MP Cheryl Gillan and co-sponsored by fellow Conservative then-MP Angela Browning (now Baroness Browning), and was eventually adopted after a laborious process, with the government of the day only stepping at that point, being then tasked with taken it forward along the road of implementation.⁴

The strategy used was similar to the grassroots initiative undertaken in Israel, as to the amendment of the National Insurance Law, to extend the Law's coverage to relevant therapies, services and support. Valerie Zilka, attorney at disability advocacy organisation and service provider Beit Issie Shapiro, headed a coalition that lobbied lawmakers to introduce, discuss and subsequently pass the relevant amendments through the Knesset.⁵

This exercise, apart from cutting across political lines, also bridged the sometimes deep divides in Israeli society that run on both religious and ethnic lines. The final vote by which the legislation in question was adopted by the Knesset also testified to such unified concerted effort.

This is the same approach being currently adopted by the Autism Coalition in Ireland, as described further in Section 11.2.3 of this thesis, after legislation introduced in the Dáil Éireann in 2012 remains at a roadblock in the legislative process.

² Interview with Amanda Batten, Policy Officer, National Autistic Society, London, February 2014.

³ Autism Bill 2008.

⁴ Interview with Baroness Angela Browning, House of Lords, London, February 2011.

⁵ Interview with Attorney Valerie Zilka, Beit Issie Shapiro, Ra'anana, June 2011, detailing the concerted effort she spearheaded on behalf of Beit Issie Shapiro in amending the Israeli national Insurance Law to cater for the needs of autistic persons, this process being detailed more fully later in this Chapter.

12.3.2.2 Hammering out a Compromise

The Bill itself was a compromise document, especially that it functioned more as a framework that was also extremely ‘politically safe’, rather than a piece of legislation with much teeth. The document gave the government the power to oversee the introduction of specific strategies related to autism,⁶ as well as to oversee their implementation and collect data for reporting purposes in shaping policy.⁷ This was the final outcome, rather than one providing any more concrete measures, and that can lead to serious issues of justiciability, especially that much of this power is delegated to regional and local authorities, leading to issues of who is to be held responsible for what.

The lobbying that led to the moving of the Private Members’ Bill was initiated after a lengthy consultation and lobbying process involving the different stakeholders under the NAS’ umbrella, through the ‘I Exist’ campaign.⁸ However, the main focus in this regard was on services,⁹ one of the reasons why the Bill in the end focused on adult autism issues, to the exclusion of childhood autism, although the area of transitioning into adulthood and employment was one of the areas that eventually made its way into policy being developed under the enacted legislation,¹⁰ growing out of the previous policies in place that later consolidated into the up-and-coming UK National Autism Strategy.

The main argument being raised at present is the fact that different stakeholders, from the grassroots, having different views, managed to coherently lobby UK lawmakers into pushing forward a coherent piece of legislation. One which, it is being argued, lacks teeth, but one which is definitely a start. This is the case, since it provides for a centralised first step, upon which further elements can be built, and which can then be further developed or amended as necessary. This can be done in line with developing social pressures, in order to make sure that the rights of autistic persons in England, whose interests such legislation is ultimately meant to serve, will be safeguarded at their fullest.

⁶ Interview with Baroness Angela Browning, op. cit.; Autism Act 2009, c. 15, at 1.

⁷ Interview with Baroness Angela Browning, op. cit.; Autism Act, op. cit., at 2.

⁸ Interview with Baroness Angela Browning, op. cit.

⁹ Ibid.

¹⁰ UK Department of Health, ‘Fulfilling and rewarding lives: the strategy for adults with autism in England’, 3 March 2010, accessed online at http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113405.pdf, at Chapter 15.

This phenomenon testifies to the usefulness of the coalition approach of the NAS in tackling the lobbying leading up to the introduction of the Autism Bill in UK Parliament. One might speak of the usual concern related to the participation of parent-led groups in such processes, in that they would try to push forward their ‘traditional’ autism advocacy agenda. However, the consultation of stakeholders who were themselves autistic, as part of the process conducted by the NAS, was also reflected in the greater emphasis on services, rather than a more ‘classical’ focus on childhood autism, and was part of the ‘compromise package’.

The feedback of such groups acted as an effective counterweight to the voices of more ‘traditional’ parent- and guardian-led groups under the NAS umbrella. This not by trying to uproot traditional ideas with more modern ones, but by offering a more direct voice, to update older, albeit well-meaning attitudes, with the final goal of creating feedback that would be beneficial to the autistic community. Due to this matter regarding, the NAS had to walk a very fine line when presenting its conclusions to UK lawmakers. However, this was, in the end, an exercise which managed to get matters off the ground.¹¹

12.3.2.3 Perception and the Roadblock

Still, issues of perception were still at play, this view being expressed by certain autistic-self advocates and autistic-led groups about the NAS-led process, including the London Autistic Rights Movement (LARM). They felt that the issue of empowerment was grossly lacking in such an approach.¹² They expressed concern as what they still saw as an underlying, patronizing medicalised approach, rooted in a perception of autistic persons’ inability to function, and that sees it as too impossible or risky for certain autistic persons to be able to independently take on necessary life tasks, or too risky to allow them to do this at all, or to do this unaccompanied.¹³

They highlighted certain specific issues which had been neglected in the past, such as effectively making sure the voices of ‘non-verbal’ autistics were included in the debate,

¹¹ Ibid.

¹² Interview with Roderick Cobley, London Autistic Rights Movement (LARM), London, February 2011.

¹³ Ibid.

were advocated for, and shown to be possible, in particular due to the fact that such groups had first-hand experience of these processes, having within their fold members who were, for example, also ‘non-verbal’.

And as with every such exercise, militant tendencies always play a part. While the NAS embarked on a nationwide consultation process with autism-related groups in compiling its final feedback, both those groups under its umbrella, as well as non-affiliated groups, some of the latter participated wholeheartedly in the process, while others chose not to continue pursuing this option. In the case of LARM, the reason given was the nature of certain elements of the questionnaire presented by the NAS to these groups. LARM discontinued cooperation, as it felt that the NAS’ approach was too medicalised and in line with the establishment, in order to be able to bring about effective change.¹⁴

While the process still went ahead, and a compromise of sorts was forged, this still meant the exclusion of certain autistic voices from the process. On the one hand, one might cite the need for an approach that showed more sensitivity and contact with the autistic community’s actual concerns.

However, on the other hand, this is impossible if the other side refuses to engage in communication – in this case, deep-rooted negative perceptions of the NAS and its past conduct playing a part. Whatever might have happened in the past, there is a need to bridge the divide and move forward. And while the NAS started on a good path, and has since intensified its efforts to engage the autistic community in the UK,¹⁵ a similar exercise of reform and rapprochement is equally necessary on the self-advocates’ side.

¹⁴ Ibid.

¹⁵ One can point to the regular publication of a magazine targeted those members of the self-advocate community diagnosed with Asperger Syndrome, entitled ‘Asperger United’; the appointment of self-advocate Damian Milton as an NAS Trustee and Head of Autism Knowledge and Expertise, and; the involvement of self-advocates in the organisation of the XI Autism-Europe International Congress hosted by the NAS in Edinburgh in September 2016, as well as including elements such as colour-coded communication badges and specific information concerning ex. lunches in the conference materials, and reaching out to autistic-led group ARGH (Autism Rights Group Highland) and including their parallel Autistic Fringe events within the main programme materials.

12.4 The Problem (and Solution) to Self-Advocates' 'Militant Tendencies'

As discussed earlier, autistic self-advocates frequently point to the problem of parents' and professionals' (P&P) groups focusing on cure and 'normalisation'/'indistinguishability', while not grasping the whole concept of what autism is, as well as related concepts of acceptance, personhood and identity. The aim in this regard is to 'fix' broken persons, rather than focusing instead on supports and services.¹⁶

However, although the issue of P&P groups, and their relevant radical or 'black and white' thinking is a bar to moving forward, it always takes two in every issue. Therefore, there is also the need, in light of the circumstances described, to tackle issues on the 'other side'. Namely, the issue of self-advocate radicalisation, and of how to also bring such self-advocates into the same fold.

12.4.1 Shakespeare and Watson: 'Absolutist Sacred Cow' Problem

Activists and academics Tom Shakespeare and Nicholas Watson broke with the main UPIAS-inspired line, stating that what was the very success of the social model is now its main weakness.¹⁷

Shakespeare even goes as far as stating that UPIAS were the founders of the modern-day rights of disabled people,¹⁸ which at a first glance seems plausible enough, especially when one views the official line pursued by governmental institutions such as the UK Disabled Rights Commission, which apart from the wording in its name, stated since its inception in 1997 that it "claims to be guided in everything it does by the social model of disability."¹⁹

¹⁶ Interview with Ari Ne'eman, Founder and President – ASAN (Autistic Self-Advocacy Network), New York, May 2011.

¹⁷ Tom Shakespeare and Nicholas Watson, 'The social model of disability: an outdated ideology?', *Research in Social Science and Disability*, Vol. 2, 2002, at 9, 12.

¹⁸ Tom Shakespeare, 'Looking Back, Moving Forward, Opinion Column, 2006, at http://www.bbc.co.uk/ouch/columnists/tom/250906_index.shtml, as cited by Andrew Fallon, 'Beyond the Social Model of Disability', *Enable Disability* blog, 27 February 2007, accessed online at <https://enabledisability.wordpress.com/2007/02/27/beyond-the-social-model-of-disability/>.

¹⁹ Mike Oliver, 'If I had a hammer: the social model in action', in J Swain, S French, C Barnes and C Thomas (eds), *Disabling Barriers – Enabling Environments*, Sage, London, 2004, at 7, as cited by Fallon, op. cit.

However, they argue that being such a powerful tool, so central to the disability movement, the social model became a sacred cow,²⁰ and consequently an ideology which could not easily be challenged. Shakespeare further states that the original ideology had changed to an extent that it is reversing the good it once did.²¹

Shakespeare and Watson cite the concept's simplicity as having been key to its effectiveness, giving as examples the 6-word slogan 'disabled by society not by our bodies,' and seemingly easy ways to evaluate organisations and policies ex. use of identity-first ('disabled people') rather than person-first ('people with disabilities') language (considered 'social model language' and 'medical model language' respectively), or else focus on barrier removal or else on medical intervention and rehabilitation.

They state that this led to being able to use the social model to view the world in black or white, even if this was not its original framers' intention.²² They state their divergence with the views of UPIAS veterans such as Sally French and Carol Thomas was the 'strong' social model itself having now become a problem, with the concept now unable to be reformed, claiming also that the British version of the social model has outlived its usefulness. They suggest starting over rather than trying to fill the gaps still presenting themselves in the current manifestation of this model.

These commentators are of the opinion that this specific problem originates from a dangerous tendency to equate this notion with purity and orthodoxy in disability politics and studies.²³ They refute this, citing the example of the Liberation Network of People with Disabilities, who defined disabled people as an oppressed social group without needing to define disability as social oppression.²⁴

²⁰ Shakespeare et., op. cit., at 12.

²¹ Shakespeare, op. cit. in Fallon, op. cit.

²² Shakespeare et., op. cit., at 16.

²³ Ibid., 17.

²⁴ Ibid. The authors further state the example of Allen Sutherland, a member of the Network, who wrote the pioneering *Disabled We Stand* in 1981, without drawing upon the social model in his argument for a radical politics of disability.

12.4.2 *Beyond the Social Model and the 'Enemy on the Other Side'*

Further to the more general criticism of the current state of play of social model thought, Shakespeare also focused on the specific issue of impairment in the context of current arguments concerning disability.²⁵ As outlined earlier, the overriding view among UPIAS-aligned authors and activists was that disability ceases to be something that someone has, and instead is something that is done to the person – thus shifting the focus from the problematic aspect being impairment, essentially a personal quality, to disability, essentially a social phenomenon in line with the more orthodox interpretations of the UPIAS line.

However, Shakespeare argues that one must put aside this erstwhile emphasis on the impairment vs disability debate, and instead debate disability more holistically, including impairments as a component of this discussion to the relevant extent.²⁶ In this regard, he views the social model v. medical model paradigm to be damaging. This he puts forward specifically as to those disabled persons whose disability leaves them completely dependent on care and on medicine.

He specifically targets identifying the non-disabled as an enemy or immediate oppressor, as a new strain emerging from social model thinking. While emphasising the need of society to change to allow inclusion of disabled people, this cannot be the only mantra, and a shift towards recognising the role of non-disabled professionals such as doctors and teachers in the process is required²⁷ – it is understandable that radical disability advocates, finally feeling liberated, will especially want to prevent their own re-oppression by the people running a medicalised system, at whose hands they might have suffered abuse.

As Shakespeare later states, though, such an approach will only mirror the same end result of exclusion of disabled people that the medical model was responsible for,²⁸ just through different means, especially since not every disabled person is also either willing or capable to committing to a life of radical disability activism.²⁹

²⁵ Shakespeare, op. cit, in Fallon, op. cit.

²⁶ Ibid.

²⁷ Ibid.

²⁸ Ibid.

²⁹ Ibid.

He states that the best way forward is a combination of the medical and social models, taking in the best points from each, while efforts are made in the meantime to create new modes of thinking aimed at helping overcome the barriers that disabled people still face.³⁰

12.5 The Role and Obligations of the State

12.5.1 To Listen and To Regulate

This is where the Canadian state – and any state that acts likewise – has failed, and is failing the autism and autistic communities. The state has the obligation to build bridges, to ensure that the necessary structures are there. This is necessary in order for information and awareness to be in place, for there to be structures that allow for input and consultations, enabling access to resources and accommodations that allow persons who need them to be able to participate in such consultations.

There is, likewise, a need for a strong focal point within government, and for a strong independent regulator. The latter would bring together different parts of civil society, liaise with government, and mediate appropriate links with third-party stakeholders and service providers. This would be done in order to review and regulate therapies and interventions, and ensure that they are person-centred, comply with a person's best interests, and are not abusive of or degrading to these persons, in a physical, psychological or pharmacological manner.

Personally talking to parent advocate Norah Whitney, the author could see beyond the clouds put in place by animosity between opposing groups of activists. Whitney had initially refused a request to be interviewed by the author, after learning he was also interviewing autistic self-advocate Michelle Dawson.

However, two years later, the author and Whitney met for five hours, had an extremely constructive dialogue, and was followed up by the author putting Whitney in contact with academic and autistic self-advocate Jason Nolan at Ryerson University. This was as to her son's possible participation in the University's joint initiative with autistic-friendly

³⁰ Ibid.

employer SAP for autistic youth, to which there was a positive response from both mother and son, both to the programme, as well as to associating with the self-advocate.

This is what the Canadian state should have been doing, instead of trying to fend off any kind of effort by raising technicalities and purportedly trying to save its own people's money, instead of spending it on its own people's betterment, in line also with the international obligations it had ratified years earlier to the start of this fracas, and instead simply paying lip service to autism rights by passing an Act recognising WAAD.

Civil society was vocal, and the opposition was vocal too. Some may argue that it is easy for the opposition to criticise, since it is not in power. However, the point being made is that there were considerable sectors of society that felt that there should be a change in direction by the Canadian government, not least renowned persons within Canadian society such as Senator Jim Munson, who started supporting autism legislation after meeting a father staging a sole protest in front of the Canadian Houses of Parliament.³¹

The important thing is to have a structure in place, in order to not simply give in to public pressure and do something, but also to do it right. Although activism can push for many different aims, having the right information and resources available is key, together with the state's overarching obligation to provide a forum, conditions and resources for building this bridge and fostering an understanding towards a way forward. Not only will it save a state money in the long run, it is also the single most important matter that will both kickstart relevant progress in the field, and also ensure a state's fulfilment of the obligations it has ratified in terms of the CRPD.

12.5.2 To Participate in a Tripartite Approach Towards Empowerment

The issue of the need to empower the autistic community, to encourage more people to come out and be active, was also raised specifically by autistic self-advocates.³² This was a concern in Israel, especially that, while the National Insurance Law enacted a few years

³¹ Interview with Senator Jim Munson, supporter of autism advocacy and of Bill S-210 leading to An Act respecting World Autism Awareness Day, Ottawa, May 2011.

³² Interview with Amit Fleiss, Chen Gershuni, Sola Shelly, and Assaf Markowitz, Autistic Community of Israel (ACI), Ra'anana, July 2015.

back allows for funding for certain interventions, in the same way as funding for medical conditions, policies were not being made or enforced by the State in order to support and encourage civil society in this regard.

Aside from implementing new Accessibility Regulations,³³ mentioned in Section 12.5.2, there was the issue of the recent Community Living law for autistic persons.³⁴ Rather than facilitating de-institutionalisation and empowering autistic persons, in line with Israel's CRPD obligations, this was instead just re-working the idea of institutionalisation into a decentralised structure, motivated in part by commercial interests of long-standing operators in the sector.

In this regard, states must provide a legislative and policy basis, but also a relevant framework, in which all involved stakeholders in the state can be co-creators of the destiny of the beneficiaries, either as parents or professionals, or else, even more importantly, as autistic persons themselves.

The Maltese Persons within the Autism Spectrum (Empowerment) Act seeks to do this through the Autism Advisory Council established by said Act,³⁵ a consultative council composed of ex-officio professionals and civil society representatives. It is tasked with drafting the Autism State Support Plan during its first year,³⁶ and to monitor its implementation thereafter, as well as that of other related policies which it can also propose and advise the Minister about. The functions of such Council are similar to those of the Inter-Agency Autism Coordinating Committee (IAACC) in the United States,³⁷ and the proposed Office of the Autism Commissioner in Northern Ireland.³⁸

³³ Equal Rights for People with Disabilities (Regulations on Accessibility to Services), 2013 (unofficial translation of the Hebrew original), Statute 7240, 25 April 2013 (hereinafter the 'Accessibility to Services Regulations').

³⁴ Rehabilitation, Advancement, and Incorporation of Persons with Autism into the Community Bill, 2013.

³⁵ Persons within the Autism Spectrum (Empowerment) Act, Cap. 557 of the Laws of Malta, at art. 3.

³⁶ Ibid., at art. 10(1)(a).

³⁷ Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2014 or Autism CARES Act of 2014, H.R. 4631, Pub.L. 113–157, at s. 5.

³⁸ This office was proposed in the Autism Bill (Northern Ireland) of 2010, Bill 2/10, but the relevant provision did not make the final Act due to financial considerations raised during the debate on the Bill in the All-Party Group on Autism of the Northern Ireland Legislative Assembly, as reported on the Assembly's website at <http://www.niassembly.gov.uk/visit-and-learning/autism-and-the-assembly/autism-legislation/autism-bill-as-introduced-explanatory-and-financial-memorandum/>.

Even where a state has a comprehensive strategy basis in law or policy, including innovative aspects such as in the rights field, the relevant ship must be steered to make the most of available tailwinds, while navigating relevant obstacles. Thus, while guaranteeing the independent functioning of such mechanisms, also through the provision of relevant resources, governments must ensure the necessary conditions and oversight for such exercises to be able to flourish.

This is especially important when bearing in mind that current legislation enacted to date in the field of autism, in different jurisdictions, is in the form of framework laws,³⁹ laying strategic groundwork and mechanisms allowing for the development of further policies and actions. This would include national autism strategies, which would also be the sole guiding document in states without a specific autism law.⁴⁰ The generality and open-endedness of such make for very promising opportunities for progress in this area, should the metaphorical ship be steered properly.

However, it is important to use that open-endedness to flesh out policies that will allow for real empowerment, rather than allowing for a worst-case scenario to pan out, should definitions and approaches, such as with interventions and therapies, be dealt with without the right knowledge about and approach to the topics. Such mechanisms are important to prevent outcomes such as a completely pro-cure law as was the case with the initial incarnation of the US Combating Autism Act in 2006,⁴¹ or constitutional amendments

³⁹ For example, Italy's "Disposizioni in materia di diagnosi, cura e abilitazione delle persone con disturbi dello spettro autistico e di assistenza alle famiglie" (Dispositions as to matters of diagnosis, care and rehabilitation of persons with autism spectrum disorders and of assistance to families), Law No. 344 of 5 August 2015, is framework legislation requiring adoption and specific substantive implementation by every Region in Italy, which apart from flying in the face of coherence, greatly acts as a bar to efficient steps forward, especially in those Regions having a Statute of Autonomy, as well as Regions facing less favourable socio-economic circumstances, as mentioned by Donata Vivanti, former President and current Council of Administration Member of Autism Europe, during an Interview, in Geneva, in August 2015.

⁴⁰ This would include countries such as Spain and France, the latter's strategy also made reference to in Section 3.2.1 of this thesis, in the context of litigation before the Council of Europe's Committee of Social Rights, and Hungary, which had adopted a 5-Year Strategy for Autism in 2009, which organisations such as Autism-Europe felt was under threat following the adoption of the new Hungarian Constitution of 2012, arguing that it enshrined discrimination, also extendable to autistic persons, due to references to 'limited mental capacity' in Article XXIII of the text, as reported, on 19 April 2011, at <http://www.autismeurope.org/publications/newsletter-subscribe/test-5/new-constitution-enshrines-discrimination-hungary.html>.

⁴¹ Pub. Law No. 109-416.

considered discriminatory and overriding guarantees previously present in policy, as was the case in Hungary.⁴²

12.6 Beyond Rights: Equal Partners for Autistic Justice

This final section will tackle the issue of a progression from a rights-based approach, to a justice-based approach. The coordination described in the previous sections should lead to a scenario where we move from disability rights to disability justice, and from autistic rights to autistic justice, on the basis of accessibility being present, rooted in the principle of Universal Design for all.

12.6.1 Not Rights But Justice

A good final source of inspiration as to how to move towards a model of disability in line with the notion of an up-to-date rights model, is the work of Mia Mingus,⁴³ who advocates moving further ahead of both the social model, as well as the usual rights models, and instead move towards a justice model.

In addressing disabled activists, she identifies accessibility as the core concept linked to the liberation of disabled people. However, she entreats activists not to allow this to be boiled down to logistics, rather understanding and practising an accessibility that moves disabled people ‘closer to justice, not just inclusion or diversity.’ In this regard, she states that:

“As organizers, we need to think of access with an understanding of disability justice, moving away from an equality-based model of sameness and “we are just like you” to a model of disability that embraces difference, confronts privilege and challenges what is considered “normal” on every front. We don’t want to simply join the ranks of the privileged; we want to dismantle those ranks and the systems

⁴² See Footnote 40 above.

⁴³ Mia Mingus, ‘Changing the Framework: Disability Justice – How our communities can move beyond access to wholeness’, *Disability Justice newsletter*, November/ December 2010, accessed online at <https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/>.

that maintain them. [...] Just because disabled people are in the room doesn't mean there is no ableism.⁴⁴

Mingus speaks of achieving justice through making the world around us accessible for all. This ties in with the importance of Universal Design as a notion, and of having it as a starting point, in creating a world that is, from the ground up, and by definition, designed as from the very start according to a common blueprint that would accommodate everybody. This would be the case, whether such persons would be autistic or not, disabled or not.

It would be a world in which autistic persons, their allies, and everyone else in society, would have the same level of accessibility because of a shift in perception to a different, universal concept. This rather than a world in which matters are granted as a matter of exemptions, exceptions or reasonable accommodations to a design based on prevailing majoritarian social norms. Universal Design would be the rule, as opposed to world based on prevailing majoritarian social norms that grants exceptions at times.

Mainstreaming would be a key world in every field of design, not least in the field of legislation, an area where reform, although slow, is being attempted. This can be seen, for example, in the case of the current European Commission Proposal for a European Accessibility Act.⁴⁵

However, even with accessibility legislation, the legislation itself has to be accessible. For example, Israel has been taking the matter of accessibility very seriously, at least on paper. It was attempting to implement the CRPD obligations in this regard, through promulgation of more than 100 pages of subsidiary legislation, covering all areas from accessibility of buildings and commercial establishments, to accessibility in situations of disasters and emergencies.⁴⁶

⁴⁴ Ibid.

⁴⁵ Proposal for a Directive of the European Parliament and of the Council on the approximation of the laws, regulations and administrative provisions of the Member States as regards the accessibility requirements for products and services, COM (2015) 615/2 (draft), published on 2 December 2015 (Proposal for a European Accessibility Act); see also, Alistair de Gaetano (lead author), *The Autistic Position on the European Accessibility Act*, Feedback on the Directive of the European Parliament and of the Council on the approximation of the laws, regulations and administrative provisions of the Member States as regards the accessibility requirements for products and services, Autistic Minority International, Geneva/ Valletta, 2 February 2016.

⁴⁶ Accessibility to Services Regulations, op. cit.

Notwithstanding such, the main concern, raised both by persons within the regulator,⁴⁷ as well as by self-advocates,⁴⁸ was the fact that having reams of paper is one thing, and implementing it and changing attitudes is another thing. In this regard, both sides expressed the view that changing perceptions of both intended implementing addressees, as well as the general population, would prove to be a challenge.

In particular, self-advocates mentioned that, rather than having voluminous regulations on how to ‘deal’ with an autistic person accessing services in a government department, a general exhortation, and relevant implementation, ensuring that employees in government departments would act ‘nice and human’ towards everyone, would have a much better effect.

12.6.2 Through Interdependence, Towards Justice

Returning specifically to the concept of disability justice, Mingus states that, in this respect, we should move away from the ‘myth of independence’,⁴⁹ that everyone can and should be able to do everything on their own.

She states that:

“I am not fighting for independence, as much of the disability rights movement rallies behind. I am fighting for an interdependence that embraces need and tells the truth: no one does it on their own and the myth of independence is just that, a myth.”⁵⁰

Mingus states that this involves re-imagining relationships that centre interdependency, in which able-bodied people move from being simply ‘supportive allies’ to political comrades, who are actively incorporating a disability justice understanding into their work and lives.⁵¹

It is through this interdependence, rooted in disability justice allowing accessibility based

⁴⁷ Interview with the Office of the Commissioner for Equal Rights of Persons with Disabilities, op. cit.

⁴⁸ Interview with Autistic Community of Israel (ACI), 2015, op. cit.

⁴⁹ Mingus, op. cit.

⁵⁰ Ibid.

⁵¹ Ibid.

on universal design, that a properly regulated framework can bring both sides together, and allow for efforts that will properly ensure autistic justice, instead of continual rights breaches that can be classified as falling within the realm of genocide.

BIBLIOGRAPHY

A. PRIMARY SOURCES	326
1. Legal Instruments.....	326
a) Statutes Presently/ Previously in force.....	326
Supranational	326
United Nations	326
European Union	327
Council of Europe	327
Domestic	328
Canada.....	328
France.....	328
Germany (Post-WWII Allied Occupation)	328
Hong Kong	328
Hungary.....	328
India.....	328
Ireland	328
Israel.....	329
Italy	329
Jamaica.....	329
Kosovo	329
Malta	329
Nigeria.....	330
Northern Ireland.....	330
Poland.....	330
Russian Federation	330
Spain.....	330
Turkey	331
United Kingdom.....	331
United States of America	331
b) Draft Statutes.....	332
Supranational	332
United Nations	332
European Union	332
Domestic	332
Canada.....	332

Ireland	332
Israel.....	333
Malta	333
Northern Ireland.....	333
Scotland.....	333
United Kingdom.....	333
2. Case Law	333
Supranational	333
Committee of Social Rights (Council of Europe).....	333
East African Court of Justice	333
European Court of Human Rights.....	334
European Court of Justice	334
International Court of Justice.....	334
International Military Tribunal at Nuremberg (Nuremberg Tribunal).....	334
International Criminal Tribunal for the Former Yugoslavia (ICTY).....	335
International Criminal Tribunal for Rwanda (ICTR).....	335
Domestic	335
Botswana.....	335
Canada.....	335
Hong Kong.....	337
India	337
Ireland	337
Israel.....	337
The Netherlands	337
South Africa	337
Uganda	338
United Kingdom.....	338
United States of America	338
Zimbabwe.....	339
B. SECONDARY SOURCES	339
1. Books and Book Chapters.....	339
Books	339
Book Chapters.....	343
2. Medical Manuals.....	345
3. Academic Articles.....	345
4. Supranational Resolutions and Declarations.....	351
	324

United Nations	351
European Union	351
5. Policy and Strategy Documents	352
6. General Comments and Reviews by UN Treaty Bodies	352
7. Records of Parliamentary Business.....	353
Malta	353
Northern Ireland.....	353
8. Print, Online and Audiovisual Media	353
Print and Online Media	353
Audiovisual Media.....	357
9. Statements, Position Papers and Petitions.....	357
Statements	357
Position Papers.....	358
Petitions	359
10. Recommendations, Opinions and Guidelines	359
11. Reports, Information and Statistics	360
Reports	360
States and Supranational Bodies	360
Non-State Actors.....	362
Statistics	363
States and Supranational Bodies	363
Non-State Actors.....	363
Other Information	364
12. Conference Presentations, Interventions and Proceedings.....	364
13. Interviews, Meetings and Communications	366
Conversations and Discussions.....	366
Meetings.....	368
Other.....	368
14. Internet Articles, Newsletters, Social Media and Blog Posts.....	368

A. PRIMARY SOURCES

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Supranational

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*Lawrence Dabbagh, an infant, by his Guardian ad Litem, Anita Dabbagh, and the said Anita Dabbagh in her personal capacity; R.D., an infant, by his Guardian ad Litem, Y.D., and the said Y.D. in her personal capacity; Hayden Ewing, an infant, by his Guardian ad Litem, Arleene Ewing, and the said Arleene Ewing in her personal capacity; Nicholas Frank, an infant, by his Guardian ad Litem, Debbra Mackie, and the said Debbra Mackie in her personal capacity; P.G., an infant, and J.G, an infant, both by their Guardian ad Litem, R.G., and the said R.G. in her personal capacity; Gary Matthew Groenke, an infant, by his Guardian ad Litem, Gary Groenke, and the said Gary Groenke in his personal capacity; Clinton Kam, an infant, and Brendan Kam, an infant, both by their Guardian ad Litem, Janny Kam, and the said Janny Kam in her personal capacity; Aaron Lewis, an infant, by his Guardian ad Litem, Jean Lewis, and the said Jean Lewis in her personal capacity; Matt Rowan, an infant, by his Guardian ad Litem, Mark Rowan, and the said Mark Rowan in his personal capacity; Allison Marshall, an infant, by her Guardian ad Litem, Beverley Sharpe, and the said Beverley Sharpe in her personal capacity; Alexander McLeod, an infant, by his Guardian ad Litem, Barbara McLeod, and the said Barbara McLeod in her personal capacity, Derek Paciejewski, an infant, by his Guardian ad Litem, Barbara Paciejewski, and the said Barbara Paciejewski in her personal capacity; Tessa Spiller, an infant, by her Guardian ad Litem, Franca Pastro, and the said Franca Pastro in her personal capacity; Kyle Pike, an infant, by his Guardian ad Litem, Kim Pike, and the said Kim Pike in her personal capacity; McKenzie Querns, an infant, and Nolan Querns, an infant, both by their Guardian ad Litem, Douglas Querns, and the said Douglas Querns in his personal capacity; Ariel Raskin, an infant, by her Guardian ad Litem, Avery Raskin, and the said Avery Raskin in his personal capacity; Adam Schertzer, an infant, by his Guardian ad Litem, Ruth Wingerin, and the said Ruth Wingerin in her personal capacity, and John Lyons Walter, an infant, by his Guardian ad Litem, Robert Walter, and the said Robert Walter in his personal capacity v. The Attorney General of British Columbia, Supreme Court of British Columbia, per Pitfield J, 22 August 2003, 2003 BCSC 1299, Docket: L0305662003 (Vancouver), (*Anderson et al. v. Attorney General of British Columbia*).*

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