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Amplifying Disabled People's Voices:

The Role of National Human Rights Institutions

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Doctoral Thesis in Law (PhD, Law)

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Dedication

For my wife Sarah, who always keeps me on the right path.

Abbreviations

AHRC - Australian Human Rights Commission

BCODP - British Council of Organisations of Disabled People

CHRC - Canadian Human Rights Commission

CQC - Care Quality Commission

CEDAW – Convention on the Elimination of Discrimination Against Women

CERD – Convention on the Elimination of Racial Discrimination

CSOs – Civil Society Organisations

DIHR - Danish Institute for Human Rights

DCEDIY -

IHREC-DAC – Disability Advisory Committee

DAC - Disability Advisory Committee

DARE - Disability Advocacy Research in Europe

DCC - Disability Consultation Committee

DLCG - Disability Legislation Consultation Group

DPCN - Disability Participation and Consultation Network

DPI - Disability Power Ireland

DRC - Disability Rights Commission

DSG - Disability Stakeholder Group

DPAC - Disabled People Against Cuts

DPM - Disabled People's Movement

DPOs - Disabled People's Organisations

EHRC - Equality and Human Rights Commission

EHRC-DAC – Disability Advisory Committee within Equality and Human Rights Commission

ECHR – European Convention on Human Rights

ECt.HR- European Court of Human Rights

ENNHRI - European Network of National Human Rights Institutions

FDP – Forum of Disabled People

FLAC – Federation of Legal Action Clinics

GANHRI – Global Alliance of National Human Rights Institutions

GC – General Comment

GC7 - General Comment 7

GIHR - German Institute for Human Rights

HRA - Human Rights Act 1998

ICESCR – International Convention on Economic Social and Cultural Rights

IDPM – Irish Disabled People’s Movement

IHREC Act 2014 – Irish Human Rights and Equality Commission Act 2014

ILMI – Independent Living Movement

IMM - Independent Monitoring Mechanism

ICC - International Co-ordinating Committee of NHRIs

IHREC - Irish Human Rights and Equality Commission

IHREC-DAC – Disability Advisory Committee in Irish Human Rights and Equality Commission

IHRC - Irish Human Rights Commission

JCHR – Joint Committee on Human Rights

NDAP - National Disability Action Plan

NDA - National Disability Authority

NDDA – National Disability Data Asset

NDIS - National Disability Inclusion Strategy

NHRIs - National Human Rights Institutions

NPSA - National Platform of Self Advocates

NSO - National Statistics Offices

NZHRC - New Zealand Human Rights Commission

NHRI (IMM) - NHRIs who have been designated as Independent Monitoring Mechanisms

NI – Northern Ireland

NDPB - Non-Departmental Public Body

NGOs - Non-government organisations

NIHRC - Northern Ireland Human Rights Commission

ODI - Office for Disability Issues

OHCHR - Office of the High Commissioner for Human Rights

OfDP - Organisations for Disabled People

PSED – Public Sector Equality Duty

PSHRED - Public Sector Human Rights and Equality Duty

ROFA - Reclaiming Our Futures Alliance

RADAR - Royal Association for Disability and Rehabilitation

SCA - GANHRI Sub Committee on Accreditation

SHRC – Scottish Human Rights Commission

UKDPM - UK Disabled People’s Movement

UN CAT – United Nations Convention against Torture

UN CRC – United Nations Convention on the Rights of the Child

UN SR Disability - UN Special Rapporteur on the rights of persons with Disabilities

UPIAS - Union of the Physically Impaired Against Segregation

UNCRPD - United Nations Convention on the Rights of Persons with Disabilities

WEC - Women and Equalities Committee

Chapter 1 Introduction

1.1 Background to Research

This thesis was funded under the Disability Advocacy Research in Europe (DARE) Marie Curie Innovative Training Network. The Network was sponsored by the EU by way of grant agreement 814249. The grant agreement included 15 work packages that are to be delivered by way of the development of a PhD thesis. The work package for the author of this thesis is titled ‘Amplifying Disability Voices: The Role of National Human Rights Institutions.’¹

National Human Rights Institutions (‘NHRIs’) played a key role in the development of the United Nations Convention on the Rights of Persons with Disabilities (‘CRPD’). One of the most unique features of the CRPD is the requirement on states to designate an Independent Monitoring Mechanism (‘IMM’). This requirement is set out at Article 33(2) of the CRPD:

2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

Article 33(2) makes reference to NHRIs, and in practice NHRIs have been designated as their state’s Independent Monitoring Mechanism.² In requiring the development of domestic architecture to promote compliance the drafters of the CRPD sought to build on the pre-existing network of NHRIs.³ As the literature concerning Article 33 demonstrates, there was significant hope that NHRIs designated as IMMs would collaborate effectively with disabled people and their representative groups in order to influence domestic politics.⁴ In this research I explored to what extent this goal was being realized in practice. In doing so I have sought to identify

¹ European Commission, Disability Advocacy Research in Europe, 30 August 2018, Available at: <https://cordis.europa.eu/project/id/814249> (Accessed 1 June 2022)

² Janet E Lord and Michael Ashley Stein, ‘The Domestic Incorporation of Human Rights Law and the United Nations Convention on the Rights of Persons with Disabilities’ (2008) 83 Wash L Rev 462

³ Meredith Raley, ‘The Drafting of Articles 33 of the Convention on the Rights of Persons with Disabilities: The Creation of a Novel Mechanism’ (2016) 20 IJHR 138

⁴ Gerard Quinn, ‘Resisting the “Temptation of Elegance”’: Can the Convention on the Rights of Persons with Disabilities Socialize States to Right Behaviour?’ in Oddny M Arnardóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Person with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009), p. 252

how Disabled People's Organisations ('DPOs') and NHRIs are collaborating to strengthen the voice of disabled people and to influence change.

I have embarked on this exploration firstly by reviewing existing academic literature and reports by international bodies. I then proceeded to carry out empirical research at the international level and most substantively through conducting case studies of arrangements in Ireland and in Great Britain. In doing so I have carried out 51 interviews with key informants and held three engagement events.

Prior to commencing this research, I was Director of Policy, Research and Legal at the Northern Ireland Human Rights Commission ('NIHRC') - one of the UK's three NHRIs and designated as part of the UK's IMM. In this role, I led the monitoring work relating to the CRPD and engagement with the disabled people's movement ('DPM') for the NIHRC. Furthermore, I served as a member of the European Network of NHRIs Working Group on the UNCRPD and worked closely with the UNCRPD Committee in developing guidelines for engagement with NHRIs.⁵ Through my work I observed that the potential transformative effect of the CRPD was being hampered due to a general lack of understanding amongst both NHRIs and the DPM regarding the opportunities for collaboration. By undertaking this research, I aim to provide empirical insights into how NHRIs and the DPM are collaborating to inform discussions on how mutually beneficial relationships can be developed and sustained.

1.2 Perspective of Researcher

All forms of social research, including legal and policy research, contain an element of subjectivity and may be influenced by the prior assumptions of the researcher.⁶

Mason encourages researchers to consider their own ontological perspective before embarking on an inquiry.⁷ Mason highlights how a range of ontological properties can influence a researcher's approach to their evidence gathering. In conducting this exercise, I observe that it is important to understand how my background in relation to NHRIs may influence my own perspective. Through my role within the NIHRC and numerous roles within the Global Alliance of NHRIs I regularly provided presentations highlighting the unique and significant

⁵ UNCRPD Committee Guidelines on Independent Monitoring Frameworks and their participation in the work of the Committee' 2018

⁶ Marilyns Guillemin and Lynn Gillam. (2004) "Ethics, Reflexivity, and "Ethically Important Moments" in Research." *Qualitative Inquiry* 10 (2): 261, p. 274

⁷ Jennifer Mason, *Qualitative Researching*. Second ed. Sage Publications Ltd, 2002.

contribution which NHRIs make towards human rights compliance and advocated for NHRIs to be provided with additional resources and powers. In light of my background there is a risk that I may overstate the potential for an NHRI designated as an IMM to effect change.⁸ Furthermore, my experiences may lead to an emphasis on the contribution of NHRIs in bringing about human rights compliance above the contribution of the DPM. To address this risk, I took a number of steps including undertaking training with the Harvard Kennedy School of Government on addressing one's biases when undertaking research.⁹

Mason also encourages researchers to consider their epistemological position and to reflect upon the value which they place on the various forms of data.¹⁰ Throughout my professional experience, I have worked within environments which emphasise the importance of evidence-based policy making. These organisations have tended to prioritise official statistics and reports and are inclined to undervalue experiential knowledge or the lived experience of individuals. As a result I would generally place a high value on evidence or data which has been developed through the rigorous application of scientific criteria.¹¹ I consider that this perspective is in contrast to the value which the CRPD and the DPM place on the lived experience of disabled people.¹² In order to broaden my perspective of the validity of various forms of evidence, I have investigated the perspective of researchers who engage in phenomenological research.¹³ In particular, I considered the views of disability researchers who have advocated for participatory approaches to evidence gathering.¹⁴ I have also reviewed literature exploring the concept of evidence-based policy. The writings of Smith-Merry on the incorporation of experiential knowledge in instrumental policy processes have been particularly insightful.¹⁵ In addition I engaged with colleagues within my training network who have experience of utilizing a variety of evidence gathering processes. Through these activities I have broadened my appreciation for the value of experiential knowledge. Furthermore, I have enhanced my

⁸ R.J. Robinson, "Errors in Social Judgment: Implications for Negotiation and Conflict Resolution," Part 2: Partisan Perceptions, *Harvard Business Review*: 9-897-104 (February 6, 1997).

⁹ Rob Wilkinson, 4 P Model for Strategic Leadership: Perception Podcast available at <https://bsc.cid.harvard.edu/podcasts/4p-leadership-framework-episode-7-perception> (Accessed on 2 May 2022)

¹⁰ *ibid*

¹¹ Jenny Fleming and Rob Rhodes, 'Can experience be evidence? Craft knowledge and evidence-based policing, *Policy & Politics*' [2018], vol 46, no 1, 3

¹² Laufey Love, Rannveig Traustadottie & James Rice, Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People's Organizations in Securing a Seat at the Table, 8 *Laws* 1 (2019).

¹³ McIntosh, I. and Wright, S. (2018) Exploring what the notion of lived experience might offer for social policy analysis. *Journal of Social Policy*,

¹⁴ Marcia Rioux, Paula C. Pinto, Gillian Parekh (ed) *Disability, Rights Monitoring, and Social Change. Building Power out of Evidence* Canadian Scholars Press 2016

¹⁵ Jennifer Smith-Merry, Evidence-based policy, knowledge from experience and validity [2019] 16 *Evidence & Policy* 305, 312

understanding of how the prioritisation of certain forms of knowledge has influenced policy making discourse.

I have sought to address my epistemic or ontological perspective in designing my evidence gathering approach. I considered that given that my field of enquiry was relatively small it was inevitable that I would be conducting interviews with and reviewing reports developed by individuals who were previously my professional peers or colleagues. I considered that there was a potential risk that I may be overly deferential to the views of my former colleagues or peers within NHRIs and perhaps unduly dismissive of criticism by DPOs. Fortunately, my fellow PhD researchers both at NUI Galway and Leeds University had extensive experience within the DPM, many holding senior positions within DPOs. I met with my fellow PhD researchers on a monthly basis, and they provided a useful sounding board to test whether my approaches and assessments were being unduly deferential towards NHRIs. When carrying out my evidence gathering, I sought insights at key stages from academic colleagues with experience within DPOs. For instance, when developing my interview questions, I sought the views of a colleague with experience of the DPM in Ireland. When conducting my interviews, I maintained a journal and reflected on any occasions in which I felt that my professional perspective was impacting on my assessment of the data. In addition, I limited my contact with former colleagues in both the Equality and Human Rights Commission ('EHRC') and the Irish Human Rights and Equality Commission ('IHREC') and avoided engaging with their broader activities. These measures effectively mitigated the risk that my previous experience would unduly interfere with the integrity of my research.

In addition to acknowledging the risk that my background may influence any assumptions which I make, I consider that it is also important that I acknowledge how my background may assist me in conducting my research and in developing my findings. NHRIs are multi-faceted and complex institutions, my experience of working within an NHRI(IMM) and with NHRI(IMM)s more generally assisted me in understanding the challenges and opportunities experienced by NHRI(IMM)s.

1.3 Field of Enquiry

My field of enquiry spans several disciplines. At its core this enquiry is focused on the interaction between two distinct forms of organisation: NHRIs - which are unique statutory

bodies accredited by way of a UN based procedure - and representative groups of disabled people or DPOs. Literature concerning the study of organisations is therefore generally relevant to this enquiry.¹⁶ Furthermore, there are emerging bodies of literature charting the development of DPOs and NHRIs respectively.

Literature relating to DPOs tends to be informed by social movement studies. Much of the published literature relating to DPOs tends to be specific to the national contexts. However, a number of academics have considered broader trends.¹⁷

A distinct body of literature has emerged examining the development of NHRIs and the roles that they perform.¹⁸ Numerous commentators who write on the activities of NHRIs draw on studies of public bureaucracies.¹⁹ However, the applicability of this body of literature to NHRIs, which are required to be independent of government, is in my view questionable. NHRIs are a new form of state entity - a state body that is established not to further the priorities of the government of the day, but to advance the international human rights standards to which the state has committed to.²⁰

A related body of work has developed assessing how compliance with international human rights is achieved.²¹ Theories of compliance with international human rights law regards civil society organisations ('CSOs') and NHRIs as central actors in bringing about compliance.²² De Búrca, in one of the most recent explorations, has highlighted how dynamic interactions between domestic CSOs and the international system has enhanced the persuasive power of international human rights norms.²³ I will draw on these theories in considering interactions between civil society and NHRIs.

¹⁶ Charles Handy *Understanding Organizations* (Penguin Books 1993)

¹⁷ Maya Sabatello and Marianne Schulze (eds), *Human rights and disability advocacy* (University of Pennsylvania Press 2014)

¹⁸ Ryan Goodman and Tom Pagram, *Human Rights, State Compliance and Social Change: Assessing National Human Rights Institutions* (Cambridge University Press 2012)

¹⁹ L.B. Jensen, *Lessons from Research on National Human Rights Institutions* (Danish Institute for Human Rights 2018) 6.

²⁰ Sonia Cardenas, *Chains of Justice: The Global Rise of State Institutions for Human Rights* (University of Pennsylvania Press 2014)

²¹ X. Dai, The Compliance Gap and the Efficacy of International Human Rights Institutions, in T. Risse, S. C. Ropp and K. Sikkink (eds.) *The Persistent Power of Human Rights. From Commitment to Compliance*, Cambridge University Press (2013)

²² B. Simmons, *Mobilizing for Human Rights: International Law in Domestic Politics* (Cambridge University Press 2009)

²³ Gráinne de Búrca, The activation of the Convention on the Rights of Persons with Disabilities in Argentina in Gráinne de Búrca (ed) *Reframing Human Rights in a Turbulent Era* (Oxford 2021) p. 128

Human rights compliance theorists often either explicitly or implicitly draw upon the writing of political scientists concerning policy influencing processes. I will draw upon the writings of political scientists in this enquiry.²⁴

1.4 Contribution to existing literature

Informed by the terms of reference for my work package I began this enquiry by completing a thorough review of existing literature to identify current levels of understanding of the relationship between civil society and NHRIs. Noting existing levels of understanding I formulated my central research question as: *In what ways are DPOs and NHRIs collaborating to strengthen the voice of disabled people and influence change?*

My enquiry is specifically focused on circumstances in which an NHRI is designated as an IMM. There is a small body of literature which has been developed to consider such circumstances.²⁵ A considerable amount of this literature is now quite dated, much of it having been written in anticipation of NHRIs being designated as IMMs. There is an absence of literature which critically assesses the suitability of NHRIs as IMMs.

More recently international bodies have published research relating to the activities of NHRIs designated as IMMs.²⁶ However, this research has tended to record the activities undertaken by NHRIs without critically assessing whether the activities are being effectively executed. My research will critically assess the activities of NHRIs which have been designated as IMMs. I will therefore seek to determine whether the activities of NHRIs are having a positive effect on disabled people and their representative groups. In addition to contributing to this relatively small and quite specific body of literature my research will contribute to three related bodies of work. Namely literature relating to NHRIs, literature relating to human rights compliance and literature relating to the relationship between social movements and the state.

²⁴ Richard Goodman and Derek Jinks, *Socializing States: Promoting Human Rights Through International Law* (Oxford University Press 2013).

²⁵ Gauthier De Beco, 'Article 33 (2) of the UN Convention on the Rights of Persons with Disabilities: Another Role for National Human Rights Institutions?' [2011] *Netherlands Quarterly of Human Rights* 29 (1): 84–106 ; Samson, Rita M. 2015. "Securing the Full Participation of Persons with Disabilities and Their Representative Organizations in Disability Rights Monitoring." In *Disability, Rights Monitoring and Social Change Building Power out of Evidence*, edited by Marcia H. Rioux, Paula C. Pinto, and Gillian Parekh. Toronto: Canadian Scholars' Press, 237–248; LFA Gatjens 'Analysis of article 33 of the UN Convention: The critical importance of national implementation and monitoring' (2011) 8 SUR – International Journal Human Rights 87

²⁶ GANNHRI Working Group on UNCRPD 2019 survey, available at: <https://ganhri.org/2019-survey-report/>

As I will discuss, much of the existing literature examining NHRIs focuses on their institutional design and their relationship with the state.²⁷ There has been comparatively little written concerning how to assess the activities and performance of NHRIs.²⁸ Explorations of potential performance indicators for NHRIs have not led to their widescale adoption.²⁹ There is a lack of critical analysis of the ways in which an NHRI can support civil society. Much of the pre-existing literature is premised on the assumption that the development of an NHRI is in the interests of civil society. This assumption has informed the general trend for NHRIs to be designated as IMMIs.³⁰ Through providing a critical assessment of the opportunities which the designation of an NHRI as an IMM presents to DPOs this research will address the broader question of how an NHRI can support civil society more generally.

This enquiry will also contribute to literature relating to the relationship between social movements and the state. Existing social movement literature has a tendency to perceive the state as a unitary entity.³¹ Whilst there is a growing body of literature considering how the women's movement has engaged with government entities specifically designed to promote gender equality, there is an absence of literature considering how social movements have engaged with NHRIs.³² In this enquiry I will consider the opportunities which engagement with independent public bodies - in particular NHRIs - opens up to social movement organisations.

Existing literature on human rights compliance tends to focus on the contribution which civil society makes to the international system.³³ There is a lack of analysis which asks whether the ratification of international conventions strengthens the capacity of civil society to effect change. Due to the unique way in which it was developed, the CRPD has encouraged reflection on the potential of the international human rights system to benefit civil society. As I will discuss, the CRPD was developed largely through advocacy by the international DPM which hoped that its establishment and ratification would strengthen the voice of national DPMs.³⁴

²⁷ Paul Rosenblum, 'Tainted Origins and Uncertain Outcomes' in Goodman R and Pegram T (eds), *Human Rights, State Compliance, and Social Change: Assessing National Human Rights Institutions* (Cambridge University Press 2012).

²⁸ Rachel Murray R, 'National Human Rights Institutions: Criteria and Factors for Assessing Their Effectiveness' [2007] 25(2) *Netherlands Quarterly of Human Rights* (2007).

²⁹ Sarah Spencer S and Harvey C, 'Context, Institution or Accountability? Exploring the Factors that Shape the Performance of National Human Rights and Equality Bodies' [2014] *Policy and Politics* 89, p. 93

³⁰ See chapter 4 for analysis of trends in states examined by the CRPD Committee.

³¹ Sidney Tarrow, *Power in Movement: Social Movement and Contentious Politics*, Cambridge 1999 p. 255

³² True, Jacqui, and Michael Mintrom. 2001. "Transnational networks and policy diffusion: The case of gender mainstreaming." *International Studies Quarterly* 45 (1): 27-57

³³ Simmons BA. *International Law*. In: *Handbook of International Relations*. (Sage Publications ; 2012).

³⁴ Gerard Quinn and Theresia Degener, *Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability* (2002 United Nations Publications).

This enquiry will assess how ratification of the CRPD has impacted on the Irish and UK DPMs, assessing specifically how the obligation to designate a IMM has impacted on the movement.

1.5 Methodology

This thesis is grounded in human rights law. I will be guided in my analysis by the CRPD and by a range of soft law instruments, most significantly the Paris Principles relating to the status and functioning of NHRIs.³⁵

A purely normative analysis of the CRPD and other relevant instruments can only go so far.³⁶ A critical analysis of human rights law requires an assessment of the social processes which human rights law influences.³⁷ Legal analysis of the international human rights systems rarely reveals the limited impact of the system on the ground.³⁸ Epstein and Martin argue that ‘...well-executed (legal) research with a data component is likely to make more important, influential, and, frankly, better contributions to policy and law because the study’s authors can accurately gauge the uncertainty of their conclusions’.³⁹ I would posit that any human rights enquiry cannot refer exclusively to human rights laws and must adopt a multidisciplinary approach in order to understand fully the role human rights laws and systems perform in a given context.

Commenting on existing approaches to human rights research, Stein and Lord have called for ‘...a more nuanced and interdisciplinary exercise that sees human rights law as a socially transformative process of change and culture-building’.⁴⁰ Some academics have suggested that ‘human rights studies’ should develop its own methodological approaches. However, this has not yet been established as a defined discipline.⁴¹ Therefore, in common with other human rights researchers I have adopted a distinct multi-disciplinary approach to my research. This started with a legal analysis of the CRPD and related provisions. I then drew on social movement literature to examine the activities of DPOs. In examining the activities of NHRIs I have drawn extensively on both the views of human rights practitioners and the writings of

³⁵ UN General Assembly 1993. *Principles relating to the status and functioning of national institutions for the protection and promotion of human rights ('Paris Principles')*. Resolution 48/134, UN Doc. A/RES/48/134.

³⁶ McInerney-Lankford S, Legal methodologies and human rights research: challenges and opportunities.” in Andreassen H, Sano H and McInerney-Lankford S, *Research Methods in Human Rights: A Handbook* (Edward Elgar Publishing 2018), p. 46

³⁷ Hilary Charlesworth ‘International Law: A Discipline of Crisis’ [2002] *The Modern Law Review* 377, 380

³⁸ McInerney-Lankford, Siobhán. 2018. (n. 36), p.50

³⁹ Lee Epstein and Andrew D. Martin, *An Introduction to Empirical Legal Research* (OUP Oxford 2014), p.4.

⁴⁰ Janet E. Lord & Michael Ashely Stein, ‘The Domestic Incorporation of Human Rights Law and the United Nations Convention on the Rights of Persons with Disabilities’ [2008] *Wash. L. Rev.* 449, 479

⁴¹ Madsen, Mikael Rask, and Gert Verschraegen. ‘Introduction to Sociology of Human Rights’ in *Making human rights intelligible: towards a sociology of human rights*, edited by Mikael Rask Madsen and Gert Verschraegen. (Oxford:Hart 2013)

political scientists. Following my review of the literature I embarked on my empirical analysis to determine how human rights laws have impacted on social processes.

1.5.1 Legal analysis

Human rights legal scholarship has been criticized for failing to appropriately emphasize methodological rigour.⁴² Crook has stated that ‘...wishful thinking and sloppy legal analysis tend to be too common in international human rights law’.⁴³ By employing robust legal analysis I sought to ensure that this thesis would not be subject to such criticism.

In my legal review I conducted doctrinal analysis drawing principally on relevant provisions of the CRPD, in particular Article 33. This included a review of the travaux préparatoires relating to the UNCRPD. In addition, I drew extensively on soft law sources of international human rights law.⁴⁴

By way of its jurisprudence the CRPD Committee have provided guidance on the institutional prescription of an IMM. To identify these prescriptions, I reviewed all concluding observations issued by the CRPD Committee up to May 2021.⁴⁵ Furthermore, I critically assessed all relevant General Comments (‘GCs’) issued by the CRPD Committee. I also drew on reports issued by the UN Special Rapporteur on the rights of persons with Disabilities (‘UN SR Disabilities’). Finally, I drew on reports and guidance produced by the Office of the High Commissioner for Human Rights (OHCHR). Whilst these sources do not technically meet the definition of international soft law, they do offer authoritative guidance to states on meeting their human rights obligations.⁴⁶

To inform my analysis of the CRPD I conducted interviews with several representatives of the international human rights system, including a representative of the CRPD Committee Secretariat, a senior official within OHCHR and a representative of the Office of the UN SR Disabilities.

⁴² Bård A. Andreassen, Hans-Otto Sano and Siobhán McInerney-Lankford, *Handbooks of Research Methods in Law series* (Edward Elgar 2017)

⁴³ John R. Crook ‘The International Court of Justice and Human Rights’ [2004] *Northwestern Journal of International Human Rights* 8

⁴⁴ McInerney-Lankford, Siobhán ‘Legal methodologies and human rights research: challenges and opportunities’ in *Research Methods in Human Rights: A Handbook*, edited by Bård A. Andreassen, Hans-Otto Sano, Siobhán McInerney-Lankford, (Cheltenham: Edward Elgar Publishing 2018)

⁴⁵ All concluding observations issued from the establishment of the Committee until May 2021

⁴⁶ Sébastien Lorion ‘The institutional turn of international human rights law and its reception by state administrations in developing countries’ PhD Thesis University of Copenhagen 2019, p. 42

A key soft law instrument which I will draw upon in my study of NHRIs is the Paris Principles which, although developed outside of the international human rights system, were subsequently adopted by the UN General Assembly by way of resolution in 1993.⁴⁷ In my analysis of the Paris Principles I have drawn on General Observations issued by the Sub Committee on Accreditation in the Global Alliance of NHRIs.

1.5.2 Empirical Research

In developing the empirical element of my enquiry, I drew from grounded theory. Grounded theory is premised on the view that a theory can be developed through rigorous analysis of empirical data.⁴⁸ It emphasises critical analysis of how meanings, actions and social structures are constructed.⁴⁹ This approach ensured that my empirical research was sufficiently robust to generate sound and credible findings.

Grounded theory informed my approach to data collection which had two principal phases. In the first phase of my empirical research, I sought to develop an evidence base documenting how NHRI designated as IMMs and DPOs have collaborated at the international level. As part of this phase, I completed a three-month secondment with the UN SR Disability. During my secondment I conducted a critical analysis of how the UN SR Disability has collaborated with NHRI(IMM)s, including in supporting the UN SR Disability's engagement with disabled people and their representative organisations.

To inform my analysis, with the assistance of the Global Alliance of NHRI and the regional networks of NHRIs under the auspices of the UN SR Disability, a questionnaire was issued to all NHRIs in June 2020. The questionnaire invited NHRIs to identify good practices and lessons learnt during the term of the first mandate holder. It included questions relating both to the relationship between NHRIs and the UN SR Disability and relating to the relationship between NHRIs and DPOs. A total of 20 replies were received from NHRIs across all regions of the world.⁵⁰

The results of the questionnaire provided me with important insights into the activities of NHRIs and assisted in the identification of NHRIs which were engaging in innovative practices

⁴⁷ UN General Assembly resolution 48/134 on "National Institutions for the Promotion and Protection of Human Rights" 20 December 1993

⁴⁸ Love et. al (n. 12)

⁴⁹ Charmaz, Kathy. 2014. *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, 2nd ed. Thousand Oaks: Sage p. 151

⁵⁰ Copies of responses held by Office of UN Special Rapporteur on Disabilities.

in monitoring the CRPD. I contacted and conducted interviews with representatives of seven NHRIs. Namely the German Institute for Human Rights ('GIHR'), the Danish Institute for Human Rights ('DIHR'), the Fijian Human Rights Commission, the New Zealand Human Rights Commission ('NZHRC'), the Australian Human Rights Commission ('AHRC'), the Scottish Human Rights Commission ('SHRC') and the NIHRC. In addition, I reviewed relevant documentation relating to their role as an IMM. Due to time constraints and travel restrictions, I was unable to carry out interviews with representatives of DPOs in the states of the seven NHRIs. In order to address this potential gap, I selected NHRIs in states which have been examined by the CRPD Committee. Documentation submitted by DPOs for the purposes of the examinations provided me with an insight into the relationship between the NHRIs designated as IMMs and the national DPM. The first phase of my research informed the design of my case study analysis.⁵¹

The second phase of my empirical research involved two case studies. Early in my research I recognised that I needed to comprehensively review the relationship between NHRIs and DPOs in real world scenarios. Yin recommends that explanatory case studies be utilized where a researcher is seeking to explore a relationship.⁵² Yin defines a case study as '... an empirical inquiry that investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident'.⁵³ I therefore selected an explanatory case study as my principal method of enquiry.

I developed several criteria for the selection of case studies in order to ensure that the most insightful would be identified.

I sought out countries which hosted active DPMs. In doing so I considered whether there were DPOs who actively engaged in rights-based advocacy. I also considered whether the DPM had a history of influencing change.

I limited the scope for selection to jurisdictions in which the NHRI has either been formally designated or is in the process of being formally designated as the IMM.

⁵¹ Della Porta, Donatella, and Michael Keating, 'How many approaches in the social sciences? An epistemological introduction' in *Approaches and Methodologies in the Social Sciences*, edited by Donatella della Porta and Michael Keating, 19-39. (Cambridge: Cambridge University Press 2013)

⁵² Yin, R. K. *Case study research: Design and methods*. (Sage 1994).

⁵³ *Ibid* p. 23

In my analysis of NHRIs, I noted that there is significant diversity within the range of bodies that have been accredited as NHRIs. Broadly speaking there are four distinct structural formats which NHRIs reflect namely, the Commonwealth Commission model; the francophone Commission model; the Institute model and the Ombudsman model. These models are discussed in Chapter 3. I decided that my research would be most impactful if I selected NHRIs which reflected the same model. In light of its popularity, I decided to limit the scope for selection to NHRIs which reflect the Commonwealth Commission model. This is the model which I am most familiar with.

In order to further assist with the selection process, I reviewed global trends in the designation of NHRIs as IMMs. I noted that in most circumstances NHRI have been solely designated as the IMM without the state establishing a broader Independent Monitoring Framework. In addition I noted that the global trend was for NHRIs to also be appointed as a state's national equality body. In order to ensure the broadest possible relevance for this research I therefore determined that I should ensure that my case studies reflect these trends.

One final factor I considered was my own knowledge of the potential case study. NHRIs are complex institutions, the roles that they perform and the impact they have tends to depend significantly on the context in which they operate. In light of this, I considered that in selecting a case study I should consider my own knowledge of the legal, political and social context in the states in which a NHRI operates.

Drawing upon these considerations, I used the following criteria to select my case studies:

1. The presence of an active DPM that has been active in rights-based advocacy
2. The NHRI should reflect the Commission model prominent throughout the Commonwealth.
3. The NHRI should also perform the role of the national equality body.
4. The NHRI should have been selected as the Independent Monitoring Mechanism for the purposes of Article 33(2).
5. The state should not have established a Monitoring Framework composed of DPOs.
6. The NHRI should have been accredited by the Global Alliance of NHRI as an A status NHRI.
7. Pre-existing knowledge and insight of the researcher

Based on the application of this set of criteria, I selected the EHRC in Great Britain and the Irish Human Rights and Equality Commission ('IHREC'). Both institutions met each of the above criteria.

The UK ratified the CRPD in 2009 and its initial report on compliance has been examined by the UNCRPD Committee. In addition, the UK was the first State Party to be the subject of a systemic inquiry by the CRPD Committee. In contrast, the Irish Government ratified the CRPD in 2018. During the period of my evidence gathering the Irish Government prepared and submitted its initial state report to the CRPD Committee.

Both institutions in fact have similar structures for engagement with the DPM. What makes the two countries specifically of interest for this inquiry is that both jurisdictions host active DPMs. The UK DPM has been active for several years and, as I will set out, has gone through periods of growth and transformation. In contrast the Irish DPM is in a process of development.

Case Studies Research Methods

I have set out my case studies in two separate chapters and discuss my evidence gathering there. I adopted a common methodological approach to each case study.

The first stage of my case study analysis was to review the legal mandate of each NHRI and to map out their activities. Furthermore, I reviewed the structures within each organisation and where possible I reviewed the minutes of relevant committees. The strategic plans and annual reports of each organisation also provided important sources of information on their respective activities.

When engaging with representatives of both institutions I was mindful of the comments of Sano and Martin that state bodies '...tend to represent researchers as having 'hostile interests' in order to protect themselves'.⁵⁴ They highlight that 'informal ties' inside an organisation can prove crucial in gaining access. Therefore, I drew on my network and previous working relationship with several senior staff and officers within each of the respective Commissions to ensure that I was able to gain a high level of access.

⁵⁴ Sano, Hans-Otto, and Tomas Max Martin. 'Inside the Organization. Methods of researching human rights and organizational dynamics' in *Research Methods in Human Rights: A Handbook*, edited by Bård A. Andreassen, Hans-Otto Sano, Siobhán McInerney-Lankford, (Edward Elgar Publishing 2018), p.274

In analysing the DPM in each of my case studies I initially reviewed existing academic literature. In order to develop a timeline of development I also reviewed relevant newspaper articles and the reports of key DPOs and Organisations for Disabled People ('OfDP').

When identifying organisations to participate in my research, I utilised purposeful sampling to ensure that I selected organisations which had experience of engaging with their NHRI. I identified three categories of CSOs: DPOs, OfDPs and Non-government organisations ('NGOs').

In categorising CSOs, I drew on the definition of DPOs reflected in the CRPD Committee's General Comment Number 7 ('GC 7'). In keeping with the CRPD, I prioritised the selection of disabled people and DPOs. In addition, in order to understand the relationship between OfDPs and the state I interviewed a number of OfDPs. This allowed me to make several important observations relating to the preferred partners of the Governments in both of my case studies. Furthermore, in each case study I interviewed a number of human rights NGOs. I selected NGOs which could provide me with insights into rights-based advocacy in each of my case studies. I only approached OfDPs and NGOs for interviews when I felt that they could make a unique contribution to my analysis.

Interview transcripts were coded utilising the NVivo software programme. In line with grounded theory, I developed a set of initial codes and then based on my initial analysis I developed a set of more sophisticated codes, in order to assist me in identifying a theory from the research.⁵⁵

Whilst conducting my case study on the UK I was seconded to the University of Leeds. Once I had developed a set of draft findings, I facilitated an engagement event with researchers and activists during which I shared my preliminary findings and invited their views. I refined my findings in light of a number of constructive comments received at this event. I conducted my case study on Ireland upon my return to NUI Galway. Again, once I developed a set of initial findings, I shared my findings with researchers and activists to order to invite their views and refine my findings accordingly.

⁵⁵ Kathy Charmaz, *Constructing Grounded Theory* (SAGE 2014), 124-132.

To assist in the development of my overall findings and conclusions, with the co-operation of the NIHRC, I presented my draft overall findings at two events. The first of which involved Commissioners and the staff of the NIHRC and the second event involved DPOs. On the basis of their views I reviewed my overall findings. I also had an opportunity to present my key findings at a conference organised by the DARE network in Brussels.⁵⁶ A representative of the European Network of NHRIs provided a formal response to my findings.

1.6 Structure of PhD

This PhD is structured into six chapters.

A legal analysis of the relevant articles of the UNCPRD is presented in Chapter 2. This focuses specifically on Article 33, examining the requirement on states to designate a focal point and to establish an Independent Monitoring Mechanism or Framework. Furthermore, in this chapter I will consider the right to participation. To inform my legal analysis I will draw on a number of interviews with key individuals from the international human rights system, including representatives of OHCHR and of the CRPD Committee Secretariat.

In Chapter 3 I review literature relating to the development of social movements. In this chapter I specifically consider the development of the DPM and the role of the international DPM in the development of the CRPD. I will explore how DPOs have engaged in the international human rights system.

Chapter 4 charts the development of NHRIs internationally. This includes a review of pre-existing literature relating to the establishment, development, and activities of NHRIs. In conducting this review, I critically analyse the Paris Principles which relate to the status, functioning and the accreditation of NHRIs.⁵⁷ In addition, I set out the functions of an NHRI with reference to the activities performed by IMMs.

⁵⁶ DARE, Exploring Voice, Power and Change, 12 May 2022

⁵⁷ UN General Assembly 1993. *Principles relating to the status and functioning of national institutions for the protection and promotion of human rights ('Paris Principles')*. Resolution 48/134, UN Doc. A/RES/48/134.

My first case study is presented in Chapter 5, examining the relationship between the UK DPM and the EHRC. I begin this chapter by charting the development of the UKDPM and then consider the establishment of the EHRC and its designation as part of the UK IMM.

In Chapter 6 I present my case study on the relationship between the Irish Human Rights and Equality Commission (IHREC) and the Irish DPM. This includes consideration of how the IHREC has collaborated with DPOs in calling for ratification of the CRPD.

At the conclusion of both Chapters 5 and 6 I outline the findings arising from the case studies. In Chapter 7 I present several general findings informed by my case studies, general evidence gathering and my analysis of pre-existing literature.

1.7 Terminology

Language relating to disability can be stigmatizing and reinforce the marginalization of disabled people.⁵⁸ Throughout this PhD I have endeavoured to ensure that the language used promotes positive images of disabled people. In reviewing the language employed, I have endeavoured to use language which is acceptable amongst DPOs in my case studies.⁵⁹ Throughout this thesis I will use the term ‘disabled people’. I chose this term rather than the term ‘persons with disabilities’ which is utilized throughout the CRPD. The use of the term ‘disabled people’ is considered to respect the ‘theory, principles and terminology agreed by the UK [DPM]’.⁶⁰ It is also commonly used in Ireland.⁶¹ For the purposes of this research I consider that the term ‘disabled people’ encompasses those with physical and sensory impairments, those with chronic illnesses, the Deaf community, users and survivors of psychiatry, people with intellectual or learning disabilities, autistic and neurodivergent people.

I use the term DPOs to refer to organisations which meet the definition of being a representative organisation for disabled people as put forward by the CRPD Committee in its GC 7.⁶² As the

⁵⁸ Paul Longmore, ‘A Note on Language and the Social Identity of Disabled People’ [1985] *American Behavioral Scientist* 419

⁵⁹ Mike Oliver, “Defining Impairment and Disability: Issues at Stake,” in Colin Barnes and Geof Mercer (eds.), *Exploring the Divide: Illness and Disability*, (The Disability Press 1996).

⁶⁰ Disability Rights UK Implementation of the United Nations Convention on the Rights of Persons with Disabilities in England and Wales Shadow report, (London, 2017) p. 4 Available at:

<https://www.disabilityrightsuk.org/sites/default/files/pdf/CRPD%20shadow%20report%20-%20England%20Wales%2026%20January%202017.pdf> (Accessed on 1 June 2022)

⁶¹ ILMI ‘Why we need to talk about the “Disability Sector” 15 May 2020 Available at: <https://ilmi.ie/why-we-need-to-talk-about-the-disability-sector/> (Accessed on 1 June 2022)

⁶² CRPD Committee. (2018). General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention (UN Doc CRPD/C/GC/7).

CRPD Committee have made clear this includes only organisations run and controlled by disabled people themselves.

As I will discuss there is a range of CSOs who advocate on behalf of disabled people. I will refer to organisations that speak on behalf of disabled people who do not meet the definition of a representative organisations as an Organisations for Disabled People (OfDP).

I also use the term DPM to refer to the movement composed of disabled people and DPOs. Consistent with the approach of the UN I will use the term ‘human rights NGO’ to refer to CSOs involved in rights-based advocacy.⁶³

The principal subject of this enquiry is NHRIs who have been designated as Independent Monitoring Mechanisms throughout this dissertation I will refer to these bodies using the abbreviation ‘NHRI (IMM)’.

⁶³ OHCHR ‘Working with the United Nations Human Rights Programme: A Handbook for Civil Society’ UN (New York 2006) p. 3

2. A Legal Analysis of the UNCRPD

2.1 Introduction

In this chapter, I will provide a general introduction to the CRPD, which will include the history of its development. In doing so I will set out the theory of change which underpinned the development of the UNCRPD. Articles 33 and 4(3) place unique obligations on the state to establish an IMF, to designate a CRPD focal point and to support the growth of representative groups of disabled people or DPOs.

The current UN SR Disability has described Article 33 as placing an obligation on the state to establish, ‘domestic institutional architecture for change...[that will]... meaningfully shape law reform agenda for years to come’.⁶⁴ In my view Article 33 cannot be considered in isolation from Article 4(3). Considering these articles collectively illuminates the fact that the architecture for change contains three pillars, the government focal point, the DPM and an IMM, which in most cases will be the NHRI. The three pillars are complementary and their capacity to shape law reform can only be realised when they work in concert.

This enquiry is specifically focused on the relationship between NHRI(IMM)s and DPMs. In this legal analysis I will consider how the UNCRPD creates circumstances to enable DPOs to effect change and to form new alliances.

In the first part of this chapter, I will set out the obligations on the state to designate bodies to facilitate implementation and to monitor the UNCRPD. I will then consider the obligations on the state to ensure the effective participation of disabled people and their representative groups. In doing so I will set out how the UNCRPD uniquely places an obligation on states to give priority to DPOs and to develop mechanisms to facilitate the participation of DPOs in the policy making process. Throughout this chapter I will set out how an NHRI(IMM) can support DPOs to engage in the policy making process.

There are several sources of law which will inform this legal analysis. In 2009, the OHCHR published a thematic study on the structure and role of national mechanisms for the

⁶⁴ Gerard Quin, *The CRPD as an Engine of Domestic Law Reform*. Conference of States Parties to the UNCRPD. UN Headquarters, New York City, October 31, 2008..

implementation and monitoring of the CRPD,⁶⁵ followed by a guidance document on the implementation of Article 33(2) in 2014.⁶⁶ I will also draw on the CRPD Committee's General Guidelines on Independent Monitoring Mechanisms ('the General Guidelines')⁶⁷ and the Committee's GC 7 on participation. Guidance by the CRPD Committee set out in its concluding observations on the formation of focal points and Independent Monitoring Frameworks ('IMFs') brings some additional prescriptions but has not been conclusive on all aspects and has been inconsistent in some matters. The UN SR Disability is a further source of soft law guidance that addresses this issue.⁶⁸

Terminology

The principal subject of this chapter is NHRIs who have been designated as Independent Monitoring Mechanisms throughout this thesis I will refer to these bodies using the abbreviation 'NHRI (IMM)'.

2.2 History of Development

At the turn of the century, disabled people were, in theory, protected by way of the core human rights treaties on an equal basis as everyone else.⁶⁹ This point was reiterated within the Vienna Declaration and Programme of Action which provided that '...all human rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities...'.⁷⁰ However there was a realization that disabled people often found that in practice they were unable to access and enjoy their rights on an equal basis with others.

Following the Vienna Declaration, the General Assembly in 1994 adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.⁷¹ These Rules were innovative in a number of respects, for instance requiring the establishment of Governmental coordination mechanisms relating to disabled people.⁷² The adoption of the Rules encouraged reflection internationally on the development of disability-based anti-discrimination

⁶⁵ OHCHR, 'Thematic Study by the Office of the United Nations High Commissioner for Human Rights on the Structure and Role of National Mechanisms for the Implementation and Monitoring of the Rights of Persons with Disabilities', AHRC/13/29,'

⁶⁶ OHCHR, 'National Implementation and Monitoring' UN Doc CRPD/CSP/2014/3 (1 April 2014)

⁶⁷ CRPD Committee, 'Guidelines on Independent Monitoring Frameworks and their participation in the work of the Committee' 2018

⁶⁸ UN Special Rapporteur Disabilities, Report to the Seventy-first session of the UN GA (2016) UN Doc A/71/314,

⁶⁹ Guemsey K, Committee on the CRPD in Ilias Bantekas, et al (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press 2018) p. 1016

⁷⁰ Vienna Declaration and Programme of Action, adopted by the World Conference on Human Rights in Vienna on 25 June 1993

⁷¹ UN General Assembly, 'Standard Rules on the Equalization of Opportunities for Persons with Disabilities' (1993) UN Doc A/RES/48/96, Rule 17.

⁷² *ibid*

legislation.⁷³ However, the Rules ‘set-forth an outmoded medical and charity-based understanding of disability’.⁷⁴ Furthermore, as ‘soft law’ the Rules lacked a ‘legally binding character’.⁷⁵ At the turn of the century the DPM realised that the mainstreaming of the disability rights within the UN human rights machinery required the adoption of a specific convention on the rights of disabled people.⁷⁶

In 2001 the General Assembly adopted a resolution promoted by Mexico establishing an Ad Hoc Committee to ‘...consider proposals for a comprehensive and integral convention to promote and protect the rights and dignity of persons with disabilities...’.⁷⁷ The work of the Ad Hoc Committee was informed by the publication of a study by Degener and Quinn on the use and future potential of United Nations human rights instruments in the context of disability.⁷⁸ The study found that there was a need for a convention to ‘tailor general human rights norms to meet the particular circumstances of persons with disabilities’.⁷⁹ Notably the report identified that NHRIs could play a key role in promoting the rights of disabled people in national settings.⁸⁰

At the first session of the Ad Hoc Committee State representatives, including those from the US and the EU bloc, outlined that they were not convinced of the need for a human rights instrument for disabled people.⁸¹ In contrast Mexico and other Latin American states were strongly of the view that a new convention was required.⁸² In the year between the first and second session, disability advocates embarked on a significant lobbying campaign with supportive and unsupportive states, which resulted in a change of opinion.⁸³ At the second session, it was agreed that a working group be established to prepare a draft instrument. The working group was to be composed of states, NGOs and NHRIs, and was under the chairpersonship of Don McKay.⁸⁴

⁷³ Degener, T and Begg A, *From Invisible Citizens to Agents of Change: A Short History of the Struggle for the Recognition of the Rights of Persons with Disabilities at the UN* in Fina, V, et al (ed.) *The United Nations Convention on the Rights of Persons with Disabilities : A Commentary*, (Springer 2017) p. 10

⁷⁴ Stein M and Lord J, ‘Future prospects for the UNCRPD’ in Arnardóttir OM and Quinn G (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009) p. 22

⁷⁵ *ibid*

⁷⁶ Degener and Begg (n. 73) p. 11

⁷⁷ UN General Assembly, *Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities*, December 19 2001, Resolution A/RES/56/168, para. 1.

⁷⁸ Quinn and Degener (n. 33)

⁷⁹ *ibid* p. 8

⁸⁰ *Ibid* p. 273

⁸¹ United Nations Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons With Disabilities, United Nations General Assembly, U.N. Doc. A/AC.265/2006/CRP.I (Dec. 7, 2005)

⁸² Degener and Begg (n. 73) p. 16

⁸³ *Ibid* p. 18

⁸⁴ *ibid* p. 9

The involvement of DPOs in the negotiation of a treaty was unprecedented. As Rasmussen & Lewis have stated ‘...the CRPD was the first UN Convention with significant civil society input in its drafting process. In fact, much of the final text incorporates that drafted by civil society’.⁸⁵ McCallum has highlighted that DPOs and disabled people were the ‘movers and shakers’ in negotiating the Convention.⁸⁶ The role of NHRIs during the negotiation of the treaty has also been highlighted, in particular the AHRC played a key role.⁸⁷

The Ad Hoc Committee concluded their deliberations in 2006. The Convention was adopted by the General Assembly on 13 December 2006 and entered into force on 3 May 2008, along with its Optional Protocol. At the time of writing there are 184 signatories to the UNCRPD and 164 ratifications.

2.3 Substantive Provisions of CRPD: Unique and Extensive

The CRPD places unique obligations on the state which are broad in scope and extensive. The development of the CRPD was informed by the social model of disability which puts forward the view that it is society which disables people.⁸⁸ The influence of the social model on the CRPD is seen in the significant emphasis placed on the role of the state in addressing obstacles faced by disabled people and in protecting them from abuses by others.⁸⁹ Reflecting the social model the CRPD takes an ‘expansive view of the state’s role’.⁹⁰

Human rights have traditionally been categorised into socio-economic rights and civil and political rights. Civil and political rights guarantee what has been described as ‘negative liberty’ and in doing so they seek to restrain the state, whereas socio-economic rights require positive action from the state to guarantee ‘positive liberty’.⁹¹ The CRPD represents a ‘pluralisation of human rights’ it ‘subtly reformulates and extends existing human rights to take

⁸⁵ Rasmussen M, Lewis O. Introductory Note to the United Nations Convention on the rights of persons with disabilities. *International Legal Materials*. 2007; 46(3):pg 441

⁸⁶ Ron McCallum Epilogue in in Sabatello M and Schulze M, *Human Rights and Disability Advocacy* (2013 University of Pennsylvania Press)

⁸⁷ *ibid*

⁸⁸ Theresia Degener, *Disability in a Human Rights Context* [2016] 5(3) *Laws* 35, p.14

⁸⁹ Frédéric Mégret, ‘The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?’ [2008] *Human Rights Quarterly* 494, p. 507

⁹⁰ Frédéric Mégret, ‘The Disabilities Convention: Towards a Holistic Concept of Rights’ [2008] *IJHR* 273, p. 277

⁹¹ Lord, Janet E. and Stein, Michael Ashley, “The Domestic Incorporation of Human Rights Law and the United Nations Convention on the Rights of Persons with Disabilities” (2008). 83 *Washington Law Review* 449, p. 501

into account the specific experience of persons with disability'.⁹² In drawing on the principle of non-discrimination and equality the CRPD breaks down the traditional distinction between civil and political and socio-economic rights.⁹³ As a result the implementation of its provisions requires new innovative approaches.

Article 1 of the CRPD makes clear that the Convention is intended to 'promote, protect and ensure' human rights. Article 1 reflects the categorisation of human rights obligations into the respect, protect and fulfil categories.⁹⁴ Obligations to respect are those that require the state to 'abstain from doing anything that violates the integrity of the individual'.⁹⁵ For instance the state should not unjustifiably deprive an individual of their liberty. Obligations to protect, relates to the prevention of other individuals or groups from violating the integrity, freedom of action or human rights of others. The CRPD places extensive obligations on the state to protect disabled people from abuses by private individuals. For instance, Article 9 requires states to 'ensure that private entities that offer facilities which are open or provided to the public take into account all aspects of accessibility for persons with disabilities'. Article 8 sets out extensive obligations on the state to 'foster respect for the rights and dignity of persons with disabilities' which are more detailed than 'any of its predecessors' going so far as to require state to go about 'engineering changes in attitude'.⁹⁶ Finally the obligation to fulfil requires the provision of positive measures, such as the provision of a social security system. This categorisation provides a useful guide for the exploration of a state's duties under the CRPD. As I will discuss later the CRPD places obligations on the state to respect the right of disabled people to form organisations, to protect them against attempts from other organisations to diminish their advocacy efforts and to provide funding to support their activities.

The substantive norms set out in the CRPD includes rules; standards and principles.⁹⁷ Arduin highlights that rules 'are provisions whose ex ante meaning is clear; they specify an outcome before particular cases arise'.⁹⁸ In contrast standards do not define an outcome, their 'meaning is determined, not ex ante, but at the time of their implementation'.⁹⁹ Principles are

⁹² Mégret, (n. 89) p. 277

⁹³ Alston P and Quinn G, 'The Nature and Scope of States Parties' Obligations under the International Covenant on Economic, Social and Cultural Rights' in Manisuli Ssenyonjo (ed), *Economic, Social and Cultural Rights* (Routledge 2011) p.26

⁹⁴ Ibid

⁹⁵ Ibid p.49

⁹⁶ Mégret (n. 89) p. 301

⁹⁷ Sarah Arduin, 'Taking Metaregulation to the UN Human Rights Treaty Regime: The Case of the CRPD', [2019] Law and Policy 411, p.41

⁹⁸ Ibid p. 412

⁹⁹ Ibid p. 419

‘background notions’ they are of ‘general application to be horizontally integrated across the CRPD’.¹⁰⁰ The inclusion of standards and principles reflects the fact that the experience of disability is located in society.¹⁰¹ A determination of measures required to realise the rights of disabled people must be informed by the circumstances in the society in which they will take effect. This has significant implications for NHRIs when advising on implementation of the CRPD.

The distinction between these norms can be seen in the way the CRPD frames non-discrimination.¹⁰² It is enshrined as a central principle in Article 3(b). In addition, Article 5(2) sets down the rule that states must ‘prohibit all discrimination on the basis of disability’. Article 5(3) sets down the standard that states must ‘take all appropriate steps to ensure that reasonable accommodation is provided’. This standard performs a ‘bridging role’ across the substantive provisions within the CRPD making clear that states must ensure protections are meaningful and accessible.¹⁰³ States must explore what reasonable accommodations are required to ensure that disabled people enjoy equal benefit of the law.¹⁰⁴

For the purposes of this enquiry, it is notable that a determination of a state’s obligations under the CRPD requires a detailed appreciation of domestic circumstances. This underscores the need for the examination of a state’s compliance with the CRPD to be informed both by the international system and by domestic systems. In implementing the CRPD a state must develop its understanding of the circumstances of disabled people in order to inform their public policies.¹⁰⁵ Similarly an independent monitor must develop its own systems for recording and analysing the lived experiences of disabled people and of the impact policies.

A ratifying state will have to embark on an extensive process of policy and law reform to implement its obligations. The CRPD Committee have made clear that legislative measures to implement the CRPD will include revisions to civil and criminal law.¹⁰⁶ There is a risk that states will seek to confine their obligations under the CRPD to those policies that are

¹⁰⁰ Lord, Janet E. and Stein, Michael Ashley, "The Domestic Incorporation of Human Rights Law and the United Nations Convention on the Rights of Persons with Disabilities" (2008) 83 Washington Law Review 449, p. 463

¹⁰¹ Inger Marie Lid, ‘Vulnerability and disability: a citizenship perspective [2015] Disability & Society 1554

¹⁰² Oddný Mjöll Arnardóttir, ‘A Future of Multidimensional Disadvantage Equality’ in Oddný Mjöll Arnardóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009) p. 41

¹⁰³ Lawson A, Duties to Make Adjustments and Human Rights’ in Lawson A (ed.), *Disability and Equality Law in Britain: The Role of Reasonable Adjustment* (Hart Publishing, Oxford, 2008) p. 32.

¹⁰⁴ Corsi J, Article 5 Equality And Non-Discrimination in Ilias Bantekas, et al (eds) in *The UN Convention on the Rights of Persons with Disabilities : A Commentary* (Oxford University Press 2018). p.140

¹⁰⁵ UNCRPD Article 31

¹⁰⁶ CRPD Committee, Concluding Observations on Costa Rica UN Doc CRPD/C/CRI/CO/1 (12 May 2014) para 8.

specifically targeted at disabled people. The CRPD at Article 4(1)(c) requires states to ‘take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes’. Article 4(1)(c) is linked to the concept of ‘universal design’, under which policies must be applicable ‘by all people, to the greatest extent possible, without the need for adaptation or specialized design’.¹⁰⁷ A key challenge for DPOs and NHRI(Imm) is ensuring that decision makers appreciate that the implementation of the CRPD requires reform of ‘the totality of policy measures, with intended or unintended consequences, for the welfare, living conditions, autonomy, participation and dignity of persons with disabilities’.¹⁰⁸

For the purposes of this enquiry, it is important to note that the UNCRPD contains a broad range of substantive provisions, the implementation of which will require states to embark upon a significant programme for reform. In developing reforms, a state will have to develop its own understanding of the circumstances of disabled people and the particular challenges which they may experience. Reflecting this the CRPD devotes Article 31 to setting out specific obligations on the state to develop their evidence gathering systems to ensure that they are capturing the lived experience of disabled people. An NHRI(Imm) which is responsible both for advising on measures required to bring about the implementation of the CRPD and to monitoring the state’s efforts will also have to develop its capacity to capture the lived experience of disabled people.

2.4 Models of Disability

Until the 1960s disability scholarship was dominated by the medical model of disability. This model ‘personalizes disability, casting it as deficit located within individuals that requires rehabilitation to correct the physiological defect or to amend the social deficiency’.¹⁰⁹

The social model of disability challenges the medical model and argues that it is society which disables people who have impairments.¹¹⁰ One of the earliest definitions of the social model was formulated by the UK DPO the Union of Physically Impaired Against

¹⁰⁷ UNCRPD Article 2

¹⁰⁸ Halvorsen R, Waldschmidt, A Hvinden B and Böhler K, Diversity and dynamics of disability policy Europe An analytical framework in Rune Halvorsen R et. Al (eds) *The Changing Disability Policy System Active Citizenship and Disability in Europe* (Routledge 2017) p. 13

¹⁰⁹ Arlene Kanter ‘The Law: What’s Disability Studies Got to Do with It or An Introduction to Disability Legal Studies’ 2011 *Columbia Human Rights Law Review* 403, p. 420

¹¹⁰ See R. Traustadottir, ‘Disability Studies, the Social Model and Legal Developments’, in Oddny Mjoll Arnardottir and Gerard Quinn (eds.), *The UN Convention on the Rights of Persons with Disabilities*, 3 (Martinus Nijhoff, 2009).

Segregation. It stated, ‘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’.¹¹¹ The social model of disability suggests that if ‘social barriers were broken down, disability would not exist’.¹¹² Campbell and Beckett have highlighted the important role played by the social model in positioning ‘the present (a disabling society) as unjust’ and in allowing ‘people to recognise one another as members of the same struggle, with shared values, coming together to dismantle disabling barriers’.¹¹³

Whilst the social model provided a useful oppositional device, numerous commentators raised concerns that the model failed to acknowledge the ‘the personal experiences of physical and intellectual restrictions, of illness, of fear of dying’.¹¹⁴

Degener notes that whilst the social model informed the negotiation of the CRPD, the CRPD itself goes beyond the social model and ‘codifies the human rights model of disability’.¹¹⁵

Degener further highlights that the human rights model improves on the social model by acknowledging that a person’s condition ‘...might reduce the quality of life but [their life] belongs to humanity and thus must be valued as part of human variation...’.¹¹⁶ Degener has put forward six propositions for how the human rights model improves on the social model of disability.

Lawson and Beckett have analysed the propositions put forward by Degener and offered a defence of the social model. They highlight the ‘danger that multiplying models simply multiplies confusion’.¹¹⁷ Lawson and Beckett highlight that the social model ‘operates to identify where policy reform is needed’. They acknowledge that the model cannot ‘provide a detailed blueprint or roadmap for policy responses to disability’.¹¹⁸ In contrast the human rights model is a model of disability policy. The human rights model emphasises the ‘need to

¹¹¹ UPIAS ‘Aims’, paragraph 1 (1997) available at <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-fundamental-principles.pdf> (Accessed on 2 September 2022)

¹¹² Anna Arstein-Kerslake, ‘Legal Capacity & Gender: Realising the Human Right to Legal Personhood and Agency of Women, Disabled Women, and Gender Minorities (Springer, 2020), p. 51

¹¹³ Campbell, T and Beckett, A ‘The social model of disability as oppositional device’ [2015] *Disability and Society* 270, p. 283

¹¹⁴ Jenny Morris. *Pride against Prejudice*. Philadelphia: New Society Publishers, 1991. p. 3

¹¹⁵ Theresia Degener, *Disability in a Human Rights Context* [2016] *Laws* 35, p. 22

¹¹⁶ *ibid* p. 19

¹¹⁷ Anna Lawson & Angharad E. Beckett ‘The social and human rights models of disability: towards a complementarity thesis’ [2021] *The International Journal of Human Rights* 348, p.362

¹¹⁸ *Ibid* p. 364

progress disability policy and law reform in line with human rights principles and obligations, as set out in the CRPD'.¹¹⁹

Whilst the CRPD Committee now routinely refer to the human rights model, the social model continues to provide a useful 'aid to understanding' the barriers faced by disabled people and to the problematizing processes.¹²⁰ The human rights model informed by the CRPD provides a set of principles and values which can inform the design of disability policies to address the deficiencies of the social model. I therefore see the social model and human rights model as complimentary to one another rather than in opposition.

For the purposes of this enquiry both models of disability are useful in encouraging consideration of how the internal thought processes of decision makers impact on outcomes in the policy making process. All individuals employ heuristics to assist with decision making, these are defined as 'cognitive shortcuts that allow individuals to meaningfully process probabilistic information'.¹²¹ These shortcuts can be 'rational,' which pursue clear goals, or 'irrational,' which draw on deeply held beliefs or values.¹²² The beliefs and values which an individual holds shapes their view of disabled people in society and shapes their view of the obligation of the state towards disabled people. A key challenge for NHRI(IMM) and DPOs is to change the perspectives of decision makers who perceive disabled people as medical patients who require treatment and are incapable of taking decisions for themselves.¹²³ Such perspectives can lead to decision makers discounting emancipatory public policy interventions.¹²⁴ In my case studies I will consider how a NHRI(IMM) working with DPOs have sought to challenge negative views held by decision makers.

2.5 Procedural provisions of CRPD

The negotiation of the UNCRPD took place simultaneously to broader negotiations relating to the treaty body system more broadly.¹²⁵ These negotiations informed discussions relating to the UNCRPD with both the DPM and NHRIs proposing a number of innovative approaches to

¹¹⁹ Ibid p. 365

¹²⁰ Colin Barnes, 'Understanding the Social Model of Disability' (Handikappförbundens samarbetsorgan, Halmstad 18 November 2009) , <https://silo.tips/download/understanding-the-social-model-of-disability>. Accessed 22 February 2022

¹²¹ Alex Geisinger and Michael A. Stein, A Theory of Expressive International Law, [2019] Vanderbilt Law Review 75, p. 114

¹²² Cairney Standing on the Shoulders of Giants: How Do We Combine the Insights of Multiple Theories in Public Policy Studies? [2013] The Policy Studies Journal, 1, , p. 7

¹²³ Colin Barnes, 'Re-thinking Disability, Work and Welfare' [2012] Sociology Compass 6/6: 472, p. 475

¹²⁴ Pinto P, At the crossroads: Human rights and the politics of disability and gender in Portugal [2011] European Journal of Disability Research 116, p. 127

¹²⁵ Egan S, Reform of the UN Human Rights Treaty Body System, in Frédéric Mégret, and Philip Alston (eds) The United Nations and Human Rights : A Critical Appraisal (2nd edn, Oxford University Press 2020), p. 646

the system for monitoring compliance.¹²⁶ However, as the negotiations progressed it became clear that States were unwilling to subscribe to new methods of international monitoring.¹²⁷ States were reluctant to agree to the proposed CRPD Committee taking on the character of a ‘quasi judicial’ body.¹²⁸ As a result the procedure for international monitoring provided within the UNCRPD is broadly consistent with the committee structure provided within the other treaties.

DPO leaders and NHRIs sought to develop innovative arrangements at the domestic level.¹²⁹ Noting the challenge of progressing disability policy, and the ambitious goals of the Convention, negotiators sought to facilitate the development of domestic institutional architecture. It was hoped that this architecture would play a key role in ensuring that CRPD compliance was placed on the political agenda of ratifying states.¹³⁰ As a result the provisions of the CRPD represent ‘a clear improvement for human rights implementation’ at the domestic level.¹³¹

In this section I will consider the role of the CRPD Committee, the Conference of State Parties and then I will consider the responsibility upon states to develop domestic institutional architecture to bring about compliance at the domestic level.

2.5.1 International Oversight

2.5.1.1 Role of the CRPD Committee

Article 14 of the CRPD makes provision for a committee of experts with up to a maximum of 18 members. The CRPD Committee perform five key functions, namely: consideration of State reports; receiving individual complaints; considering inter-state complaints; conducting inquiries into alleged systemic violations of treaties and preparing general recommendations

¹²⁶ Michael Ashley Stein and Janet E Lord, ‘Monitoring the Convention on the Rights of Persons with Disabilities: Innovations, Lost Opportunities and Future Potential’ [2010] 32 HRQ 689

¹²⁷ Combrinik ‘Article 36 Consideration of Reports’ in Ilias Bantekas, et al (eds) *The UN Convention on the Rights of Persons with Disabilities : A Commentary*, (Oxford University Press 2018) p. 1066

¹²⁸ Egan S, Reform of the UN Human Rights Treaty Body System, in Frédéric Mégret, and Philip Alston (eds) *The United Nations and Human Rights : A Critical Appraisal* (2nd edn, Oxford University Press 2020), p. 646

¹²⁹ Meredith Raley, ‘The Drafting of Article 33 of the Convention on the Rights of Persons with Disabilities: The Creation of a Novel Mechanism’ [2016] *IJHR* 138.

¹³⁰ De Beco G and Hoefmans A, ‘National Structures for the Implementation and Monitoring of the UN Convention on the Rights of Persons with Disabilities’, in Gauthier de Beco (ed), *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention* (Brill/Nijhoff 2013)

¹³¹ Marianne Schulze, ‘Monitoring the Convention’s Implementation’ in Maya Sabatello and Marianne Schulze (eds), *Human Rights and Disability Advocacy* (University of Pennsylvania Press 2013) p. 209

or comments to assist the interpretation of the Convention.¹³² In keeping with the other Treaty bodies the CRPD Committee augments the CRPD by resolving ‘ambiguities and indeterminacy, conflicts among its principles and rights [and work] out meanings of its grand terms’.¹³³

The Committee is permitted to establish its own rules of procedure and has done so. As set out, the Committee have also issued guidance to civil society and IMMs on monitoring the UNCRPD.¹³⁴ Within two years of ratification states are required to submit to the Committee ‘...a comprehensive report on measures taken to give effect to its obligations’.¹³⁵ The UNCRPD Committee by way of its General Guidelines have elaborated extensively on the details a state should include in the report.¹³⁶ As I will explore more fully in my evidence gathering the UNCRPD Committee provide a number of opportunities for NHRI(IMM)s and DPOs to contribute to the examination process.

2.5.1.2 Conference of State Parties

The CRPD at Article 40 makes provision for the state parties to the Convention to meet regularly in a Conference of States Parties to consider any matter regarding implementation. The Conference was established to provide a platform for sharing ideas, experience, and expertise.¹³⁷ The CRPD is the first international human rights treaty to provide for a Conference of State Parties. Bantekas highlights that provision for a conference is ‘part of an established tradition whose principal aim is to keep the Convention alive by stimulating actions, collaborations, enforcement, capacity building and others’.¹³⁸ The Conference does not have enforcement powers. However, the Conference can be used to showcase emerging good practices relating to the rights of disabled people.¹³⁹

¹³² Combrinik ‘Article 36 Consideration of Reports’ in Ilias Bantekas, et al (eds) *The UN Convention on the Rights of Persons with Disabilities : A Commentary*, (Oxford University Press 2018) p. 1066

¹³³ Steiner H, ‘Individual Claims in a World of Massive Violations: What Role for the Human Rights Committee’ in Phil Alston and James Crawford (eds.), *The Future of UN Human Rights Treaty Monitoring XXXV* (Cambridge University Press, 2000) p. 30

¹³⁴ UNCRPD Committee (n. 3)

¹³⁵ UNCRPD, Article 36

¹³⁶ UNCRPD Committee, ‘Guidelines on Treaty-Specific Document to be Submitted by States Parties under Article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities’ UN Doc CRPD/C/2/ 3 (18 November 2009) para 2.

¹³⁷ Gerard Quinn, ‘The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability’ [2009] *Texas Journal on Civil Liberties & Civil Rights* 33 p. 51

¹³⁸ Bantekas, I, Article 40: Conference of States Parties in Ilias Bantekas, et al (eds) in *The UN Convention on the Rights of Persons with Disabilities : A Commentary* (Oxford University Press 2018).

¹³⁹ Alex Geisinger and Michael A. Stein, ‘A Theory of Expressive International Law’ [2007] *Vanderbilt Law Review* 77 p. 107

During the 14th session of the Conference in 2021 the GANHRI made a statement highlighting the need to monitor the impact of Covid-19 related containment measures on disabled people. Alongside the conference many DPOs and NHRIs organise side events for sharing views and putting forward proposals for reform.¹⁴⁰ The Conference therefore can provide an opportunity for DPOs and NHRI(IMM) to highlight new approaches to meeting human rights obligations to state representatives.

2.5.2 Domestic Institutions

In this section I will consider the role and functions of a CRPD focal point and an IMF or IMM. I will also consider how DPOs can engage with both bodies.

2.5.2.1 UNCRPD Focal Points

Article 33(1) places a positive obligation on states to establish a focal point for ‘matters relating to implementation’ and to consider the development of a coordination mechanism. Focal points should be ‘within government’ and should have a clear mandate relating to the implementation of the CRPD. Article 33(1) refers to the ‘designation’ of a focal point. The OHCHR acknowledges that ‘relevant bodies’ may already exist. The mandates of existing public bodies must be revised to include ‘overseeing the implementation of the Convention’.¹⁴¹ This will include promoting awareness of the Convention, participation in the development of National Disability Action Plans (NDAPs), and monitoring implementation.¹⁴²

The OHCHR highlights that the ‘designation of the ministries of health or of welfare and labour as the government focal point should be avoided’ and the preferred administrative home of a CRPD focal point is in ‘ministries responsible for human rights, social affairs and justice’.¹⁴³ The state must ensure its focal point is of ‘a sufficiently high institutional rank to effectively carry out its duties’.¹⁴⁴

¹⁴⁰ OHCHR Sponsored Side Event, What is the role of Independent Monitoring Mechanisms in implementing the Convention on the Rights of Persons with Disabilities?, 3 December 2020

¹⁴¹ OHCHR ‘National Implementation’ (n 64) para 8

¹⁴² Ibid para 10

¹⁴³ Ibid para 11(a)

¹⁴⁴ UNCRPD Committee, ‘Concluding Observations on the initial report of Argentina’ CRPD/C/ARG/CO/1 October 2012 para 51

Whilst requiring that focal points should be part of government, the OHCHR has highlighted that it may be useful to ‘recognise the independence of the focal point structure from the parent ministry...’.¹⁴⁵ Modern state administrations tend to be modelled on the concept of a ‘weberian civil service’, in which the role of the civil servants is ‘the administration of policy decisions that ministers make and for which they are held accountable’.¹⁴⁶ The OHCHR appear to be suggesting that focal points should operate as a quasi-autonomous implementation units to promote implementation.¹⁴⁷ In my case studies I will consider the extent to which this has been realized in practice.

The OHCHR has emphasised that the principal function of a UNCRPD focal point is ‘to avoid uncoordinated action’.¹⁴⁸ The key role of a UNCRPD focal point is to address the ‘eternal and ubiquitous problem’ of coordinating public administrations to support the development and implementation of disability policy.¹⁴⁹ Quinn emphasises that focal points should act as a ‘useful corrective to the tendency in all governments to fragment disability policy depending on departmental priorities (the so-called ‘silo’ effect)’.¹⁵⁰ Many of the policy problems faced by disabled people are classed as ‘wicked problems’ which require coordinated action across government.¹⁵¹ Disabled people and DPOs seeking to bring about changes in government policy often find that responsibility for public policies relating to disabled people is dissipated across a range of government departments.¹⁵² This makes it difficult to work with decision makers to isolate problems and develop solutions. The UNCRPD Committee have made clear that a UNCRPD focal point should provide an entry point for DPOs into the policy making process.

Commentators have considered how focal points can most effectively promote implementation.¹⁵³ De Beco and Hoefmans suggest that UNCRPD focal points should establish themselves as an ‘...expertise centre for all government actors when it comes to the UNCRPD

¹⁴⁵ Ibid

¹⁴⁶ Hallsworth M, Parker S and Rutter j, *Policy Making in the Real World: Evidence and Analysis* (Institute for Governance 2011) p. 34

¹⁴⁷ Koen Verhoest, ‘Agentification in Europe’, in Edoardo Ongaro, and Sandra Thiel (eds.) *The Palgrave Handbook of Public Administration and Management in Europe* (Palgrave Macmillan 2017)

¹⁴⁸ OHCHR (n. 64) National Implementation para 4

¹⁴⁹ Perri, *Joined-Up Government in the Western World in Comparative Perspective: A Preliminary Literature Review and Exploration* [2004] *Journal of Public Administration Research and Theory* 103 p. 137

¹⁵⁰ Quinn (n. 4) p. 254

¹⁵¹ Per Lægveid, Tiina Randma-Liiv, Lise H. Rykkja and Ku’li Sarapu ‘Emerging coordination practices of European central governments’ (2015) 81(2) *International Review of Administrative Sciences*, 346, p.346

¹⁵² Janet Lord and Michael Stein, ‘The Domestic Incorporation of Human Rights Law and the UNCRPD’ [2008] 83 *Washington Law Review* 449, p.463

¹⁵³ Caughey, C. (2021). Government human rights focal points: Lessons learned from focal points under the Convention on the Rights of Persons with Disabilities. *Netherlands Quarterly of Human Rights*, 39(2), 119-139.

and its implementation...'.¹⁵⁴ Guidance from the UN SR Disability suggests that focal points should have the power to compel actions by government departments.¹⁵⁵ In practice States tend to emphasise the role of focal points in promoting, rather than requiring coordination. The UNCRPD Committee have at times suggested that a focal point should hold government department to account¹⁵⁶, and at other times suggesting a focal point should simply have a promotional role.¹⁵⁷ Overall there is a lack of guidance on how focal points should perform their coordination role. Furthermore, there is a lack of guidance on the relationship between a UNCRPD focal point and an Independent Monitoring Mechanism or Framework. I will explore in my case studies how the effectiveness of a UNCRPD focal point can impact directly on the effectiveness of an NHRI(IMM). It is clear that an effective focal point can play a key role in creating opportunities for both NHRI(IMM) and DPOs to influence change.

In addition to the obligation to establish a focal point, a state is also required to consider the development of a coordination mechanism. The OHCHR suggest that a coordination mechanism '...might take the shape of an inter-ministerial group, tasked with coordinating implementation of the Convention across respective departments/sectors or levels of government....'.¹⁵⁸ In practice most states have decided not to establish coordination mechanisms.¹⁵⁹

2.5.2.2 UNCRPD Independent Monitoring Mechanisms

In this section I will present a legal analysis of Article 33(2) of the UNCRPD. In addition to drawing on guidance from the OHCHR, I have conducted a review of the UNCRPD Committee's concluding observations and its relevant guidance. At the time of writing the UNCRPD Committee have issued concluding observations relating to 91 states. In all but one set of concluding observations the Committee have considered the state's compliance with Article 33(2). In addition, I will draw on reports of the UN SR Disability's country visit procedures and previous independent studies on Article 33(2) bodies.

¹⁵⁴ De Beco G and Hoefmans A (n. 111) p. 30

¹⁵⁵ Special Rapporteur, Report to the Seventy-first session of the UN GA (2016) UN Doc A/71/314, para 68.

¹⁵⁶ CRPD (n 20)

¹⁵⁷ CRPD Committee, 'Concluding Observations on the initial report of Ethiopia' CRPD/C/ETH/CO/1 31 August 2016 para 71

¹⁵⁸ OHCHR, 'Thematic Study' (n 64) para 32

¹⁵⁹ Sébastien Lorion (2019) A Model for National Human Rights Systems? New Governance and the Convention on the Rights of Persons with Disabilities, *Nordic Journal of Human Rights*, 37:3, 234-258.

The terms ‘Independent Monitoring Framework’ and ‘Independent Mechanism’ are often used interchangeably which has created some confusion.¹⁶⁰ The focus of this enquiry is NHRIs who have been designated as an IMM. This role may be performed within a framework but in most cases a framework has not been created. The text of Article 33(2) is not prescriptive as to the role, powers and composition of the framework or mechanism.¹⁶¹

In its Guidelines the UNCRPD Committee have made clear that states enjoy ‘a margin of appreciation’ when deciding the composition of its monitoring framework, and that they are ‘free to determine the appropriate structure according to their political and organizational context’.¹⁶²

Article 33(2) does require that the framework include an independent mechanism and adopts the wording of the Paris Principles in referring to its functions. The OHCHR has stated that NHRIs are the ‘natural core entities of the monitoring framework at the national level’.¹⁶³ Indeed, the UNCRPD Committee in its concluding observations have consistently recommended that within a monitoring framework that a State Party ‘must have an institution that is in compliance with’ the Paris Principles.¹⁶⁴

The Committee in general appears content for the framework to be composed solely of a state’s NHRI.¹⁶⁵ The Committee recommended that the Canadian Government ‘formally appoint the Canadian Human Rights Commission as the independent monitoring mechanism’, a recommendation supported by DPOs in Canada.¹⁶⁶ The Committee have specifically recommended that states should ensure that NHRIs designated as IMMs are accredited as an A status institution by GANHRI.¹⁶⁷ The accreditation of NHRIs is discussed in Chapter 4.

Where frameworks have been developed without the inclusion of an NHRI, the Committee have found them to be inadequate, and lacking the resources, capacity and, most significantly, the independence required to perform their duties effectively.¹⁶⁸ In the case of Kenya, the

¹⁶⁰ Rachel Murray and Kelley Johnson, *Implementation of Article 33 CRPD in the United Kingdom: The Need to Consolidate Civil Society Engagement in Article 33 of the UN Convention on the Rights of Persons with Disabilities National Structures for the Implementation and Monitoring of the Convention* (ed. G De Beco), p. 110

¹⁶¹ OHCHR, ‘National Implementation’ (n. 64) para 8

¹⁶² UNCRPD Committee, *Guidelines on Independent Monitoring Frameworks and their participation in the work of the Committee*, para 12

¹⁶³ OHCHR, ‘Thematic Study’ (n 64), para. 78.

¹⁶⁴ UNCRPD Committee, *Concluding observations on the initial report of Belgium, CRPD/C/BEL/CO/1* (28 October 2014) para 49

¹⁶⁵ UNCRPD Committee, *Concluding observations on the initial report of the Czech Republic, CRPD/C/CZE/CO/1* ((15 May 2015) para 62

¹⁶⁶ UNCRPD Committee, *Concluding observations on the initial report of Canada, CRPD/C/CAN/CO/1* (8 May 2017) para 55(b)

¹⁶⁷ UNCRPD Committee (n. 140)

¹⁶⁸ UNCRPD Committee, *Concluding observations on the initial report of Argentina CRPD/C/ARG/CO/1* (8 October 2012) para 52

Committee expressed concern that the framework did not comply with the Paris Principles and specifically recommended that the Kenyan National Commission on Human Rights be included to ensure compliance.¹⁶⁹ In Spain, the umbrella DPO the Spanish Committee of Representatives of Persons with Disabilities was initially solely designated as the independent monitoring framework. However, in light of concerns relating to the lack of statutory powers, the Spanish Government included the Spanish A status NHRI within the monitoring framework.¹⁷⁰ Following the joint designation of the Spanish NHRI and the umbrella DPO as the Spanish Independent Monitoring Framework the UNCRPD Committee recorded that Spain was ‘in full compliance with Article 33(2)’.¹⁷¹

Article 33 requires States to formally designate their Article 33(2) bodies.¹⁷² The Committee have made clear that the monitoring mechanisms must have ‘a stable institutional basis that allows it to operate properly’.¹⁷³ However, this designation is not a pre-requisite for ratification and some states have ratified the UNCRPD without designating Article 33(2) bodies.¹⁷⁴ An analysis of concluding observations issued by the UNCRPD Committee suggest that around a third of all states examined were yet to designate an independent framework or IMM at the time of examination.¹⁷⁵ In Chapter 4 I will consider the practices of NHRIs designated as IMMs.

Article 33(3) places a specific obligation on states to ensure that ‘Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process’. The precise form that this participation should take is somewhat unclear.¹⁷⁶

In an interview for this research, a representative of the CRPD Committee emphasised that the model in Spain, of an NHRI being designated alongside an umbrella DPO, was broadly considered best practice. However, noting the absence of national umbrella DPOs the

¹⁶⁹ UNCRPD Committee, Concluding observations on the initial report of Kenya CRPD/C/KEN/CO/1 (30 September 2015) para 24 (c)

¹⁷⁰ NUI Galway / The Centre for Disability Law and Policy, Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of Persons with Disabilities (Irish Human Rights and Equality Commission 2016) 22

¹⁷¹ UNCRPD Committee, Concluding Observations on Spain, CRPD/C/ESP/CO/1, para. 6.

¹⁷² *ibid*

¹⁷³ UNCRPD Committee, Concluding observations on the initial report of Albania CRPD/C/ALB/CO/1 (14 October 2019) para 54

¹⁷⁴ UN SR Disability ‘End of Mission Statement by the UN SR Disability, on her visit to Zambia report’, 28 April 2016

<<https://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=19890&LangID=E>> accessed 22 February 2022

¹⁷⁵ 34 of 91 concluding observations issued include a recommendation that the state designate an independent mechanism or framework in line with Article 33(2)

¹⁷⁶ (Raley n. 3) p. 149

Committee considered it was impracticable to require states to include an umbrella DPO within a monitoring framework, and such a recommendation was not included within GC 7.¹⁷⁷

The UNCRPD Committee have consistently recommended that independent frameworks or mechanisms should be required to ensure the ‘full involvement of organisations of persons with disabilities in its monitoring tasks under the Convention’.¹⁷⁸ Therefore, whilst a state may choose not to designate a DPO within the IMF, it must still facilitate their involvement in other ways. In doing this a state must respect the operational autonomy of a NHRI. In its 2019 concluding observations on Australia the UNCRPD Committee recommended that the State Party establish ‘a formal mechanism’ to ensure the meaningful participation of disabled people and their representative groups in monitoring the convention.¹⁷⁹ The UNCRPD Committee have adopted the view that a formal mechanism should be developed to facilitate the participation of disabled people and their representative groups in the monitoring activities of a NHRI(IMM)s.¹⁸⁰

2.6 Civil society

The participation of disabled people is a central principle of the UNCRPD. Lord and Stein highlight that participation of disabled people and their representative organisations is ‘woven throughout the entire fabric of the text’.¹⁸¹ The preamble to the UNCRPD notes that the participation of disabled people ‘...will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty’. The growth and development of a vibrant DPM is essential to the effective implementation of the CRPD. Underscoring this, following the opening of the CRPD for signature, the UN Expert Group on Disability adopted the Declaration of Madrid which affirms that developing the capacity of disabled people and their representative organisations is essential for the implementation of the CRPD.¹⁸²

¹⁷⁷ Interview with CRPD Committee Secretariat representative 11 December 2021

¹⁷⁸ UNCRPD Committee (n. 142) para 55(b)

¹⁷⁹ UNCRPD Committee, Concluding observations on the combined second and third periodic reports of Australia CRPD/C/AUS/CO/2-3 (15 October 2018) para 62

¹⁸⁰ UNCRPD Committee, Concluding observations on the initial report of Estonia CRPD/C/EST/CO/1 (5 May 2021) para 65

¹⁸¹ Stein, Michael Ashley and Lord, Janet E, Monitoring the Convention on the Rights of PWDs: Innovations, Lost Opportunities, and Future Potential [2010] Human Rights Quarterly 689 p.697

¹⁸² United Nations General Assembly, ‘Declaration of Madrid: Making It Work: Civil Society Participation in the Implementation of the Convention on the Rights of Persons with Disabilities’, UNGA Resolution A/62/654

The CRPD protects the right to participation in both the implementation and the monitoring of the Convention. It recognises that the inclusion of disabled people and their representative groups in both the implementation and monitoring of the CRPD will strengthen both processes.

2.6.1 The right to participation: Article 29

Article 29 of the CRPD protects a number of specific rights relating to electoral law and sets out the obligation of State Parties to ‘promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs’.

In addition to unequivocally prohibiting exclusionary laws and practices, Article 29 places a positive obligation on states to remove barriers to participation.¹⁸³ The Article specifically acknowledges the importance of the participation of disabled people in NGOs and associations, and the value of ‘Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels’. The CRPD requires states both to respect the right of individual disabled people to participate in society and to respect the right of disabled people to join and form their own organisations.

2.6.2 The right to participate in decision making: Article 4(3)

Article 4(3) provides that ‘States Parties shall closely consult with and actively involve disabled people, including children with disabilities, through their representative organizations’ in the design and implementation of UNCRPD policies. The inclusion of a reference to ‘representative organisations’ in the text of the UNCRPD came at the suggestion of the Arab Organisation of Disabled People, who were concerned that states would seek to side-line representative groups through direct participation with individuals.¹⁸⁴ The UNCRPD recognises the role of organisations or DPOs as ‘a key component in addressing social exclusion and self- advocacy and empowerment’.¹⁸⁵

¹⁸³ J Fiala-Butora, MA & Stein, JE Lord ‘The Democratic Life of the Union: Toward Equal Voting Participation for Europeans with Disabilities’ [2014] Harv. Int'l LJ 71, p.84

¹⁸⁴ Ad Hoc Committee, Daily Summary of discussions at the seventh session of UN Convention on the Rights of PWDs, (31 January 2006), available at: <<http://www.un.org/esa/socdev/enable/rights/adhocom.htm>>. Accessed 22 February 2022

¹⁸⁵ Cera R, Participation in Political and Public Life in Fina, V, et al (ed.) The United Nations Convention on the Rights of Persons with Disabilities : A Commentary, (Springer 2017) p. 536

The UNCRPD Committee have elaborated on how the state should respect, protect and fulfil the right of disabled people to engage in collective action.¹⁸⁶ States should respect the right of disabled people to form organisation and should not refuse to acknowledge their legal status, ‘because of laws and regulations that deny the legal capacity of their members’.¹⁸⁷

In addition, the Committee make clear that states must take measures to protect the right of disabled people to engage in advocacy through their organizations. The Committee note that prior to the enactment of the UNCRPD, ‘the views of persons with disabilities were dismissed in favour of those of third-party representatives’.¹⁸⁸ The UNCRPD Committee require states to give consideration to ‘structural forces’ which may undermine the growth and development of DPOs within civil society.¹⁸⁹ To address this the UNCRPD Committee seek to ensure that priority is given to the views of organisations that are truly representative of disabled people. The Committee have clarified that DPOs must have a majority of disabled people - at least half of its membership - and should be governed, led and directed by disabled people.¹⁹⁰ The UNCRPD Committee make clear that DPOs should be given priority over OfDPs ‘which provide services and/or advocate on behalf of persons with disabilities’ when addressing issues directly related to them.¹⁹¹ The UNCRPD Committee have therefore made clear that the UNCRPD places specific obligations on the state to promote the development of DPOs and to prioritise the views over other forms of CSOs.

The Committee have elaborated on the states obligation to fulfil the right of disabled people to engage in collective action. The Committee have highlighted that ‘Full and effective participation should be understood as a process’.¹⁹² The UN SR Disability has made clear that, ‘States must create an enabling environment for the establishment and functioning of representative organizations of persons with disabilities’.¹⁹³ The UN SR Disability has highlighted that NHRI(IMM)s also must play a role in establishing the enabling environment. States must strengthen the capacity of DPOs ‘to participate in all phases of policymaking, by providing capacity-building and training on the human rights model of disability, including

¹⁸⁶ CRPD Committee, General comment No. 7 (2018) on the participation of PWDs, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention CRPD/C/GC/7 (9 November 2018)

¹⁸⁷ Ibid Para 12(c)

¹⁸⁸ Ibid para 12

¹⁸⁹ Jacobs L Lomax Cook F and Delli Carpini M, Talking together: Public deliberation and political participation in America (University of Chicago Press 2009) p. 328

¹⁹⁰ UNCRPD Committee (n. 162) Ibid para 12

¹⁹¹ Ibid para 23

¹⁹² Ibid para 28

¹⁹³ Special Rapporteur, Report of the Special Rapporteur on the Rights of Persons with Disabilities: Thirty-first Session of the Human Rights Council (UN Doc A/HRC/31/62, 2016) para. 63

through independent funding'.¹⁹⁴ The Committee have made clear that the provision of funding should not impinge on the autonomy of a DPO 'in deciding their advocacy agenda'¹⁹⁵ and that this funding should be in addition to that provided to facilitate engagement with the Article 33(2) bodies.

2.6.3 Policy making process

Article 4(3) is a novel provision of international law. The duty to consult is not generally defined within international human rights law. One of the main precedents for a duty to consult is the International Labour Organisation Convention, which contains a duty to consult with Aboriginal Communities.¹⁹⁶ A compilation of thematic advice of the Expert Mechanism on the Rights of Indigenous Peoples highlights that 'consultation procedures should be culturally appropriate and undertaken in good faith', with the objective of agreement.¹⁹⁷

At a regional level, the Council of Europe Framework Convention for the protection of National Minorities at Article 15 places an obligation on states to, 'create the conditions necessary for the effective participation of persons belonging to national minorities in cultural, social and economic life and in public affairs, in particular those affecting them'.¹⁹⁸ The Advisory Committee on the Framework Convention have made clear that the participation of national minorities should ensure that national minorities have 'a substantial influence on decisions which are taken, and that there is, as far as possible, a shared ownership of the decisions taken'.¹⁹⁹ However, the Advisory Committee have not fully explained how a state should demonstrate that it has discharged its obligation to consult and to provide an opportunity to influence.

Domestic legal structures relating to public consultations tend to set out principles that should be followed during a public consultation exercise rather than prescribing specific rules. For instance, the UK courts have developed the Gunning principles to assess whether public consultations are truly consultative.²⁰⁰

¹⁹⁴ CRPD Committee (n. 163) para 61

¹⁹⁵ Ibid para 61(e)

¹⁹⁶ ILO Convention Concerning Indigenous and Tribal Peoples in Independent Countries, 1989

¹⁹⁷ OHCHR, Compilation of thematic advice of the Expert Mechanism on the Rights of Indigenous Peoples 2009-2013 (OHCHR 2014)

¹⁹⁸ Council of Europe Framework Convention for the protection of National Minorities, [1995] H (95) 10

¹⁹⁹ ACFC/31DOC(2008)001, para 19

²⁰⁰ R v Brent London Borough Council, ex parte Gunning, (1985) 84 LGR 168

Reflecting the principles-based approach to consultation the CRPD Committee have set out a number of steps which a decision maker should take to ensure the ‘Full and effective participation’ of disabled people and DPOs in consultation exercises.²⁰¹ Consultation processes should be conducted in a ‘meaningful and timely manner’ providing a real opportunity to influence the outcome.²⁰² State Parties must ensure that consultation exercises are accessible and that reasonable accommodations are made.²⁰³

The public officials responsible for the consultation exercise should seek to obtain ‘collective agreement on procedures’.²⁰⁴ The processes for the consultation exercise should ‘allow for reasonable and realistic timelines taking into account the nature of the organizations of persons with disabilities’.²⁰⁵ DPO may need to consult with their members before providing a view on a specific proposal and they should be allowed time to do so. The UNCRPD Committee emphasises that processes should be subject to ‘periodic evaluations’.²⁰⁶ The UNCRPD Committee emphasise that public officials responsible for engagement should be appropriately trained. Political scientists have highlighted that whilst often overlooked it is important that bureaucrats are appropriately trained in managing participative processes.²⁰⁷ The UNCRPD Committee have considered the need to safeguard the independence of DPOs during consultation processes and make clear that states must not ‘condition or prevent organizations of persons with disabilities from freely expressing their opinions in consultations and throughout decision-making processes’.²⁰⁸ At the conclusion of a consultation process a decision-maker must demonstrate that they have considered the representations made by DPOs and should provide an ‘explicit explanation in an understandable format of the findings, considerations and reasoning of decisions on how their views were considered and why’.²⁰⁹

The UN SR Disability has suggested that the duty towards disabled people ‘stretches beyond consultation and access to public decision-making spaces and moves into the area of partnership, delegated power and citizen control’.²¹⁰ This indicates that decision makers are

²⁰¹ CRPD Committee (n. 163) para 48

²⁰² *ibid* para 22

²⁰³ *ibid* para 45

²⁰⁴ *Ibid* para 47

²⁰⁵ *Ibid* para 47

²⁰⁶ *ibid* para 47

²⁰⁷ Janet Newman, Marian Barnes, Helen Sullivan, and Andrew Knops ‘Public participation and collaborative governance’ [2004] *Journal of Social Policy* 203 p. 212

²⁰⁸ CRPD Committee (n. 163) Para 43

²⁰⁹ CRPD (n. 163) para 23

²¹⁰ Special Rapporteur (n 82), para. 63.

required to share power with DPOs and to afford them a degree of control over the outcome. In my view this suggestion is at odds with GC 7. The UNCRPD Committee make clear that the UNCRPD places extensive obligations on the state to ensure disabled people and their representative groups are able to set out their views but does not stretch to suggesting that disabled people and DPOs should have control over the outcome or that their agreement should be required.

Political commentators highlight that policy making processes rarely consider the representativeness of organisations and instead tend to give greatest prominence to those organisations who put forward credible evidence and present convincing arguments.²¹¹ This enquiry will consider the role of a NHRI(IMM) in supporting DPOs to engage in the policy making process in two ways. Firstly, the enquiry will consider how a NHRI(IMM) can support DPOs to develop their capacity to engage in the policy making process. Second it will consider how a NHRI(IMM) can advocate for reform of policy making processes to ensure they are more accessible to DPOs.

2.6.4 Development of Domestic Mechanisms

The UNCRPD Committee have made clear that government are required to develop ‘formal procedures of engagement and liaison with’ disabled people and their representative groups.²¹² The establishment of participative mechanisms can address the risk of DPOs being excluded from policy making processes.²¹³ A CRPD focal point can take on a key role in administering formal procedures.²¹⁴ This approach reflects a corporatist approach to governance which seeks to foster the ‘institutionalized integration of interest groups in policy preparation and implementation’.²¹⁵ It is hoped that the development of participative mechanisms will facilitate the development of routinised relationship between DPOs and government which is self-sustaining.²¹⁶ Below at section 3.4 I consider the opportunities and risks which participative structures offer to DPOs, including the risk that participation in such mechanisms may lead to DPOs becoming institutionalised.

²¹¹ Howlett M, et. al, Policy formulation, policy advice and policy appraisal: the distribution of analytical tools in Jordan A and Turnpenny J (eds), *The tools of Policy Formulation* (Elgar Press 2015)

²¹² *Ibid* para 35

²¹³ Richard K. Scotch, ‘Politics and Policy in the History of the Disability Rights Movement’ [1989] *The Milbank Quarterly* 380

²¹⁴ Special Rapporteur, Report of the Special Rapporteur on the Rights of Persons with Disabilities: Thirty-first Session of the Human Rights Council (UN Doc A/HRC/31/62, 2016) para. 63;.

²¹⁵ Juho Vesa, Anu Kantola and Anne Skorkjær Binderkrantz, A Stronghold of Routine Corporatism? The Involvement of Interest Groups in Policy Making in Finland Scandinavian’ [2018] *Political Studies* 239

²¹⁶ Meyer D and Tarrow S, *The Social Movement Society* (Rowman & Littlefield Publishers 1997) p.21

A key role for a NHRI(IMM) is advising government on the design of participative mechanisms that are truly reflective of Article 4(3) and GC 7. In my case studies I will consider how the IHREC and EHRC have advocated for states to develop participative mechanisms that are truly transformative. In addition, I will assess how NHRI(IMM)s are supporting DPOs to engage in participative mechanisms.²¹⁷

2.7 Conclusion

In this chapter I have provided a legal analysis of the provisions of the CRPD of most relevance to this enquiry.

The UNCRPD is a complex legal instrument. It contains novel provisions which are unprecedented. In placing new and unique obligations its effective implementation will require the state to embark on a significant programme of reform. In addition to setting out substantive protections, the UNCRPD seeks to transform processes of reform to correct the historic exclusion of disabled people and create conditions to sustain a continual process of law reform. The CRPD at Article 4(3) places unique obligations on the state to provide for the participation of disabled people and their representative groups in the policy making process. The CRPD Committee have made clear that the views of disabled people are most effectively articulated through the collective voice of DPOs. This places an onus on the state to adapt processes of policy and law reform to ensure the inclusion of disabled people and their organisations.

NHRI(IMM) must also adapt their own systems for developing advice and monitoring compliance to ensure they are inclusive of disabled people and their representative groups. In chapter 4 I will consider the role of a NHRI. The novel provisions of the CRPD creates a need for a NHRI to develop its capacity both as a monitor of human rights and as an adviser on measures required to bring about compliance. As I will discuss a specific challenge for a NHRI(IMM) is developing its knowledge on the design and delivery of participative approaches to policy making, to ensure it is well placed to advise and advocate for the necessary reforms to realise Article 4(3). An appropriately positioned and resourced focal point can play

²¹⁷ Waldschmidt, A. Sturm, A. Karačić and T. Dins, *Implementing the UN CRPD in European countries* in Halvorsen R et al. (eds) 'The Changing Disability Policy System Active Citizenship and Disability in Europe' (Routledge 2017) p.178

a key role in working with NHRI(IMM) to ensure the values of the CRPD are internalised throughout a state's civil service.

The DPM can play a key role in realising the transformative potential of the CRPD. However, their ability to do so is dependent upon the state realising their obligations towards DPOs.

The advocates for the CRPD, informed by the experience of negotiating its development, consider that NHRI(IMM) are key allies of the DPM in advocating for implementation. In addition to advising on reforms to the policy making system, a NHRI(IMM) must develop its own capacity and processes to ensure they are able to support DPOs to take advantage of new opportunities to influence change. In this thesis I will explore whether NHRI(IMM)s are both supporting DPOs as agents of change and seeking to advocate for structural reforms to ensure their inclusion in the policy making process.

Chapter 3 - The Disabled People's Movement

3.1 Introduction

This enquiry is focused on the relationship between NHRI(IMM) and DPOs. In this chapter I will consider pre-existing literature relating to the development and activities of DPOs and of the DPM more generally. As set out in chapter 2 DPOs played a key role in convincing states of the need for the UNCRPD. They also played a key role in formulating some of its key provisions. The CRPD was designed to correct the historic exclusion of disabled people and their representative groups from the policy making process.

The relationship between civil society and human rights is mutually reinforcing. Civil society relies on human rights for protection from unwelcome interventions by the state.²¹⁸ In turn, a vibrant civil society is essential to ensuring that international human rights norms are internalized in society and in the state. Human rights compliance theorists have come to the realization that the international human rights system will only have effect if it is able to energize civil society.²¹⁹ Reflecting this, the UNCRPD places an obligation on the state to support DPOs to become agents of change who will reinforce efforts by the UNCRPD Committee and ensure the values and principles set out within the UNCRPD are internalized by state actors. Article 33 UNCRPD reinforces the role of NHRIs in protecting and promoting the rights of disabled people and places a specific obligation on NHRI(IMM) to include disabled people when they do so. As I will set out in the next chapter this has encouraged reflection on the role of a NHRI in supporting the activities of civil society.

In this chapter I will provide a brief overview of theories relating to the development of the social movements. I will make some general observations relating to the development of the DPM and the challenges which it has faced and continues to face. I will consider the question of legitimacy within the movement, the relationship between the movement and the state. Finally, I will consider tactics adopted by the movement to influence change. In investigating this, I will draw extensively on social movement literature and on insights from political scientists. This literature will inform my case studies in which I will specifically consider the DPMs in the UK and Ireland.

²¹⁸ Maina Kiai, "Report of the Special Rapporteur on the Rights to Freedom of Peaceful Assembly and of Association," UN Doc. A/HRC/20/27, 21 May 2012, para. 16, http://freeassembly.net/wp-content/uploads/2013/10/A-HRC-20-27_en-annual-report-May-2012.pdf.

²¹⁹ Simmons B, 'International Law' in Carlsnaes Walter, Thomas Risse and Beth Simmons, (eds) *Handbook of International Relations* (Sage Publications 2012).

Much of the literature relating to human rights compliance refers to CSOs.²²⁰ The central feature of a civil society is that it is independent of the state and ‘has not been colonized by the instrumental ethos of the state’.²²¹ Voluntary associations are the central actors of civil society.²²² There is a vast array of voluntary associations with a range of goals.

As set out in the terminology section of my introduction this enquiry relies on the CRPD Committee’s definition of DPOs which makes clear that DPOs should have the ‘aim of collectively acting, expressing, promoting, pursuing and/or defending the rights of persons with disabilities’.²²³ DPOs are therefore voluntary associations which seek to bring about change. The study of disability activism tends to focus on the collective activities of disabled people and disability organisations through the DPM – a social movement.²²⁴

A social movement is defined as ‘A large grouping of people who have become involved in seeking to accomplish, or to block, a process of social change’.²²⁵ Social movements are developed by individuals and organisations who come together to identify ‘common sentiments of oppression’ which they seek to address.²²⁶ Social movement literature uses the term ‘social movements organisations’ to refer to organisations within a movement.²²⁷ DPOs, which make up the DPM, therefore may be classed as social movement organisations. Drawing on social movement literature in this chapter I will discuss the DPM as a social movement and will consider its membership.

3.2 The Disabled People’s Movement as a social movement

Social movement literature is focused on the establishment and activities of organisations and individuals who come together as a social movement hoping to bring about social change.²²⁸

Literature on social movements focuses on how social movements form and establish themselves. Resource mobilization theory highlights that the key factor determining the

²²⁰ Edwards M, Introduction: Civil Society and the Geometry of Human Relations in Edwards, M (ed) *The Oxford Handbook of Civil Society* (Oxford University Press 2011) pp. 11-12

²²¹ Oscar Vilhena Vieira and A. Scott Dupree, ‘Reflections on Civil Society and Human Rights’ [2004] *Int’l J. on Hum Rts.* 47 p.55

²²² Putnam, R.D, *Bowling Alone: The Collapse and Revival of American Community* (Simon & Schuster 2000)

²²³ CRPD Committee (n.) Para 11(a)

²²⁴ Hunt J, ‘No Limits: The Disabled People’s Movement, (Creative Commons 2019)

²²⁵ Giddens, A, *Sociology* (2nd edition, Cambridge University Press 1993) p.746

²²⁶ Melucci, A, *Challenging Codes. Collective Action in the Information Age* (Cambridge University Press 1996) p.291

²²⁷ Antje Daniel & Dieter Neubert, ‘Civil society and social movements: conceptual insights and challenges in African contexts’ [2019] *Critical African Studies* 176, Daniel and Neubert highlight that organisations often used the term movement ‘to highlight their dynamic character’.

²²⁸ Antje Daniel & Dieter Neubert ‘Civil society and social movements: conceptual insights and challenges in African contexts’ [2019] *Critical African Studies* 176

success of a social movement is its ability to mobilize resources. Resource mobilization theory encourages a consideration of how through developing strategic alliances a DPO can enhance its ability to effect change.²²⁹ In contrast, political process theorists, in particular Tarrow, highlight the role of the political arena in shaping the development of social movements.²³⁰ This theory encourages consideration of the opportunities which the political arena presents to DPOs. I have drawn on both theories and the body of literature on social movements in developing this chapter.

3.2.1 Development of the Disabled People's Movement

The development of a disability consciousness has historically been undermined due to the stigmatisation of disabled people. Hahn notes, 'Persons with disabilities often are understandably reluctant to focus on that aspect of their identity that is most negatively stigmatized by the rest of society and to mobilize politically around it'.²³¹ Scotch has also highlighted that the diversity of impairment groups can create an obstacle to the creation of a collective consciousness.²³² Scotch notes, 'Blind people, people with orthopaedic impairments, and people with epilepsy may not inherently see themselves or be seen by others as occupying common ground. Even greater divisions may exist between individuals with physical impairments and those with mental disabilities.'. ²³³ Beckett in acknowledging this view has argued that 'the disability movement are united in their view that we live in a 'disabling society''.²³⁴ It is this realisation which brings a variety of impairment groups together.

The establishment of the DPM in the UK benefited from the input of disability scholars who developed the social model of disability in the 1960s.²³⁵ The social model of disability emerged as a unifying concept which brought disabled activists together.²³⁶ The social model provided the basis for the development of pan disability organisations in the UK and other countries.²³⁷

²²⁹ Nick Crossley 'From Reproduction to Transformation Social Movement Fields and the Radical Habitus' [2017] *Studies in Arts and Humanities* 6

²³⁰ Tarrow (n. 31)

²³¹ Harlan Hahn, 'Introduction: Disability policy and the problem of discrimination' [1985] *American Behavioural Scientist* 293

²³² Richard K. Scotch 'Disability as the Basis for a Social Movement: Advocacy and the Politics of Definition' [1988] *Journal of Social Issues*. 159

²³³ *Ibid* p.163

²³⁴ Angharad E. Beckett, 'Understanding Social Movements: theorising the disability movement in conditions of late modernity' [2006] *Sociological Review* 734, p. 737

²³⁵ Barnes C, Geof Mercer G, and Shakespeare T, *Exploring Disability: A Sociological Introduction*, (Cambridge 1999)

²³⁶ Theresia Degener, *Disability in a Human Rights Context* [2016] *Laws* 35

²³⁷ Stammer N, *Human Rights and Social Movements* (2009 Pluto Press)

The DPM has continued to be a broad based movement which includes a diversity of DPOs which may have ‘different, and potentially conflicting goals’.²³⁸ As I will analyse in my case studies, a key challenge for the movement is ensuring that certain impairment groups do not become marginalized.

3.2.2 Legitimacy of members of the Movement

Disability scholars have consistently highlighted the need for the DPM to distinguish between DPOs who they consider to be the legitimate voices of disabled people from organisations for disabled people (OfDP) who purport to speak on behalf of disabled people.²³⁹ OfDPs are often in receipt of public or charitable funds to provide services to disabled people, creating an obvious conflict of interest.²⁴⁰ Despite this conflict-of-interest OfDPs have at times claimed that they are best placed to represent the views of disabled people.²⁴¹ In doing so OfDPs often ‘articulate their own assumptions about the needs of disabled people’ obscuring the views of disabled people themselves.²⁴² This has created a situation of ‘testimonial injustice’ in which the authority of disabled people to speak for themselves is undermined.²⁴³ In both of my case studies I will consider how DPOs have sought to resolve this situation of testimonial injustice.

DPO tend to emerge ‘from below’, with many starting as self-help groups.²⁴⁴ These groups tend to be composed of volunteers who have personal experience of the challenges which the organization seeks to address. Disability scholars have highlighted how processes of professionalization often lead to DPOs losing their connection to their intended beneficiaries.²⁴⁵ This is a challenge which I will explore in my case studies.

As I will discuss in my case studies DPMs have also sought to address the question of whether organisations which were originally established as OfDP, who have undergone structural reforms to ensure they meet the definition of a DPO can be accepted as legitimate members of

²³⁸ Bagentos S, *Law and the Contradictions of the Disability Rights Movement* (Yale University Press 2009) p.4

²³⁹ Barnes C, Geof Mercer G, and Shakespeare T, *Exploring Disability: A Sociological Introduction*, (Cambridge 1999)

²⁴⁰ Mike Oliver and Gerry Zarb, ‘The Politics of Disability: A New Approach Disability’ [1989] *Handicap & Society* 221, p. 224

²⁴¹ Anne-Marie Callus ‘From ‘for’ to ‘of’: a typology of Maltese disability organisations’ [2014] *Disability & Society* 1, p.2

²⁴² Mike Oliver and Gerry Zarb, ‘The Politics of Disability: A New Approach Disability’ [1989] *Handicap & Society* 221, p. 224

²⁴³ Fricker M, *Epistemic Injustice: Power and the Ethics of Knowing* (OUP, 2007)

²⁴⁴ Sabatello M, ‘The New Diplomacy’ in Sabatello M and Schulze M, *Human Rights and Disability Advocacy* (2013 University of Pennsylvania Press)

²⁴⁵ Piven F and Cloward R, *Poor People's Movements: Why They Succeed, How They Fail* (Pantheon Books 1977)

the movement. Radermacher and others have cautioned that even organisations which include disabled people in their decision-making processes often are not truly participatory.²⁴⁶

As set out the CRPD Committee by way of GC 7 have now set out the essential characteristics of a DPO. Whilst the UN has developed a system to accredit CSOs who wish to speak at the UN Human Rights Council, the UNCRPD Committee have not developed its own system to accredit organisations as DPOs who wish to engage in the examination process.²⁴⁷ In my case study analysis I will consider how national DPMs have sought to informally assess the credibility of organisations putting themselves forward as DPOs and whether NHRI(IMM) can potentially play a role in assisting these processes.

3.3 Disabled People's Movement and the policy making process

Social movements tend to be developed by groups who have been excluded from the mainstream political system.²⁴⁸ Research continues to demonstrate that disabled people are significantly under-represented in political systems throughout Europe.²⁴⁹ Social movements are developed to challenge the status quo, they 'refuse to accept the boundaries of established institutionalised rules and routinized action'.²⁵⁰ For those disabled people who have found the political system inaccessible, involvement in DPOs has provided a platform from which they can challenge their exclusion and advocate for reforms to the system which has excluded them.²⁵¹

Attempts by national DPMs to make disability a political priority has historically proved unsuccessful.²⁵² In this section I will explore the challenges which DPOs have faced when attempting to engage in the policy making process. The policy making process is usually categorised into six stages, namely problem recognition, agenda setting, policy formulation, policy adoption, policy implementation and policy evaluation.²⁵³

²⁴⁶ Harriet Radermacher, Christopher Sonn, Christopher Keys and Paul Duckett 'Disability and Participation: It's About Us but Still Without Us!' [2010] *Community and Applied Social Psychology* 333, p. 344

²⁴⁷ UN 'Working with ECOSOC: A NGOs Guide to Consultative Status' (New York, 2018) Available at http://csonet.org/content/documents/ECOSOC%20Brochure_2018_Web.pdf (Accessed on 3 September 2022)

²⁴⁸ Tarrow S. *Power in Movement. Social Movements, Collective Action and Politics* (Cambridge University Press 1994) p. 3

²⁴⁹ Mitzi Waltz & Alice Schippers, Politically disabled: barriers and facilitating factors affecting people with disabilities in political life within the European Union, [2021] *Disability & Society* 517

²⁵⁰ Darnovsky M, Barbara Epstein B, and Flack R, 'Cultural Politics and Social Movements' (1995 Temple University Press) vii

²⁵¹ *ibid*

²⁵² Faye Ginsburg, Rayna Rapp, 'Crippling the new normal: Making disability count' [2017] *European Journal of Disability Research* 179, p.190

²⁵³ Arno Simons & Jan-Peter Voß, 'The concept of instrument constituencies: accounting for dynamics and practices of knowing governance' [2018] *Policy and Society* 14, p. 21

For the purposes of this enquiry, I use the broad definition of disability policy put forward by Halvorsen et. al. as including the ‘the totality of policy measures, with intended or unintended consequences, for the welfare, living conditions, autonomy, participation and dignity of persons with disabilities’.²⁵⁴

Influenced by Foucault’s theories of discourse political scientists often consider that policy making processes are ‘a discourse in which both problems and solutions are created’.²⁵⁵ In my analysis of literature relating to the DPM and to disability policy I have found that DPOs are disadvantaged at every stage of the policy making process.

The first stage in the policy making process is ‘problematization’. This is defined as ‘defining a problem that requires joint action, and set of actors who are potentially enmeshed in it’.²⁵⁶ Bacchi highlights that problems are not ‘objective’, they are constructed through political discourse which determine whether or not a problem generates a policy need.²⁵⁷ A key challenge for DPOs is that the abuses experienced by disabled people are often considered acceptable and not problems which the state is obligated to address. For instance, the underrepresentation of disabled people in the workforce is often seen as a consequence of their conditions rather than as a result of inaccessible work practices.²⁵⁸ In my case studies I will consider the role of NHRI(IMM) in shaping new understanding of the challenges faced by disabled people.

Even when ‘problems’ have been identified these have rarely been placed on the agenda of policy makers.²⁵⁹ Historically disability policy has reflected the medical model of disability, with policy makers often being closed to new ideas or approaches.²⁶⁰ Pinto has highlighted that disability policy making approaches tend to follow ‘path-dependent trajectories’, policy makers tend to base reforms on policies that are considered to have worked in the past.²⁶¹ As a

²⁵⁴ Halvorsen R, Waldschmidt, A Hvinden B and Böhler K, Diversity and dynamics of disability policy Europe An analytical framework in Rune Halvorsen R et. Al (eds) *The Changing Disability Policy System Active Citizenship and Disability in Europe* (Routledge 2017), p. 13

²⁵⁵ Foucault, M, Truth and Power in Colin Gordon (ed) *Power/Knowledge: Selected Interviews and Other Writings, 1972-1977* (Pantheon Books 1980)

²⁵⁶ Lelajo R, ‘Post-positivism and the policy process’ in Araral E, et al., *Routledge Handbook of Public Policy* (Taylor & Francis Group 2012) p.106

²⁵⁷ Bacchi C, *Analysing Policy: What’s the Problem Represented to Be?* (Frenchs Forest 2009) p.253

²⁵⁸ Interview with representative of the Australian Human Rights Commission 26 November 2020

²⁵⁹ Griggs S and Howarth D, ‘Post-structuralism, social movements and citizen politics.’ in Heln Heijden (ed.) *Handbook of Political Citizenship and Social Movements*. (2016 Elgar Publishing) p. 302

²⁶⁰ Paula Pinto, At the crossroads: Human rights and the politics of disability and gender in Portugal (2011) *European Journal of Disability Research* 116 p.121

²⁶¹ Ibid p. 118

consequence Governments rarely prioritise the development of innovative disability policies.²⁶² Instead reforms to disability policies tend to be brought forward on an incremental basis. This underscores the challenge of convincing policy makers to embark on the broad ranging reforms required to bring about the implementation of the CRPD.

When disability policies have been formulated DPOs have often been excluded from these discussions, often because the value of their contribution has not been appreciated. Political commentators highlight that when developing policies government bureaucracies tend to prioritise engagement with those organisations which they consider capable of producing ‘valuable policy-relevant research and analysis’.²⁶³ It has been suggested that the process of influencing change is a transactional process with outside bodies exchanging credible research and analysis for inclusion in decision making processes and an ability to shape outcomes.²⁶⁴ DPOs tend to focus their policy research on recording and reporting on the lived experience of disabled people.²⁶⁵ This form of research is often undervalued by modern evidence gathering systems.²⁶⁶ Decision makers often have rigid expectations as to what evidence they consider credible.²⁶⁷ As discussed above DPOs also face the challenge of organisations seeking to speak on their behalf and on behalf of disabled people more generally.

Those seeking to present evidence and influence decision makers must utilise epistemic tools to ensure their evidence is considered credible. Epistemic tools are defined as ‘language to formulate propositions, concepts to make sense of experience, procedures to approach the world, and standards to judge particular accounts of experience’.²⁶⁸ DPOs who have historically been excluded from policy making processes often do not have access to epistemic tools to assist them in framing their contributions to policy discourses in line with the expected standards.²⁶⁹ As a result their contributions can often be discounted.

²⁶² Halvorsen R et. al, The contours of the emerging disability policy in Europe in *The Changing Disability Policy System Active Citizenship and Disability* in Halvorsen R et al. (eds) *The Changing Disability Policy System Active Citizenship and Disability in Europe* (Routledge 2017)

²⁶³ Michael Howlett, The supply and demand for policy analysis in government [2015] *Policy and Society* 173 p.174

²⁶⁴ Scott J, ‘Mechanisms of influence: interest groups, lobbyists and policy formulation’ in Michael Howlett and Ishani Mukherjee (eds) *Handbooks of Research on Public Policy* series (Elgar Publishing 2017) p.479

²⁶⁵ Laufey Love, Rannveig Traustadottir, Gerard Quinn and James Rice, ‘The Inclusion of the Lived Experience of Disability in Policymaking’ [2017] *Laws* 33

²⁶⁶ Smith, D. *The Conceptual Practices of Power: A Feminist Sociology of Knowledge*. (1990 Northeastern University Press).

²⁶⁷ Michael Howlett, The supply and demand for policy analysis in government [2015] *Policy and Society* 173, p. 175

²⁶⁸ Gaile Pohlhaus, ‘Relational Knowing and Epistemic Injustice: Toward a Theory of Wilful Hermeneutical Ignorance’ [2012] *Hypatia* 715

²⁶⁹ Howlett M, et. al, Policy formulation, policy advice and policy appraisal: the distribution of analytical tools in Jordan A and Turnpenny J, *The tools of Policy Formulation* (Elgar Press 2015)

Even when progressive disability policies have been adopted they have often suffered from implementation failure due to the unwillingness of vested interests to adopt new approaches.²⁷⁰ In addition, so called ‘street level bureaucrats’ often fail to implement the spirit of emancipatory legislation in practice.²⁷¹ The DPM has consistently highlighted the damaging effects which the paternalistic attitudes of public servants and publicly funded service providers can have upon the enjoyment of human rights, even when these are provided for in law.²⁷² For disabled people, effective policy change is only realised when oppressive practices and cultures are addressed and this can only be done when individual decision makers alter their thought processes and change their behaviours.²⁷³

Once disability policies have been implemented, they have rarely been subject to evaluation with the result that even when policies have been proven to be deficient or poorly implemented, they have not been ‘readily undone’.²⁷⁴

I have set out here how at every stage of the policy making process DPOs have been disadvantaged. Love et. al. highlight that the CRPD calls for ‘fundamental realignment of the accepted and ingrained norms and procedures that have dictated how disability policy is made and who gets to participate in that process’.²⁷⁵ The CRPD also requires states to adjust their evidence gathering processes to ensure they recognise the value of lived experience. In my evidence gathering I will explore the role of a NHRI(IMM) in bringing about a realignment of the policy making systems to ensure they are accessible to DPOs. I will also consider their role in working with government and national statistics offices to reform data collection systems to ensure they accessible to disabled people and accurately recording the lived experiences of disabled people.

In my case studies I will consider how the EHRC and the IHREC have influenced public bodies to broaden the range of acceptable ‘ways in which knowledge is accumulated’ to realise the value of lived evidence and other research produced by DPOs.²⁷⁶ In addition I will consider

²⁷⁰ Halvorsen (n. 240) p. 230

²⁷¹ Lipsky M, *Street Level Bureaucracy: Dilemmas of the Individual in Public Services* (1980 Russell Sage Foundation)

²⁷² Flynn E, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2011) p. 412

²⁷³ Laufey Love, Rannveig Traustadottie & James Rice, ‘Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People’s Organizations in Securing a Seat at the Table’ [2019] *Laws* 1

²⁷⁴ Quinn (n. 136) p. 47

²⁷⁵ Love et. Al (n. 273) p. 5

²⁷⁶ Jackie Leach Scully, ‘From “She Would Say That, Wouldn’t She?” to “Does She Take Sugar?” Epistemic Injustice and Disability’ [2018] *International Journal of Feminist Approaches to Bioethics* 106

the role of a NHRI(IMM) in supporting DPOs to engage in policy making system through the acquisition of ‘new political entrepreneurial skills’ which ensure they are able to effect change when opportunities are presented to them.²⁷⁷

3.4 Disabled People’s Movement influencing change

Social movements engage in a range of tactics to influence change and advance their causes. Organisational theorists have classified the range of tactics engaged in by organisations that seek to influence change as: advocacy; activism; advising; and lobbying. These are set out in the diagram below.

Tilly developed the concept of ‘repertoires of contention’ to define the range of tactics for influencing change which a social movement may avail of.²⁷⁸ The selection of tactics should be determined through an assessment of the potential gains of their adoptions.²⁷⁹ Social movement academics and activists often disagree on the most appropriate tactics.²⁸⁰

Tactics are often classified as either outsider or insider tactics.²⁸¹ Outsider tactics involve direct action and advocacy. Insider tactics tend to involve lobbying with elected official or public bureaucrats through providing policy briefs and advising on solutions to policy issues. In their early days, social movements often have no choice but to engage in outsider tactics. In response to their activism states may provide access to decision making processes, opening up the potential for social movement organisations to engage in insider tactics.²⁸² In my case studies I will discuss how the Irish and UK DPMs have engaged in both insider and outsider tactics and how disputes relating to appropriate tactics continue to occur within both movements. I will set out that NHRIs inevitably prioritise insider tactics and will analyse whether engagement with a NHRI opens up new opportunities to DPOs.

As discussed in my legal analysis the CRPD Committee have suggested that DPOs should develop ‘formal procedures of engagement and liaison with’ disabled people and their representative groups. The CRPD Committee have recommended that states establish participative structures for DPOs in legislative and policy development, implementation, and

²⁷⁷ Quinn (n. 2) p.256

²⁷⁸ Tilly, C. (1986) *The Contentious French* (Cambridge, MA: Harvard University Press).

²⁷⁹ Tarrow (n. 31) p.114

²⁸⁰ Paul Burstein and Sarah Sausner, ‘The Incidence and Impact of Policy-Oriented Collective Action: Competing Views’ [2005] *Sociological Forum* 403

²⁸¹ Start D and Hovland I, *Tools for Policy Impact: A Handbook for Researchers* (Overseas Development Institute 2004)

²⁸² Tarrow (n. 31) p. 263

monitoring. A key challenge for DPOs is ensuring that participative structures are truly transformative.

Political scientists note that governments are adept at designing participative structures which achieve the objectives of the state.²⁸³ Participative structures can be of value to social movement organisations when they are developed to address their concerns and seek their agreement.²⁸⁴ Participative structures which recognise and seek to learn from the external expertise of social movement organisations present the greatest opportunity to influence change.²⁸⁵ However, there is a risk that states may develop participative structures which are largely ritualistic, giving participants the impression that they are being influential without actually affording them a genuine opportunity to impact the outcome or engage with the real decision makers.²⁸⁶ Moriarty and Dew highlight the significant power imbalance within participatory processes developed in New Zealand, comparing ‘the limited control persons with disabilities have over decision-making relative to government officials’.²⁸⁷ Participating in such tokenistic processes, in addition to being futile, can have a damaging effect on DPOs.²⁸⁸ Stammer notes that engaging in participative structures exposes DPOs to the risk that they will be socialized into passive organisations and move from ‘challenging the status quo to sustaining it’.²⁸⁹

In my legal analysis I set out how the CRPD Committee in GC 7 set out a number of specific requirements on the state to ensure that participative structures and processes are authentic. In my case studies I will assess whether the IHREC and EHRC have advocated for the development of structures that are truly participative and potentially transformative.

Social movement literature tends to view the state as a unitary body. However recent reforms to the way states are governed, including the development of NHRIs, have expanded the range of state bodies for movements to engage with. To effectively influence change DPOs need to acknowledge the ‘plethora of governmental players’.²⁹⁰ Sabatier has convincingly put forward

²⁸³ Ibid

²⁸⁴ Fung A (2006) Varieties of participation in complex governance. [2006] *Public Administration Review* 66, p.70

²⁸⁵ George Anderson, ‘The new focus on the policy capacity of the federal government’ [1996] *Canadian Public Administration* 469

²⁸⁶ Robert F. Drake, ‘Disabled people, voluntary organisations and participation in policy making’ [2002] *Policy & Politics* 373 p. 376

²⁸⁷ Lana Moriarty and Kevin Dew, ‘The United Nations Convention on the Rights of PWDs and Participation in Aotearoa New Zealand’ [2011] *Disability & Society* 685 p. 686

²⁸⁸ Paula Hyde and Huw T.O. Davies, ‘Service design, culture and performance: Collusion and co-production in health care’ [2004] *Human Relations* 1407

²⁸⁹ Neil Stammer. ‘Social Movements and the Social Construction of Human Rights’ [1999] *Human Rights Quarterly* 980 p. 998

²⁹⁰ Verhoeven I and Bröer C, ‘Contentious Governance’ in Duyvendak J and Jasper J (eds) *Breaking Down the State* (Amsterdam University Press 2015) p. 98

the view that the policy making system should be aggregated into policy sub systems, composed of public and private actors who are concerned with a policy problem.²⁹¹ Those seeking to bring about change should not treat public bodies as a homogenous group but should consider the priorities of public bodies. DPO leaders in developing engagement plans need to consider the range of actors within and around Government who seek to challenge or alter the policies and practices of the policy making system.²⁹² As set out in my legal analysis the CRPD has broadened the range of public bodies who DPOs can engage with, through requiring the designation of a focal point and independent mechanism. This enquiry is particularly focused on identifying the possibilities which the designation of an NHRI as a IMM opens to DPOs and to the broader movement. In my case studies I will consider the ways in which the EHRC and the IHREC have assisted DPOs to engage in the policy making process. I will also consider whether engagement with a NHRI opens up new opportunities for DPOs to engage with the state.²⁹³

3.5 The Disabled People's Movement and human rights

The DPM has been described as the last civil rights movement, as the enshrinement of legal protections for disabled people was overlooked for many years.²⁹⁴ The involvement of key DPOs in the negotiations leading up to the development of the CRPD has reinforced the integration of human rights claims into the discourses of many DPOs.²⁹⁵ Since the enactment of the CRPD national DPMs have invested significant time and resources in developing their knowledge of the CRPD and in engaging with the international human rights system.²⁹⁶ De Búrca notes that the CRPD, 'has had a notable impact on mobilization, advocacy, and policy reform in the disability field'.²⁹⁷

As I will discuss in my case studies DPOs hope that through engagement with the CRPD Committee they will be able to achieve outcomes that would not otherwise be open to them.

²⁹¹ Ibid p. 130

²⁹² Meyer D, *Social movements and Public Policy: Eggs, Chicken and Theory* in Meyer D and Ingram H, *Routing the Opposition: Social Movements, Public Policy, and Democracy*, (University of Minnesota Press 2005)

²⁹³ Quinn G, 'The International Covenant on Civil And Political Rights and Disability: A Conceptual Framework', in Theresa Degener T and Yolán Koster-Dreese, (eds.) *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments*, (Martinus Nijhoff, 1995) p.92.

²⁹⁴ Driedge D, *The Last Civil Rights Movement* (Disabled People's International 1989)

²⁹⁵ Sabatello M, *The New Diplomacy* in Sabatello M and Schulze M, *Human Rights and Disability Advocacy* (2013 University of Pennsylvania Press) p. 258

²⁹⁶ Robert D. Benford and David A. Snow 'Framing Processes and Social Movements: An Overview and Assessment' [2000] *Annual Review of Sociology* 611

²⁹⁷ Gráinne de Búrca, *The activation of the Convention on the Rights of Persons with Disabilities in Argentina* in Gráinne de Búrca (ed) *Reframing Human Rights in a Turbulent Era* (Oxford 2021)

Human rights sceptics such as Posner would question this assumption, Posner has argued that, ‘there is little evidence that human rights treaties, on the whole, have improved the well-being of people’.²⁹⁸ Analysis by Posner and others tends to focus on the extent to which international human rights treaties have been able to compel states to comply. Human rights compliance theorists emphasise that international instruments effect change not by compelling states to comply but by persuading them to do so.²⁹⁹ Advocates for the CRPD were particularly informed by the persuasion theory.³⁰⁰ This theory emphasises the role of DPOs and NHRI(IMM)s in introducing and cultivating the acceptance of CRPD norms within society and within state structures.³⁰¹ Rather than relying on the international system to effect change, the CRPD places unique obligations on the state to reform domestic policy making processes and support the development of DPOs to ensure they are able to effect change. Advocates of the persuasion approach encourage DPOs to hone their arguments and engage in public deliberation to persuade state actors to internalise human rights norms.³⁰² De Búrca has highlighted that national DPM have been successful in going ‘back-and-forth between national and international levels’ to advocate for change.³⁰³ NHRI(IMM) as statutory bodies who are often provided formal roles within the international human rights system, can provide valuable insights to DPOs on moving between the international and domestic level to bring about human rights compliance.

Convincing state bureaucracies to integrate human rights considerations into their bureaucratic routines is considered the key to bringing about compliance with the CRPD.³⁰⁴ In recent years, a range of sophisticated techniques for the internalisation of human rights at the domestic political level have been developed. These include robust monitoring activities, human rights impact assessment and mainstreaming activities.³⁰⁵ As I will discuss in the next chapter the international human rights system has invested significant resources in supporting NHRIs to develop their expertise in these processes. In my case studies I will explore

²⁹⁸ Posner E, *The Twilight of Human Rights Law* (Oxford University Press 2014)

²⁹⁹ Hathaway, ‘Do Human Rights Treaties Make a Difference?’ [2002] *Yale L.J* 1935 p. 1955

³⁰⁰ Gerard Quinn, ‘The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability’ [2009] *Tex. J. on C.L. & C.R.* 33

³⁰¹ Finnemore and Sikkink. ‘International norm dynamics and political change’ [1998] *International Organization* 887 p.900

³⁰² Harry Koh, ‘Internalization Through Socialization’, [2005] *Duke LJ* 975

³⁰³ Gráinne de Búrca, ‘The activation of the Convention on the Rights of Persons with Disabilities in Argentina’ in Gráinne de Búrca (ed) *Reframing Human Rights in a Turbulent Era* (Oxford 2021) p. 126

³⁰⁴ Cardenas S, *National Human Rights Institutions and State Compliance* in Goodman, R and Pegram, T *Human Rights, State Compliance, and Social Change* (Cambridge University Press 2011) p. 37

³⁰⁵ *Ibid*

whether the EHRC and the IHREC have shared their expertise in techniques for internalising human rights with DPOs.

3.6 Conclusion

In this chapter I have brought together social movement literature and literature relating to the DPM. In my case studies I will discuss the history and activities of the DPMs in Ireland and GB. In this chapter I have set out a number of common challenges experienced by disabled people and their organisations when engaging in the policy making process. I have discussed how policy making processes have been inaccessible to DPOs with the result that the voice of disabled people has largely been silenced and policies relating to disabled people have failed to guarantee their rights. The CRPD was enacted to correct the deficiencies within domestic policy making processes.³⁰⁶ Whilst human rights sceptics would question the potential for an international instrument to affect change, the DPM consider that the UNCRPD provides a manifesto for change and has provided a basis on which to frame their advocacy positions.

Disability scholars acknowledge that the UNCRPD will not be self-executing and have given detailed consideration to how the DPMs in states that have ratified the CRPD can be energized and empowered to effect change. National DPM have sought to upskill themselves and are prepared to invest time and resources in engaging with the Committee. NHRI (IMM)s who have consolidated experience of the international human rights system and knowledge of sophisticated approaches to bringing about human rights compliance can be valuable allies to DPOs seeking to utilise the CRPD to bring about change.

In my case studies I will explore how NHRI(IMM)s are collaborating with national DPMs to bring about change. A NHRI operates at both the international and the domestic level and can potentially strengthen the influence of DPOs at both levels. In my case studies I will consider the role of the EHRC and the IHREC in narrowing the gap between the standards set out in the CRPD and the lived experience of disabled people.

In this chapter I have identified that to be effective DPMs not only need to develop skills to engage in the policy making system they also need policy making systems and evidence gathering systems to change. NHRIs as state bodies with a specific role to advise on measures required to bring about human rights compliance can play a key role in advocating for the

³⁰⁶ Quinn (n. 4)

reform of policy making systems to address obstacles to participation. Furthermore, through their engagements with public bureaucrats NHRIs can potentially change the rigid expectations of decision makers which have historically excluded disabled people. In the next chapter I will consider how NHRIs can support the activities of DPMs. I will then set out my two case studies in which I will specifically consider how the EHRC and the IHREC have engaged with their DPMs.

Chapter 4: National Human Rights Institutions and their role as Independent Monitoring Mechanisms

4.1 Introduction

In this chapter, I will introduce the concept of a NHRI. I will explore the development of NHRIs and the growth in their number. As I will discuss the establishment of a NHRI is seen as an essential building block in ensuring human rights compliance. However, as set out in my introduction there has been a lack of critical analysis of the contribution which NHRIs make to the enjoyment of human rights. There has also been a lack of analysis of the contribution which a NHRI can make to the advocacy activities of civil society.

As discussed in chapter 2 a report by Degener and Quinn which informed the development of the CRPD suggested that NHRIs were well placed to support DPOs in bringing about changes in the domestic policy making process.³⁰⁷ In this chapter I will explore how NHRIs have interacted with DPOs when engaging in the domestic policy making process. I will consider what the unique features of a NHRI are and whether these features result in a NHRI being able to influence changes that are not open to a CSO.

I will also consider the relationship between NHRIs and civil society more generally. In doing so I will highlight that there has been limited exploration of the ways in which a NHRI can include civil society in their activities and decision-making processes. The result of which is that NHRIs have not always been well placed to mainstream the participation of disabled people and their representative groups in their roles as a NHRI(IMM).

I will explore the relationship between NHRIs and DPOs through looking at the functions performed by a NHRI and consider how a NHRI can collaborate with a DPO in exercising their functions. In doing so I will draw on published literature and reports from international bodies. In developing this analysis to augment published research I conducted interviews with representatives of seven NHRIs who I identified as having engaged in innovative practices relating to the rights of disabled people. I also conducted an interview with a representative of the Global Alliance of NHRIs.

³⁰⁷ Quinn, Gerard, and Theresia Degener. 2002. Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability. United Nations Publications, p. 285

I will begin this chapter by discussing the development of NHRIs and will then consider a number of their key features. In doing so I will highlight the role of GANHRI and the role which it has played in promoting the concept of a NHRI. Using the CRPD Committee's General Guidelines on Independent Monitoring Mechanisms I will explore the functions of NHRIs and how they have collaborated with DPOs in executing them. In concluding this section, I will set out a number of issues for further exploration within my case studies.

4.2 Development of National Human Rights Institutions

The concept of a NHRI emerged during negotiation of the International Covenant on Civil and Political Rights. NHRIs were initially viewed principally as domestic bodies which could transmit information to the international system 'on the observance of human rights in their countries'.³⁰⁸ Throughout the 1980s many states accepted the concept of domestic monitoring and established their own national institutions.³⁰⁹

In 1991 the Commission on Human Rights brought together the leaders of national institutions for the promotion of human rights in the first international workshop on NHRIs in Paris. The discussions amongst experts and NHRIs gave birth to the Paris principles.³¹⁰ The Paris Principles were subsequently endorsed by the Commission on Human Rights at the 1993 World Conference on Human Rights.³¹¹ In addition, the Principles were endorsed by the UN General Assembly.³¹² The endorsement and adoption by international bodies of a document that was developed outside the formal UN system and which was not the creation of member states makes the Paris Principles unique.³¹³ The establishment of the Paris Principles was a red letter moment in history of the establishment of NHRIs as it set down the formal safeguards which any institution described as a NHRI must have.³¹⁴

In 1993 the World Conference on Human Rights in Vienna recommended that the representatives of NHRIs convene to share experiences and as a means of improving their

³⁰⁸ United Nations General Assembly Resolution 2200 A (XXI) B

³⁰⁹ Cardenas (n. 20) p. 36

³¹⁰ Principles relating to the status and functioning of national institutions for protection and promotion of human rights, UN General Assembly (1993) Resolution A/ RES/48/134 (20.12.1993) available at: <http://www2.ohchr.org/english/law/parisprinciples.htm> (02.09.2008).

³¹¹ Vienna Declaration and Programme of Action, adopted by the World Conference on Human Rights, Vienna, 25 June 1993, A/CONF.157/24, part I, para. 36

³¹² UN General Assembly adopted resolution 48/134 1993

³¹³ Katerina Linos and Tom Pegram, 'Architects of Their own Making: National Human Rights Institutions and the United Nations' [2016] Human Rights Quarterly 1109, p.1110

³¹⁴ *ibid*

mechanisms.³¹⁵ At the second international workshop for national institutions, the establishment of a coordinating committee was agreed which would become the International Co-ordinating Committee (ICC) of NHRIs - subsequently renamed as the GANHRI. The establishment of the ICC provided a guarantee that the process for accrediting and regulating NHRIs would exist outside of the formal structures of international system. In the words of Linos and Pegram, NHRIs could be described as ‘architects of their own making’.³¹⁶

The establishment of the Paris Principles and the ICC heralded the proliferation of NHRIs throughout the world. The establishment of a NHRI is now considered a necessary precondition for states who wish to take on a role within the international human rights system.³¹⁷ At the time of writing there are 121 NHRIs accredited with GANHRI.³¹⁸

International human rights bodies, in particular international treaty bodies, have encouraged states to develop NHRIs. The growth in the number of NHRIs has taken place concurrent with the search for new methods and approaches to bring about compliance with the international human rights system.³¹⁹ The establishment and strengthening of NHRIs is seen as a key building block in the development of national systems for the protection of human rights.

Having originally been conceived of as the eyes and ears of the international system, NHRIs are now seen as key receptors of human rights standards who vernacularise global standards into the local language. In the words of Merry Smith NHRIs can ‘put global human rights ideas into familiar symbolic terms ... combining both transnational human rights concepts and local ways of thinking about grievances’.³²⁰ In addition to supporting international bodies NHRIs can play a key role in domesticating human rights standards.

As set out in chapter 3 strategies for bringing about human rights compliance have become increasingly sophisticated. Reflecting this NHRIs have sought to develop their own approaches to protecting and promoting human rights. The OHCHR has sought to develop the capacity of NHRIs and foster the professionalisation of their staff through the provision of training and capacity building programmes.³²¹ Training programmes have moved well beyond educating

³¹⁵ See Vienna Declaration and Programme of Action, 25 June 1993, A/Conf.157/23, para 36, Part I.

³¹⁶ Linos and Pegram (n. 313) p.1110

³¹⁷ Cardenas (n. 20) p.183

³¹⁸ See <https://nhri.ohchr.org/EN/Pages/default.aspx> (Accessed on 17 March 2021)

³¹⁹ Dai X, The ‘Compliance Gap’ and the Efficacy of International Human Rights Institutions in Risse T, Ropp S and Sikkink K (eds.), *The Persistent Power of Human Rights: From Commitment to Compliance* (Cambridge University Press 2013).

³²⁰ Merry Smith, ‘Vernacularization on the Ground: Local Uses of Global Women’s Rights in Peru, China, India and the United States’ [2009] *Global Networks* 441 p.444

³²¹ UNDP, GANHRI and OHCHR, ‘Tripartite Partnership to Support NHRIs’ 2016 - <<https://ganhri.org/tripartite-partnership/>> Accessed on June 21 2021

NHRIs as to the content of international standards and tend to focus on developing the expertise of NHRIs to utilise techniques of implementation, such as the design of national action plans, new approaches to national censuses and the application of human rights based indicators.³²² NHRIs have developed significant expertise in the development of techniques to bring about compliance.

The establishment of a competent NHRIs has now become central to theories of change informing the work of international human rights bodies. The OHCHR has developed the concept of a ‘national human rights protection system’.³²³ This concept builds on regulatory approaches towards human rights compliance.³²⁴ It draws attention to the multiplicity of actors involved in monitoring human rights compliance and seeks to maximise the impact of ‘regulatory webs of influence’ within a state party.³²⁵ These webs include state regulators and civil society bodies. Focusing on systematic changes required to bring about human rights compliance is valuable to this exploration as it encourages an analysis which considers the various levers of change open to both NHRIs and to civil society.

Some commentators have suggested that the treaty bodies, including the CRPD Committee, should be seen as meta regulators which delegate regulatory capacity to NHRIs and to DPOs.³²⁶ In my evidence gathering I will explore how NHRIs have sought to establish themselves as regulators who can make pronouncements on compliance with international human rights obligations. I will also consider the relationship between NHRI(IMM)s and the CRPD Committee and the role of a NHRI(IMM) in advocating for compliance with the Committee’s recommendation.

4.3 Accreditation of NHRIs

The GANHRI is uniquely entrusted with assessing compliance of state institutions with the Paris principles. The GANHRI Sub Committee on Accreditation (‘SCA’) which is composed of NHRIs, makes decisions as to whether a state body can be accredited as a NHRI.³²⁷

³²² *ibid*

³²³ OHCHR Management Plan 2014–2017, Working for Your Rights, (OHCHR, 2014) <digitallibrary.un.org/record/768573> Accessed on 23 February 2022

³²⁴ Stéphanie Lagoutte, ‘The Role of State Actors Within the National Human Rights System’ [2019] *Nordic Journal of Human Rights* 177

³²⁵ Charlesworth H, A regulatory perspective on the international human rights system in Peter Drahos (ed.) *Regulatory Theory: Foundations And Applications* (ANU Press 2017), p.362

³²⁶ Arduin (n. 94) p. 414

³²⁷ OHCHR, ‘NHRIs: History, Principles, Roles and Responsibilities Professional Training Series number 4’ (OHCHR 2010) p. 46

Institutions seeking accreditation as an NHRI must apply to the SCA to be assessed against the Paris Principles. In carrying out their work the SCA are supported by a specific unit within the OHCHR.³²⁸ During this assessment the SCA will consider the legislative instrument establishing the NHRI; its organizational structure and its annual report into its activities.³²⁹ The SCA may accredit an institution as being either A status, meaning it is in full compliance with the Paris Principles, or as B status indicating partial compliance.

The SCA have issued General Observations which provide further elaboration on the structure and functions of a NHRI.³³⁰ The SCA have issued a General Observation which addresses circumstances in which a NHRI has been designated as a IMM or as a National Preventative Mechanism for the purposes of the UN Convention against Torture.³³¹

Following its initial accreditation an NHRI must apply for reaccreditation every 5 years. The requirement for reaccreditation, in my view, provides a safeguard against a state encroaching upon the independence of a NHRI once established. In addition, it provides an opportunity for an assessment of any additional responsibilities allocated to the NHRI.

The process for accrediting an NHRI is unique. It provides ‘an independent system of monitoring and institutional design and performance’.³³² States are not involved in the accreditation process - it is the NHRIs appointed to the SCA which make decisions concerning the accreditation of NHRIs. As GANHRI is effectively the professional body for NHRIs, the accreditation process is a form of self-regulation.

Rosenblum has questioned the centrality of GANHRI to the accreditation process describing it as ‘a very curious organisation to rely on for the critical evaluation of NHRIs. As an association composed of NHRIs - whose purpose is to ‘promote and strengthen’ them - its critical engagement is necessarily limited’.³³³ De Beco and Murray have offered a defence of the accreditation process. They argue that as a peer review mechanism, ‘it has the buy in and legitimacy of those it is assessing who know that the assessors recognise the unique challenges and difficulties the institution faces ...’.³³⁴

³²⁸ Ibid 46

³²⁹ GANHRI Sub-Committee for Accreditation’s Rules of Procedure 2019, Article 3(4)

³³⁰ GANHRI General Observations of the Sub-Committee on Accreditation 2018

³³¹ Ibid para 2.8

³³² Corina Lacatus, ‘Explaining Institutional Strength: The case of national human rights institutions in Europe and its Neighbourhood’ [2018] *Journal of European Public Policy* 1657 p. 1665

³³³ Rosenblum P, ‘Tainted Origins and Uncertain Outcomes: Evaluating NHRIs’ in Ryan Goodman and Thomas Pagram (eds) *Human rights, state compliance and social change: assessing national human rights institutions* (Cambridge University Press 2012) p. 298.

³³⁴ De Beco G and Murray R, *A commentary on the Paris principles on national human rights institutions* (Cambridge University Press 2014) p. 137

Rosenblum has also criticised the accreditation process for failing to assess the ‘actual, contribution’ which an NHRI has made to the protection and promotion of rights.³³⁵ Carver similarly criticised the process for focusing on compliance with structural requirements and lacking a focus on ‘performance on the ground’.³³⁶ It is notable that the SCA General Observations tend to focus on matters that are outside the operational discretion of the NHRI. For instance, four of the five criteria set out in the SCA’s General Observations on IMM relate to the legal mandates and resources of the NHRI. The criteria do not require the NHRI to set out how it has engaged with disabled people and DPOs. For the purposes of this enquiry, it is notable that there is a reasoned view amongst academics that the SCA accreditation process insufficiently scrutinises the operations of a NHRI and does not explore a NHRI’s relationship with civil society.³³⁷

The development of processes to evaluate the practical impact of NHRIs is complex.³³⁸ NHRIs rarely have powers to compel action by public authorities or private entities, as a result the impact of an NHRI will often ‘depend upon the commitment of other institutions to act on their findings’.³³⁹ The capacity of a NHRI to effect change is largely dependent on whether it is able to influence the priorities of other state institutions.³⁴⁰ Assessing the influence of a particular institution in what are inevitably complex systems is a difficult task.³⁴¹ However, the lack of focus on assessing the effectiveness of NHRIs has in my view contributed to a lack of critical reflection amongst NHRIs on how they are effecting change in their domestic contexts.

Whilst the SCA is supported by the OHCHR it has limited ‘fact-finding capabilities’.³⁴² The SCA do allow CSOs to submit comments on NHRIs which are applying for accreditation or reaccreditation. However, whilst the OHCHR advertise forthcoming accreditation hearings on their website there are no specific awareness raising activities undertaken within the state.³⁴³ Research indicates that there is limited input from CSOs to the procedures of SCA.³⁴⁴ It is

³³⁵ Rosenblum P, ‘Tainted Origins and Uncertain Outcomes: Evaluating NHRIs’ in Ryan Goodman and Thomas Pegram (eds) *Human rights, state compliance and social change: assessing national human rights institutions* (Cambridge University Press 2012) p. 303

³³⁶ Carver R, *Assessing the Effectiveness of National Human Rights Institutions International* (Council on Human Rights Policy 2005) p. 7

³³⁷ Rosenblum P, ‘Tainted Origins and Uncertain Outcomes: Evaluating NHRIs’ in Ryan Goodman and Thomas Pegram (eds) *Human rights, state compliance and social change: assessing national human rights institutions* (Cambridge University Press 2012) p. 298.

³³⁸ Catherine Renshaw, Andrew Byrnes and Andrea Durbach, ‘Testing the Mettle of National Human Rights Institutions: A Case Study of the Human Rights Commission of Malaysia’ [2011] *Asian Journal of International Law* 165, p.184

³³⁹ Meyer D, *National Human Rights Institutions, Opportunities, and Activism in Goodman R, and Pegram T (eds) Human rights, state compliance and social change: assessing national human rights institutions* (Cambridge University Press 2012) p. 328

³⁴⁰ Jensen L, *Lessons from Research on National Human Rights Institutions* (Danish Institute for Human Rights 2018) p. 6

³⁴¹ Tsui J. *The effectiveness of measuring influence* (University of Birmingham 2013)

³⁴² Catherine Renshaw, ‘National Human Rights Institutions and Civil Society Organizations: New Dynamics of Engagement at Domestic, Regional, and International Levels’ [2012] *Global Governance* 299, p.310

³⁴³ Upcoming sessions of the GANHRI Sub-Committee on Accreditation (SCA) Available at <https://www.ohchr.org/EN/Countries/NHRI/Pages/UpcomingSessions.aspx> visited 1 September 2021

³⁴⁴ De Beco, G ‘Compliance with the Paris Principles and the ICC Sub-Committee on Accreditation’ in Meuwissen, K. and Wouters, J (eds.) *National Human Rights Institutions in Europe: Comparative, European and International Perspectives* (Intersentia 2013) p.254

notable that there is limited guidance available to CSOs on how to submit evidence to the SCA and submissions are not made public. Whilst I identified a number of DPOs providing comments on the performance of NHRIs designated as IMMs during the CRPD Committee's periodic examinations of states compliance, I did not identify examples of DPOs contributing to SCA hearings.³⁴⁵ As discussed in my case studies DPOs had limited awareness of the accreditation process.

4.4 Mandate of National Human Rights Institution

The Paris Principles require that an NHRI be 'vested with competence to promote and protect human rights' and should have 'as broad a mandate as possible'. Whilst the mandate of an NHRI should be broad, inevitably an NHRI will have to adopt a strategic approach which will involve prioritising certain rights over others. NHRIs have at times been criticized for failing to fully address all rights. The Committee for Economic Social and Cultural Rights in its GC on NHRIs observed that in practice NHRIs had 'neglected or given a low priority' to economic, social and cultural rights.³⁴⁶

The requirement to have a broad mandate creates a risk that an NHRI will be allocated additional responsibilities by government without a need for its founding statute to be amended. The GANHRI has often encouraged states to allocate additional responsibilities to an NHRI in the hope that this will lead to a NHRI receiving additional powers and funding.³⁴⁷ However states have often allocated additional responsibilities to NHRIs, including designating them as IMMs, without providing appropriate legal powers or additional resources.³⁴⁸ Meuwissen and Wouters have highlighted that, 'Each additional task puts an extra burden on staff and financial resources Consequently, prioritisation and balancing of roles are increasingly proving challenging for NHRIs'.³⁴⁹ In my case studies I will consider the process of designating a NHRI as a IMM and I will assess how the designation of a NHRI as a IMM has impacted on its priorities.

³⁴⁵ Ibid See further discussion relating to the examination of the UK.

³⁴⁶ Committee on Economic, Social and Cultural Rights, General Comment No. 10: The role of national human rights institutions in the protection of economic, social and cultural rights, 10 December 1998, HRI/Gen/Rev 7 para 4

³⁴⁷ Interview with representative of GANHRI 11 December 2022

³⁴⁸ Gliszczyńska-Grabias A and Sękowska -Kozłowska K, NHRI in Poland: As good as it gets? in Meuwissen, K. and Wouters, J (eds.) National Human Rights Institutions in Europe: Comparative, European and International Perspectives (Intersentia, 2013) p.66

³⁴⁹ Katrien Meuwissen and Jane Wouters J, Conclusion in Meuwissen, K. and Wouters, J (eds.) National Human Rights Institutions in Europe: Comparative, European and International Perspectives (Intersentia, 2013) p.305

4.5 Structure of NHRIs

The Paris Principles do not prescribe a specific structure which should be reflected within a NHRI, they provide that a state may choose a structure which best suits its needs.³⁵⁰

There are four specific models of NHRIs: the Commonwealth Commission model: the Francophone Commission model: Institute model and the Ombudsmen model. In this enquiry I will focus on NHRIs that reflect the Commonwealth Commission model in which the decision-making body is a collegiate body of Commissioners.³⁵¹ This body of Commissioners will usually be headed by a Chief Commissioner. Individual Commissioners may be allocated with specific responsibilities relating to marginalized groups, for instance the AHRC includes a Disability Commissioner.³⁵²

The absence of guidance on the structure of NHRIs has in my view restricted analysis of the optimal mechanisms to facilitate the participation of civil society originations.

4.6 Independence of National Human Rights Institutions

The key feature of a NHRI is that it is a state body independent of government.

Much of the commentary on NHRIs suggests that they are unique in being independent bodies created by the state. However, states often create quasi autonomous bodies which ‘operate at arm’s length from the central government, without an immediate hierarchical relationship existing with a minister or a parent department’.³⁵³ Indeed as recently documented, there has been a proliferation of government bodies established with a human rights remit - often referred to as Government Human Rights Focal Points.³⁵⁴

The Paris Principles elaborate extensively on how independence is to be realised in practice. Whilst an NHRI is to be established and funded by the state, they must be independent of

³⁵⁰ UN General Assembly 1993. *Principles relating to the status and functioning of national institutions for the protection and promotion of human rights* (‘Paris Principles’). Resolution 48/134, UN Doc. A/RES/48/134.

³⁵¹ Reif L, ‘The shifting boundaries of NHRI definition in the international system’ in Ryan Goodman and Thomas Pegrām (eds) *Human rights, state compliance and social change: assessing national human rights institutions* (Cambridge University Press 2012) p.64

³⁵² Australian Human Rights Commission Act 1986, section 8(7)

³⁵³ Anthony M. Bertelli, ‘Governing the Quango: An Auditing and Cheating Model of Quasi-Governmental Authorities’ [2006] *Journal of Public Administration Research and Theory* 239 p.241

³⁵⁴ Caughey (n. 129)

government and must operate without ‘higher authority’.³⁵⁵ Once established an NHRI should be ‘rendered autonomous by cutting any umbilical cord or organic link with a given branch of authority, in particular the Executive’.³⁵⁶

The Paris Principles seek to ensure the independence of NHRI office holders by requiring that they are appointed through ‘a clear, transparent and participatory selection and appointment process’.³⁵⁷ The appointment itself must be ‘effected by an official act which shall establish the specific duration of the mandate’.³⁵⁸

Neither the Paris Principles nor the SCA prescribe an appointing authority. In many NHRIs it is the government which is the appointing authority. For instance, the Commissioners of the EHRC are appointed by the UK Government.³⁵⁹ However this arrangement is considered to lack independence. In the words of Anne Smith such an arrangement means that ‘NHRIs are at the mercy of governments who have the final say as to who and when appointments are made’.³⁶⁰

The SCA have suggested that the appointment procedures should be pluralistic.³⁶¹ It suggests that governments ‘promote broad consultation [of CSOs] and/or participation in the application, screening, selection, and appointment process’.³⁶² Despite these observations there are limited examples of CSOs being involved in the appointments process. There has recently been a trend towards involving the legislature in the appointments process. However, commentators have warned that such approaches may politicise the appointment process.³⁶³

4.6.1 Composition

The Paris Principles imply that representatives of state actors may be included within an NHRI. The SCA have clarified that the rationale for their inclusion was ‘not in order to take part in decision making, but to give and receive information and to engage in as regular and trustful a

³⁵⁵ UN General Assembly 1993. *Principles relating to the status and functioning of national institutions for the protection and promotion of human rights* (‘Paris Principles’). Resolution 48/134, UN Doc. A/RES/48/134. ‘competence and responsibilities’

³⁵⁶ *ibid*

³⁵⁷ *ibid*

³⁵⁸ *ibid*

³⁵⁹ See UK Chapter

³⁶⁰ Anne Smith, ‘The Unique Position of National Human Rights Institutions: A Mixed Blessing?’ [2006] *Human Rights Quarterly* 937 p.924

³⁶¹ SCA (n. 306) para 1.7

³⁶² *ibid*

³⁶³ De Beco, G and Murray, R ‘A commentary on the Paris Principles’ on national human rights institutions’ Cambridge University Press 2014, p. 142

dialogue as possible'.³⁶⁴ The SCA have highlighted that the role of Government representatives should be to assist the NHRI.³⁶⁵

4.6.2 Independence: Budget

The Paris Principles emphasise that NHRIs should 'have an infrastructure which is suited to the smooth conduct of its activities, in particular adequate funding'. SCA General Observations require the provision of adequate funding to provide for accommodation, the employment of staff on competitive salaries, payment to Commissioners and the establish of communication systems.³⁶⁶

Whilst additional sources of funding are permissible, the onus is on the state to provide adequate funding.³⁶⁷ An NHRI should be able to operate with an assurance that it will receive sufficient core funding to execute their duties. NHRIs consistently raise concerns relating to the adequacy of their funding and their ability to effectively execute their functions for the funding provided.

NHRIs often highlight that additional responsibilities are allocated to them without accompanying resources. I identified only two NHRI(IMM)s in Europe who received substantial additional resources upon their designation as an IMM. Notably both NHRI(IMM)s had established their own unit within their staffing structure with specific responsibility for monitoring the CRPD.³⁶⁸

An NHRI must have control over its own budget, which should be allocated to the institution directly from Government.³⁶⁹ The Paris Principles require that NHRIs should not 'be subject to financial control which might affect its independence'.³⁷⁰ The SCA has made clear that an NHRI should have 'complete financial autonomy' with 'absolute management and control'.³⁷¹ A NHRI should not have to seek financial approval for specific projects.³⁷² As I will discuss in

³⁶⁴ Meuwissen, K 'NHRIs and the State: New and Independent Actors in the Multi-layered Human Rights System?' [2015] Human Rights Law Review 441, p. 455

³⁶⁵ SCA (n. 306) para 1.9

³⁶⁶ Ibid para 1.10

³⁶⁷ Smith (n. 359) p.918

³⁶⁸ Interview with representative of GIHR 28 January 2021 and Interview with representative of DIHR 4 January 2021

³⁶⁹ SCA (n. 306) para 1.10

³⁷⁰ UN General Assembly 1993. *Principles relating to the status and functioning of national institutions for the protection and promotion of human rights ('Paris Principles')*. Resolution 48/134, UN Doc. A/RES/48/134.

³⁷¹ SCA (n. 306) para 1.10

³⁷² Joint Committee on Human Rights - Fourteenth Report: Work of the Northern Ireland Human Rights Commission of Session 2002–03 HC 142 15 July 2003

my case study on the EHRC where a NHRI has a concern that their actions may lead to a reduction in their budget this can significantly impact on their independence.

4.6.3 Independence: Founding legislation

The Paris Principles make clear that the mandate of an NHRI must be set forth in ‘a constitutional or legal text’. NHRIs established by administrative measure or royal decree cannot obtain ‘A’ status as their founding legal instrument does not offer sufficient protection against amendment by the government.³⁷³ For the purpose of this enquiry, it is notable that the SCA have not required that the designation of an NHRI as an Independent Monitoring Mechanism is reflected in the founding legislation of a NHRI. However, the UNCRPD Committee have on occasion suggested that the designation of a NHRI as a IMM should be reflected in their founding statute.³⁷⁴

4.7 Pluralism

The Paris Principles require that NHRIs are pluralistic. The composition of a NHRI should reflect the composition of society.³⁷⁵ The OHCHR has confirmed, ‘pluralism is best demonstrated when an institution’s membership visibly reflects the social forces at play in the State’.³⁷⁶ The Paris Principles do not prescribe a specific approach to ensuring pluralism. Pluralism is a malleable concept which can depend upon local contexts and traditions.³⁷⁷ The SCA has elaborated on how pluralism can be reflected within a NHRI including through diverse membership of a decision-making body; through inclusion of societal groups in the appointments process; through procedures enabling effective cooperation with diverse societal groups (for example advisory committees); and through the staff.³⁷⁸

The participation of civil society within a NHRI is considered an essential safeguard to ensure the independence of the NHRI. The involvement of civil society is seen as a counterbalance to the role of the state in establishing and funding an NHRI.³⁷⁹

³⁷³ UN General Assembly 1993. *Principles relating to the status and functioning of national institutions for the protection and promotion of human rights* (‘Paris Principles’). Resolution 48/134, UN Doc. A/RES/48/134.

³⁷⁴ CRPD Committee Concluding observations on the initial report of Rwanda CRPD/C/RWA/CO/1 (3 May 2019) para 62

³⁷⁵ UN General Assembly 1993. *Principles relating to the status and functioning of national institutions for the protection and promotion of human rights* (‘Paris Principles’). Resolution 48/134, UN Doc. A/RES/48/134.

³⁷⁶ OHCHR (n. 303)

³⁷⁷ Meuwissen, K. NHRIs and the State: New and Independent Actors in the Multi-layered Human Rights System? [2015] Human Rights Law Review 441, p.454

³⁷⁸ SCA (n. 306) para 1.7

³⁷⁹ Gonzalo Elizondo and Irene Aguilar, “The Ombudsman Institution in Latin America : Minimum Standards for its Existence”, in (eds,) Birgit Lindsnaes, Lone Lindholt, Kristine Yigen, *National Human Rights Institutions, Articles and working papers*, (The Danish Centre for Human Rights 2012) p. 217

Whilst individuals may be appointed to a NHRI's decision making body due to their membership or knowledge of a specific group, when appointed it is expected that they will have regard for the rights of all individuals when taking collective decisions. The SCA provides that office holders must be appointed 'to serve in their own individual capacity rather than on behalf of an organization they represent'.³⁸⁰ Whilst the SCA suggests that representatives of sectoral interests within an advisory committee is acceptable, their inclusion in decision making bodies is not. NHRI representatives interviewed for this research shared the view of commentators that if NHRI office holders were appointed to represent sectoral interests this may lead to office holders placing the priorities of certain sectoral groups over the priorities of the NHRI.³⁸¹ Furthermore there is a concern that it may undermine collegiality amongst members and create division.³⁸² This is an issue which I will explore later in this chapter.

4.8 The relationship between civil society and National Human Rights Institutions

Civil society regularly advocate for states to establish a NHRI and have influenced the international system to place pressure on states to do so.³⁸³ Civil society make these demands in the hope that NHRIs will provide a new independent institution to hold the government to account for its human rights abuses. However, a number of states have established NHRIs with the intention of controlling or silencing civil society.

Even when an NHRI has been established following campaigning by civil society a government may design the NHRI to control civil society. A state may use an NHRI to occupy 'space' once filled by civil society, 'thereby controlling the human rights agenda and silencing calls for accountability'.³⁸⁴ A representative of the OHCHR interviewed for this research recalled at least one case in which there were concerns that a NHRI designated as an IMM was seeking to dissuade DPOs from being critical of state activities during an examination by the CRPD Committee.³⁸⁵ It is important to note therefore that whilst civil society often call for the establishment of a NHRI, recalcitrant states have also established them to silence critical voices in civil society. This underscores the need for civil society to be involved in discussions relating the development of NHRIs to ensure they are institutions which will truly support civil society.

³⁸⁰ SCA (n. 306) para 1.8

³⁸¹ Murray, (n. 23) p. 207

³⁸² Smith, (n. 359)

³⁸³ *ibid* p.937.

³⁸⁴ Sonia Cardenas 'Emerging Global Actors: The United Nations and National Human Rights Institutions' [2003] *Global Governance* 23, p.37

³⁸⁵ Interview with OHCHR representative 23 December 2020

Disabled people and their representative organisations have often been absent from domestic discussions relating to the establishment of NHRIs. However, in recent years DPOs have taken greater interest in the establishment and effectiveness of their NHRIs. For instance, the Belgian Disability Forum has called on the Belgium Government to ensure the establishment of an A status NHRI.³⁸⁶ A number of DPOs have provided comments on the performance of NHRIs designated as IMM during the CRPD Committee's periodic examinations of states compliance.³⁸⁷

There is surprisingly limited literature assessing the benefits which the establishment of a NHRI can bring to civil society. Some commentators have highlighted the role of a NHRI in providing a bridge between civil society and the state. Smith has suggested that NHRIs can provide civil society with 'channels to make their claims' to the state.³⁸⁸ The conceptualisation of NHRIs as the bridge between civil society and the state is premised on the assumption that channels do not already exist. Literature relating to the DPM tends to emphasise that participative structures do exist, but these are ineffective.³⁸⁹ Indeed the establishment of the UNCRPD has led many states to develop new participative structures. In my evidence gathering I will explore whether NHRI(IMM) are establishing new channels for DPOs to engage with the state and whether they are assisting DPOs in ensuring that channels which exist afford them genuine opportunities to effect change. I will also consider whether NHRIs are supporting DPOs in making their claims through these channels.

As I will set out NHRIs will have powers to access materials and investigate state practices which many CSOs would wish for. Furthermore, NHRIs often have a power to raise matters with the state and to require a response. As I will discuss in my case studies disputes have often emerged when DPOs consider that a NHRI should exercise their powers and the NHRI refuses to do so. These disputes can often damage the relationship between an NHRI and DPOs, and lead to a perception that the NHRI is unresponsive. Existing literature and guidance have largely underexplored how NHRIs make strategic decisions relating to the exercise of their powers and the potential to involve civil society in decision making processes.

³⁸⁶ Belgium Disability Forum, 'Submission to the XXI session of the CRPD Committee List of issues prior to reporting for Belgium' February 2019

³⁸⁷ Ibid See further discussion relating to the examination of the UK.

³⁸⁸ Smith (n. 359) p. 909

³⁸⁹ Lana Moriarty and Kevin Dew, 'The United Nations Convention on the Rights of PWDs and Participation in Aotearoa New Zealand' [2011] Disability & Society 685 p. 686

Rather than exploring collaborative working between NHRIs and civil society, guidance from the OHCHR tends to emphasise the role of civil society in informing and supporting the activities and decision making of a NHRI.³⁹⁰ Okafor and Agbakwa have highlighted ‘in most cases, the NGO is viewed as the resource that the [NHRI] deploys or utilizes. In such a conceptual model, the [NHRI] is the agent while the NGO is the resource. Rarely, if ever, is this relationship imagined in the reverse’.³⁹¹ As set out in my legal analysis, the CRPD puts forward DPOs as the key agents of change in bringing about compliance with the CRPD. In this enquiry I will seek to address the existing gap in the literature and assess how a NHRI can be a resource for a DPO.

Much of the literature on NHRIs presupposes that they are influential bodies. In their 2002 report Quinn and Degener described NHRIs as ‘catalysts for change’ who make a meaningful contribution to the processes of domestic reforms.³⁹² In contrast to this view research by Goodman and Pegram indicate that the recommendations and reports from NHRIs often go unnoticed by decision makers.³⁹³ There is a lack of literature which explores how a NHRI becomes influential. Commentators tend to suggest that existing in a liminal space ‘somewhere between the state and civil society’ enables NHRIs to influence changes that are not attainable to CSOs.³⁹⁴ However, as I will discuss in my case studies the assumption that influence flows from the unique status of NHRIs has not always been demonstrated in practice.

In my review of the literature, I have sought to determine the key factors which are considered to lead to an NHRI being influential.³⁹⁵ Murray suggests that NHRIs as statutory bodies are ‘in a unique position to influence politicians and civil servants, as they may be able to build personal relationships’ and to develop knowledge and insight into the process of policy making.³⁹⁶ The privileged position of NHRIs provides them with opportunities to influence which are not open to CSOs. Other commentators have highlighted that a more significant deciding factor is the expertise and experience of a NHRI’s office holders and staff. Carver highlights how experienced office holders have given NHRIs ‘a certain leverage over the

³⁹⁰ OHCHR, *A Manual for National Human Rights Institutions on Monitoring Economic, Social and Cultural Rights* OHCHR (2011) p.119

³⁹¹ Obiora Chinedu Okafor and Shedrack C. Agbakwa, ‘On Legalism, Popular Agency and Voices of Suffering: The Nigerian National Human Rights Commission in Context’ [2002] *Human Rights Quarterly*, 662 p. 690

³⁹² Quinn and Degener (n. 28) p. 273

³⁹³ Goodman R and Pegram T, ‘Introduction: National Human Rights Institutions, State Conformity, and Social Change’ in Ryan Goodman and Thomas Pegram (eds) *Human Rights, State Compliance and Social Change* (Cambridge University Press 2012) p. 15

³⁹⁴ Mertus, J.A. 2009. *Human rights matters: Local politics and national human rights institutions*. Stanford: Stanford University Press. pg 3

³⁹⁵ Reif, L, ‘Building Democratic Institutions: The Role of National Human Rights Institutions in Good Governance and Human Rights Protection’, [2000] *Harv. Hum. Rts. J.* 1, p. 27

³⁹⁶ Murray (n. 23) p. 195

powerful institutions of state'.³⁹⁷ Pegram has similarly highlighted that many senior NHRI office holders have experience working within ministries and other branches of the state, and have developed interpersonal skills and networks that enhance the ability of the NHRI to positively influence public authorities and deliver human rights protections in real world scenarios.³⁹⁸ This view reflects the findings of political scientists.³⁹⁹ Mintrom, in particular, has highlighted how those who wish to influence policy makers need to have a mixture of technical and personal skills to persuade policy makers of the case for reform and to steer the process of reforms to bring about a desired outcome.⁴⁰⁰

Reif has highlighted that a NHRI will become influential if it develops a reputation for producing credible evidence and advice which is relevant to ongoing policy discourses.⁴⁰¹ NHRI representatives interviewed for this research consistently emphasised that to become influential their institutions needed to ensure their findings and advice are credible. To do so it is important that NHRIs ensure 'rigour, objectivity and independence' in the way in which they develop their findings and advice.⁴⁰²

From my analysis of pronouncements and reports issued by NHRIs I noted that they tend to emphasise that their analysis and findings are based on a strict legal analysis of the human rights obligations placed on the state, by virtue of both the domestic and international human rights system. When in post as Chief Commissioner of the NIHRC Professor O'Flaherty commented 'The Commission interprets human rights to mean no more and no less than the standards found in the international human rights treaties ratified by the UK. The rock on which the Commission secures its work is the law and nothing else'.⁴⁰³ NHRI representatives interviewed for this research considered that basing their advice on legal obligations increases its credibility and shield the NHRI from allegations of politicisation.⁴⁰⁴ This approach has some merit as policy makers tend to consider that legal advice must be complied with, whereas policy advice may be followed.⁴⁰⁵

³⁹⁷ Carver, Richard 'Performance and Legitimacy: National Human Rights Institutions International Council on Human Rights Policy', (Versoix, Switzerland, 2000) p. 35

³⁹⁸ Pegram, Tom 'The New Architecture in Global Human Rights Governance' [2015] *Millennium* 618

³⁹⁹ Wu, X et al. *The public policy primer: Managing public policy* (Routledge 2010)

⁴⁰⁰ Michael Mintrom, 'The Policy Analysis Movement', in Laurent Dobuzinskis, David H. Laycock and Michael Howlett (eds) *Policy Analysis in Canada: The State of the Art* (University of Toronto Press 2005) p. 146

⁴⁰¹ Reif, (n. 395)

⁴⁰² Glusac, L, 'National Human Rights Institutions and Oversight of the Security Services' *Journal of Human Rights Practice*, Volume 10, Issue 1, February 2018, Pages 58–82 pg 65

⁴⁰³ NIHRC Annual Statement on human rights compliance (NIHRC 2002), Foreword

⁴⁰⁴ Interview with representative of the AHRC

⁴⁰⁵ Edward Page 'Bureaucrats and Expertise: Elucidating a Problematic Relationship in Three Tableaux and Six Jurisdictions' (2010) 52(2) *Sociologie du Travail* 255, 271.

The approach of NHRIs differs from the approach often taken by CSOs. Koskenneinin notes that CSOs who engage in human rights advocacy tend not to confine themselves to rights that have been adjudicated either in the domestic system or international system.⁴⁰⁶ Indeed disability advocate Melish in referring to the norms protected within the CRPD has encouraged the DPM to develop ‘our own interpretation of those norms, with the goal of reaching the desired result in advocacy’.⁴⁰⁷

The suitability of the approach advocated by Professor O’Flaherty when advising on the CRPD is questionable. As set out in my legal analysis, the CRPD contains a range of standards and principles, the application of which depends on an assessment of the challenges faced by disabled people. Gerard Quinn highlights that a legal analysis of the CRPD, in common with other international human rights instruments, is unlikely to lead to ‘one right answer on every question’.⁴⁰⁸ The CRPD puts forward a range of standards and principles the application of which requires an assessment of domestic standards. If a NHRI limits itself to restating the standards set out in the CRPD and does not extend its advice to suggesting policy solutions to the challenges faced by disabled people, its advice will be of limited value. In addition to providing legal advice on the CRPD a NHRI must provide policy advice ‘on what to do in order to achieve compliance’.⁴⁰⁹ This may require a NHRI to develop its capacity and resources to ensure it well placed to interpret the CRPD with reference to domestic circumstances and provide advice on the obligations it places on state parties.

In my case studies I consider the influence exerted by the EHRC and the IHREC and how this differs from that exerted by DPOs and other CSOs. I also consider how each institution have engaged with DPOs when developing their advice on the CRPD and whether any disputes have arisen when interpreting and utilising the CRPD.

4.9 The role of NHRIs designated as IMMs

So far in this chapter I have considered the role of NHRIs in general, in the remainder of this chapter I will consider the structure of NHRIs designated as Independent Monitoring

⁴⁰⁶ Martti Koskeniemi, ‘The Politics of International Law – 20 Years Later’, [2009] *European Journal of International Law* 7

⁴⁰⁷ Melish, T J, ‘An Eye Toward Effective Enforcement: A Technical-Comparative Approach to the Drafting Negotiations.’ Maya Sabatello and Marianne Schulze (eds), *Human rights and disability advocacy* (University of Pennsylvania Press 2014) p. 74

⁴⁰⁸ Quinn (n. 136) p. 12

⁴⁰⁹ Aichele V, Article 33 National Implementation and Monitoring in Ilias Bantekas, et al (eds) in *The UN Convention on the Rights of Persons with Disabilities : A Commentary* (Oxford University Press 2018) p. 992

Mechanisms and will then consider their functions. In considering their functions I will consider how NHRI(IMM)s have collaborated with DPOs.

As set out in my legal analysis Article 33(3) specifically provides for the participation of civil society within the ‘monitoring process’. As set out in my legal analysis, in my view Article 33(3) is poorly worded. Broadly speaking it places an obligation on states to ensure disabled people and their representative groups are involved in a IMF or IMM.

In only two states, New Zealand and Spain, have DPOs been included in a IMF alongside a NHRI. However, in the majority of states NHRIs have been solely designated as the IMM. This trend has encouraged reflection on the pluralistic nature of a NHRI and on the extent to which disabled people are reflected in the composition of a NHRI.

In a number of states, the composition of the NHRI has been amended to ensure the participation of disabled people. In New Zealand the ratification of the CRPD led to the inclusion of a Disability Commissioner within the New Zealand Human Rights Commission.⁴¹⁰ The New Zealand Human Rights Commission is composed of four commissioners; a Chief Commissioner; a Disability Rights Commissioner; a Equal Employment Opportunities Commissioner and a Race Relations Commissioner.⁴¹¹ Commissioners are appointed by the New Zealand Government but can be nominated by interest groups, such as DPOs.⁴¹²

In Denmark provision was made for an additional member of the Danish Institute for Human Rights decision-making board to be nominated by Danish DPOs.⁴¹³ A DPO nominee is therefore involved in setting the strategic direction of the DIHR.⁴¹⁴ It is notable therefore that the DPM is effectively the appointing authority for this office holder. This creates a direct link between the Danish Institute for Human Rights and the national DPM.

As explained in my legal analysis, the UNCRPD Committee have recommended that NHRI(IMM)s develop formal mechanisms to facilitate the inclusion of disabled people and their representative groups.⁴¹⁵ A representative of the UNCRPD Committee Secretariat

⁴¹⁰ CRPD Committee, Concluding observations on the initial report of New Zealand CRPD/C/NZL/CO/1 (31 October 2014) para 4

⁴¹¹ Ministry of Justice New Zealand Government, *Guidance for the appointment of the Human Rights Commissioners*, (2020).

⁴¹² *ibid*

⁴¹³ CRPD Committee, *Concluding observations on the initial report of Denmark*, CRPD/C/DNK/CO/1, (30 October 2014) para 66

⁴¹⁴ Interview with Institute for Human Rights 4 January 2021

⁴¹⁵ CRPD Committee, *Concluding observations on the initial report of the Philippines*, CRPD/C/PHL/CO/1, (16 October 2018) para 60(b)

highlighted that the UNCRPD Committee have developed a view that ‘...only a formal mechanism ensures that [DPOs] are going to be called for every time that there is a decision’.⁴¹⁶ The representative highlighted that formal mechanisms should provide an opportunity for disabled people to be ‘heard as a movement’.⁴¹⁷ An OHCHR representative emphasised that there was a need for NHRIs to understand ‘the nature of belonging to a representative organisation’.⁴¹⁸ Their view reflects the emphasis which the UNCRPD in Article 4(3) places on disabled people being represented through their organisations. As I will discuss in my case studies both the EHRC and IHREC emphasise that individuals appointed as Commissioners should serve in their individual capacity rather than as a representative of an organisation or identity group. This is consistent with a general trend within public bodies. Zald et. al. note that ‘members of an identity group that climb in an organization will typically be expected to distance themselves from the goals of identity groups’.⁴¹⁹

A number of NHRI(IMM) are currently giving consideration to the merits of establishing a formal participation arrangement. Several NHRI(IMM)s interviewed for this research emphasised that establishing formal arrangements was often resource intensive and that there was value in keeping arrangements on an informal footing.⁴²⁰ A number of NHRI representatives also expressed concern that the development of formal participation arrangements which includes representatives of DPOs may present governance issues.⁴²¹ Their views corresponded with research conducted by Quinn and Crowther for the Asia Pacific Forum of NHRIs.⁴²² Quinn and Crowther noted that ‘NHRIs have expressed concern about the impact of involving persons with disabilities on their ‘de facto’ independence, as required by the Paris Principles’.⁴²³ They further noted that NHRIs were concerned that establishing participative arrangements to involve DPOs in their activities may ‘in the eyes of some, taint any recommendations for change that emerge from the partnership’.⁴²⁴ I note that much of the existing literature and guidance tends to emphasise the need for a NHRI to separate itself from civil society. The OHCHR has emphasised that when seeking input from

⁴¹⁶ Interview with representative of CRPD Committee secretariat 11 December 2020

⁴¹⁷ *ibid*

⁴¹⁸ Interview with representative of OHCHR 23 December 2020

⁴¹⁹ Zald, M., Morrill, C., & Rao, H. The impact of social movement organisations: environment and responses. in G. Davis, D. McAdam, W. Scott, & M. Zald (Eds.), *Social Movements and Organization Theory (Cambridge Studies in Contentious Politics)*, (Cambridge: Cambridge University Press 2012), p.275

⁴²⁰ Interview with representative of AHREC, 26 November 2020

⁴²¹ Interview with representative of NIHRC, 27 November 2020 .

⁴²² Quinn, Gerard and Crowther, Neil ‘Human rights and disability: A Manual for NHRIs’ (Asia Pacific Forum 2017), p. 111

⁴²³ *Ibid*, p. 111

⁴²⁴ *Ibid*

CSOs NHRIs need to be cautious that, CSOs ‘may exaggerate results or have a particular agenda to advance’.⁴²⁵

Aichele has suggested that the Paris Principles ‘requires equidistance from the state and any civil society forces’.⁴²⁶ This assertion in my view overstates the risk posed by civil society. NHRIs are established to monitor the activities of the state and to take measures, potentially including litigation or an investigation, if they consider that a state has breached the rights of individuals. There are numerous examples of states attempting to restrict or limit the activities of NHRIs.⁴²⁷ Whilst NHRIs need to critically assess assertions made by CSOs, CSOs do not pose the same risk of co-option as that posed by the state. Furthermore, CSOs lack the power to do so. The concerns of NHRIs seem to largely relate to the way in which advice and activities developed in conjunction with DPOs will be perceived. As I will explore in my case studies there is a concern that if a NHRI is perceived as simply echoing the views of DPOs or other actors in civil society this may lead to the state questioning their value.

The experience of NHRI(IMM)s who have established formal mechanism has been mixed.⁴²⁸ A representative of the GIHR, who hold regular consultation exercises with disabled people and representative groups, recounted that the GIHR found the development of inclusive mechanisms challenging. He stated, ‘I find it very hard to be very serious with participation in the sense that you involve DPOs, you discuss a matter, then you go back home, you’re switched to the responsibility side and say okay, we have to fulfil our mandate, we need to sort of set the priorities ourselves, because we are responsible for the priorities that we set’.⁴²⁹ The views of the GIHR are in my view indicative of a lack of reflection within NHRIs of what it means for a NHRI to include disabled people and their representative groups in their monitoring activities. In my analysis of the activities of NHRIs I noted a lack of emphasis on explaining decision making approaches, with limited evidence of NHRIs providing a justification for how they have chosen to prioritise topics or issues over others. There has been limited exploration amongst NHRIs of approaches which they can take, to manage the expectations of civil society

⁴²⁵ OHCHR (n. 364) p. 119

⁴²⁶ Aichele V, Article 33 National Implementation and Monitoring in Ilias Bantekas, et al (eds) in *The UN Convention on the Rights of Persons with Disabilities : A Commentary* (Oxford University Press 2018) p. 996

⁴²⁷ Sonia Cardenas, *Chains of Justice: The Global Rise of State Institutions for Human Rights* (University of Pennsylvania Press 2014), p.

⁴²⁸ Mahomed, F., Lord, J. E., & Stein, M. A. (2019). Transposing the Convention on the Rights of Persons with Disabilities in Africa: The Role of Disabled Peoples’ Organisations. *African Journal of International and Comparative Law*, 27(3), 335–358. 356

⁴²⁹ Interview with representative of GIHR, 28 January 2021

and ensure their confidence in their decision making.⁴³⁰ In my case studies I will explore how the EHRC and the IHREC have explained their decision making approaches to DPOs.

A particular challenge for NHRI(IMM)s who have established formal mechanisms is how to address circumstances in which the decision-making body within the NHRI, chooses not to follow the advice or views of disabled people or DPOs they have consulted with. In preparation for its designation as an IMM the South African Human Rights Commission (SAHRC) established an advisory committee on disability matters including DPOs and international experts.⁴³¹ When the advice of the advisory committee that the SAHRC should conduct an inquiry into circumstances in a mental health institution was not followed this led to a number of high profile resignations from the advisory committee.⁴³² This has had a damaging effect on the credibility of the SAHRC and on its relationship with the DPM.

NHRI(IMM) are conscious that the act of developing workable participative mechanisms presents potential risks. The potential benefits to both the NHRI(IMM) and the DPM of developing participative mechanisms did not appear to be fully appreciated amongst NHRIs interviewed for this stage of my research. In my case studies, I will consider the opportunities and risks presented through the establishment of participative mechanisms. I will also consider whether the views of representatives of the international human rights system and the guidance provided by the SCA are reconcilable.

Functions

The Paris Principles provide an overview of the functions which a NHRI should perform. In practice there is significant diversity in the range of functions performed by NHRIs and in the specific functions which a NHRI focuses its resources upon.⁴³³ Within its General Guidelines the UNCRPD Committee have set out an extensive list of functions which a IMM should perform. The General Guidelines were informed by the Paris Principles and GANHRI provided advice to the Committee on their content.⁴³⁴ As set out in my legal analysis the designation of a NHRI as an IMM has rarely led to amendments to their legal basis to expand their functions.

⁴³⁰ Meyer (n. 339) p. 330

⁴³¹ Faraaz Mahomed, Janet E. Lord & Michael Ashely Stein, 'Transposing the Convention on the Rights of Persons with Disabilities in Africa: The Role of Disabled Peoples' Organisations' [2019] African Journal of International and Comparative Law 335, p. 347

⁴³² Ibid

⁴³³ De Beco, G and Murray, R 'A commentary on the Paris Principles on national human rights institutions' (Cambridge University Press 2014), p. 138

⁴³⁴ GANHRI 'Submission to call for evidence on guidelines relating to independent monitoring frameworks' 2017

However, to ensure compliance with the General Guidelines a NHRI must adapt the way in which they execute their functions.

In this section I will discuss the functions performed by a NHRI with a specific focus on how through exercising these functions a NHRI can support DPOs. In doing so I will draw on published literature and on my empirical analysis of the activities of NHRIs.

4.9.1 Provision of training and capacity building to DPOs

The CRPD Committee General Guidelines make clear that the IMM must engage in promotional activities including training initiatives.⁴³⁵ A number of NHRI(IMM)s have delivered training to DPOs relating to the CRPD and engagement in the international human rights system.⁴³⁶ For example, when it was initially designated as the IMM the GIHR received funding to provide training to DPOs on the CRPD.⁴³⁷ A number of NHRIs including the SHRC have developed discrete training programmes for DPOs.⁴³⁸ However, NHRIs interviewed for this research tended to emphasise that they were not resourced to provide training to DPOs or to civil society more generally.

Whilst NHRIs have rarely established formal training programmes, representatives of the international human rights system highlighted that through their activities NHRIs can share their expertise with DPOs and provide an example of the sort of activities which influence change.⁴³⁹ A representative of the UN SR Disability interviewed for this research highlighted a number of states where NHRIs have assisted DPOs to become more attentive to the policy making process.⁴⁴⁰ Flynn, writing on national disability strategies, suggests that ‘...grassroots organisations must learn from government leaders how to negotiate, compromise and facilitate implementation...’.⁴⁴¹ In my view the designation of a NHRI as an IMM provides an alternative body upon which DPOs can model their activities and learn from.⁴⁴²

⁴³⁵ CRPD Committee (n. 132) para 12

⁴³⁶ NIHRC Press Release, ‘Workshops on getting involved in the CRPD reporting process’ 12 December 2013

⁴³⁷ Interview with representative of GIHR 28 January 2021

⁴³⁸ Interview with representative of SHRC 18 March 2021

⁴³⁹ Interview with representative of OHCHR 23 December 2020

⁴⁴⁰ Interview with representative of UN SR Disability 30 November 2020

⁴⁴¹ Flynn E, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2011) p. 206

⁴⁴² Crowther, N., & Priestley, M. Assessment of the mandate of the United Nations Special Rapporteur on the rights of persons with disabilities: Lessons from the term of the first mandate holder, Catalina Devandas Aguilar. (OHCHR 2020) <https://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/evaluation.aspx> (Accessed on 3 July 2022)

The CRPD Committee report that the very act of participating can generate agency within DPOs.⁴⁴³ NHRIs can potentially contribute to the capacity of DPOs by developing new forums for the discussion of policy issues which can provide important learning opportunities. Political scientists highlight that through participating in policy discussions organisations and individuals engage in ‘policy-oriented learning’.⁴⁴⁴ Through providing DPOs with opportunities to deliberate over policy issues can enhance their capacity to ‘weigh evidence and arguments from various points of view’.⁴⁴⁵ NHRIs can also share with DPOs ways to frame research and policy positions to influence change.

I identified a number of examples of NHRIs creating opportunities for DPOs to engage in deliberation over policy issues. The New Zealand Human Rights Commission (NZHRC) organise engagement events to facilitate conversations within the DPM on emerging policy issues. These events offer the movement an opportunity ‘...to have the difficult conversations, to conceptualise, articulate and build that sort of shared vision and understanding...’ to inform their engagement in the policy making process.⁴⁴⁶ Similarly the NI Human Rights Commission has developed a disability forum. At meetings of the forum the Commission shares its expertise and insights on emerging policy issues with DPOs.⁴⁴⁷

In my case studies I will consider whether through their participative mechanisms the IHREC and EHRC are providing opportunities for disabled people and DPOs to become discursively competent and skilled in the process of critical assessment and reflection.⁴⁴⁸

4.9.2 Monitoring: International Human Rights Examination and Follow Up

One of the principal benefits which NHRIs are considered to bring to the monitoring of the CRPD is their extensive ‘consolidated experience’ and expertise in engaging with the international human rights system.⁴⁴⁹

⁴⁴³ CRD Committee (n. 62) para 23

⁴⁴⁴ Diane Stone “Learning Lessons, Policy Transfer and the International Diffusion of Policy Ideas” CSGR Working Paper No. 69/01 April 2001

⁴⁴⁵ Lindeman M, Opinion quality and policy preferences in deliberative research in Delli Carpini MX et al., (ed) Research in Micropolitics: Political Decisionmaking, Deliberation and Participation, (JAI Press 2002), p. 199

⁴⁴⁶ Interview with representative of NZHRC 13 April 2021

⁴⁴⁷ Interview with representative of NIHRC 27 November 2020

⁴⁴⁸ Margaret Kohn, Language, Power, and Persuasion: Toward a Critique of Deliberative Democracy (2000), p. 425

⁴⁴⁹ Luigino Manca, ‘Article 33 [National Implementation and Monitoring]’ in Valentina Della Fina, Rachele Cera and Giuseppe Palmisano, *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer 2017).

The CRPD examination process is often at the centre of DPOs advocacy efforts.⁴⁵⁰ Whilst states are not bound to implement the CRPD Committee's recommendations they have the potential to '...play a catalytic and complementary role in ensuring that domestic policy and political narratives adjust to the values of the convention and bring about local solutions acceptable to the universal norms of the convention'.⁴⁵¹ NHRI(IMM)s can play a key role in supporting DPOs to engage in the examination process and in collaborating with DPOs to engage with CRPD Committee to ensure the Committee's recommendations are workable solutions that resonate with domestic audiences.

In this section I will first consider how NHRI(IMM)s have supported DPOs to engage in the examination process and will then consider their role in following up to CRPD examination processes.

CRPD examination

The key event in the examination process is the dialogue between a delegation of state party representatives and the CRPD Committee which takes place in Geneva over two days.⁴⁵² To inform this session NHRI(IMM) and DPOs are entitled to submit parallel reports to the CRPD Committee. Parallel reports provide the Committee with first-hand insight into local conditions and provide feedback on the actions of the state party.⁴⁵³ Creamer and Simmons have highlighted the importance of Treaty bodies being appropriately informed of developments in the state party in advance of the state dialogue.⁴⁵⁴ This ensures that the Treaty body members are able to challenge accounts put forward by the state party delegation and to put forward constructive criticisms.

NHRI(IMM)s can cooperate with DPOs in the development of reports in a range of ways. NHRIs can consult with DPOs in the development of their shadow reports to the CRPD Committee.⁴⁵⁵ A representative of the DIHR interviewed for this research emphasised that when developing their shadow reports they sought out DPOs and disabled people who were

⁴⁵⁰ Combrinik 'Article 36 Consideration of Reports' in Ilias Bantekas, et al (eds) *The UN Convention on the Rights of Persons with Disabilities : A Commentary*, (Oxford University Press 2018), p. 1067

⁴⁵¹ Quinn (n. 4) p. 219

⁴⁵² CRPD Committee, 'Working Methods' UN Doc CRPD/C/5/4 (2 September 2011)

⁴⁵³ Cosette D. Creamer and Beth A. Simmons, 'The Dynamic Impact of Periodic Review on Women's Rights' [2018] *Law and Contemporary Problems* 81

⁴⁵⁴ *Ibid* 31.

⁴⁵⁵ Interview with representative of DIHR 4 January 2021

unlikely to have sufficient expertise or resources to develop their own reports.⁴⁵⁶ In this way the NHRI(IMM) can provide a voice to those DPOs unable to submit their own reports expanding the number of DPOs who are able to engage in the examination process.

The CRPD Committees provide opportunities for NHRI(IM)s to participate in the formal session through making opening and closing statements.⁴⁵⁷ DPOs tend to engage with the Committee through private briefings and side events. There is a lack of research looking into the approaches of NHRI(IM)s and DPOs to the examination process. Melish highlights how, during the negotiation of the UNCRPD, grassroots DPOs tended to focus their advocacy on setting out the experiential or lived experience of disabled people. By contrast, transnational DPOs and NHRIs drew on their technical expertise to identify how human rights protections could be placed into law.⁴⁵⁸ Noting this trend I reviewed submissions to the CRPD Committee in the seven states hosting NHRIs interviewed for this stage of my research to ascertain if this practice was reflected in the CRPD examination process.

I noted a number of examples of DPOs setting out the experience of rights holders and cross referencing their submission to the NHRI(IMM), who provided a more technical analysis.⁴⁵⁹ In particular I noted that in their submissions to the CRPD Committee the DIHR submission focused on technical issues ‘regarding gaps in the law or overlapping administrative structures’.⁴⁶⁰ Whilst a shadow report from an umbrella group of Danish DPOs set out a number of case studies illustrating the need for reform and cross referenced the analysis contained in the DIHR’s report.⁴⁶¹ Their collaboration meant that the Committee understood both the practical impact of current laws and of the potential policy solutions. This approach appears to play to the respective strengths of DPOs and NHRI(IM)s. However, it is difficult to make general observations on the best approach towards CRPD examination processes. I will explore in my case study on Great Britain how the EHRC have worked with the DPM in the examination process.

⁴⁵⁶ *ibid*

⁴⁵⁷ CRPD Committee (n. 408) para 21 (h)

⁴⁵⁸ Melish, T J, An Eye Toward Effective Enforcement: A Technical-Comparative Approach to the Drafting Negotiations. In Maya Sabatello and Marianne Schulze (eds), *Human rights and disability advocacy* (University of Pennsylvania Press 2014) p. 74

⁴⁵⁹ Submission to the United Nations Committee on the Rights of Persons with Disabilities on autistic Australians and our actual Rights from Autism Aspergers Advocacy Australia July 2019

⁴⁶⁰ Interview with representative of DIHR 4 January 2021

⁴⁶¹ Responses from the Danish Disability movement to List of Issues from the CRPD-Committee, RPD/C/DK/Q/1, April 17th 2014

The reporting process provides both NHRI(IMM) and DPOs with a ‘window of opportunity to have a serious dialogue with senior government officials’.⁴⁶² The CRPD Committee have made clear that NHRI(IMM) should facilitate and promote the meaningful participation of DPOs in the reporting process.⁴⁶³ In my case studies I will consider how the IHREC and EHRC have supported DPOs to engage in the examination process.

In its report the CRPD Committee will identify a number of concluding observations which it requires the state party to respond to within one year.⁴⁶⁴ Creamer and Simmons highlight that treaty examinations can ‘...set in motion bureaucratic routines to gather, authenticate and analyse information that might not have occurred in the absence of the obligation to report’.⁴⁶⁵ The requirement to provide follow up information and to develop periodic reports can provide a basis for NHRIs and DPOs to advocate for the establishment of domestic reporting procedures. There is limited publish research on this topic. However, I identified that the New Zealand Human Rights Commission have collaborated with DPOs in advocating for the inclusion of follow up reporting requirements within the New Zealand Disabled National Action Plan.⁴⁶⁶ NHRIs can play a key role in linking international reporting to domestic processes.

Monitoring Implementation of CRPD concluding observations

The CRPD Committees General Guidelines emphasize that NHRI(IMM)s should play a key role in ensuring that the state gives ‘...due consideration to the Committee’s concluding observations’.⁴⁶⁷

The CRPD Committee recommendations are often set out in broad terms.⁴⁶⁸ Research by Lawson and Beckett highlights that the Committee will often recommend that the state embarks on reforms to policy areas to ensure the incorporation of the human-rights model of disability, without specifically identifying the reforms which should take place.⁴⁶⁹ Stein and Lord writing

⁴⁶² Samuel Kabue, Disability Rights, Development and the Roles of the Disability Movement in Marcia H. Rioux, Paula C. Pinto, Gillian Parekh (eds) *Disability, Rights Monitoring, and Social Change* (Canadian Scholars’ Press, 2015) p. 203

⁴⁶³ CRPD Committee ‘Guidelines’ (n. 4) para 21

⁴⁶⁴ See discussion in chapter on UK

⁴⁶⁵ Cossette D. Creamer and Beth A. Simmons, ‘Ratification, Reporting, and Rights: Quality of Participation in the Convention against Torture’ (2015) *Human Rights Quarterly* 579, 608

⁴⁶⁶ Interview with representative of NZHRC 13 April 2021

⁴⁶⁷ CRPD Committee ‘Guidelines’ (n. 4) para 21(k)

⁴⁶⁸ CRPD Committee representative interviewed 11 December 2020

⁴⁶⁹ Lawson & Beckett (n. 117)

in 2020 encouraged the CRPD Committee to ‘move beyond vague directives to more specific guidance’.⁴⁷⁰

The UNCRPD Committee have in my view been rightly criticised for the vagueness of some of its recommendations. However the potential for the Committee to become more exacting in its recommendations is limited. As set out in my legal analysis determining the requirements of the CRPD must be informed by a rigorous assessment of the domestic context. Furthermore many of the concepts set out in the CRPD are not sharply defined and in many areas it would not be possible for the CRPD Committee to set out specific directions.⁴⁷¹

This presents a significant challenge to DPOs and to NHRIs. Political scientists highlight that policy makers tend to give greatest attention to recommendations that are presented as credible and workable solutions.⁴⁷² If the recommendations which emerge from the CRPD Committee examination process are left in vague terms they are unlikely to capture the attention of domestic policy makers. The drafters of the CRPD were conscious of this risk and put in place a ‘double track’ approach to oversight, with responsibility for international oversight resting with the CRPD Committee and responsibility for domestic oversight with the NHRI(IMM).⁴⁷³ As set out above Arduin suggests that the NHRI(IMM) provide an ‘internal compliance system’ to compliment the ‘meta-regulatory system’ managed by the CRPD Committee.⁴⁷⁴ This characterisation to a degree overstates the roles performed by both the Committee and a NHRI(IMM). In my view a NHRI(IMM) plays a role in domesticating the recommendations that emerge from the CRPD Committee. The CRPD Committee identify issues that need to be addressed to realise compliance and a NHRI(IMM) with its knowledge of domestic processes and circumstances identifies actions required to bring about that compliance. To perform this role effectively a NHRI(IMM) must ensure the inclusion of disabled people and their representative groups in both the examination process and in the process of domesticating the recommendations.

This is a key observation which is not always acknowledged in discussions relating to the treaty body process. The journey towards human rights compliance requires not only international

⁴⁷⁰ Janet Lord and Michael Stein, ‘The Committee on the Rights of Persons with Disabilities’ in Philip Alston and Frédéric Mégret (eds) *A Critical Appraisal* (2nd Edition OUP 2020) p. 575

⁴⁷¹ *Ibid* p. 576

⁴⁷² Kingdon J. Agendas, alternatives and public policies. 2nd ed. New York: Harper Collins; 1995.

⁴⁷³ Luigino Manca, ‘Article 33 [National Implementation and Monitoring]’ in Valentina Della Fina, Rachele Cera and Giuseppe Palmisano, *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer 2017). p. 592

⁴⁷⁴ Arduin (n. 94)

processes but domestic processes which turn treaty body recommendations into workable policy solutions. Responding to this need, a number of NHRIs have developed their own systems for tracking and reporting on the implementation of treaty body recommendations.

These systems see the NHRI(IMM)s assessing implementation efforts and making pronouncements on whether recommendations emerging from the Treaty body system have been adopted.⁴⁷⁵ For instance, the NIHRC produce an annual statement in which they assess the implementation of recommendations emerging from the treaty body system, including the CRPD Committee, classifying progress based on a traffic light system.⁴⁷⁶ The OHCHR has recently developed a software programme to facilitate the development of domestic trackers by NHRIs. The Samoan NHRI is utilising this software to develop domestic reporting systems.⁴⁷⁷ The system is largely intended for internal use by NHRIs. I will consider in my evidence gathering the approach to the IHREC and EHRC to tracking treaty body recommendations and will consider how these approaches have been informed by the views of DPOs, in particular when making a determination relating to the implementation of the CRPD Committee's concluding observations.

4.9.3 Engaging in the international Human Rights System

An OHCHR representative interviewed for this research highlighted that it was central to the success of the CRPD that DPOs are empowered to engage not only with the CRPD Committee, but also with other treaty body processes and with the special procedures of the UN.⁴⁷⁸

NHRIs are required to have broad mandates and tend to engage in the full range of treaty bodies and with the UN human rights council examinations.⁴⁷⁹ As such, NHRIs are well-placed to assist DPOs to engage in the UN human rights system more generally.⁴⁸⁰ The CRPD Committee and GANHRI have underscored the role of NHRIs in making linkages across the human rights system, in particular through issuing a joint declaration recognising that 'NHRIs have a unique and critical role in the promotion and protection of the rights of persons with

⁴⁷⁵ See discussion of tracker in Chapter 5

⁴⁷⁶ NIHRC Annual Statement 2012

⁴⁷⁷ Interview with representative of Fiji NHRI 10 December 2020

⁴⁷⁸ Interview with representative of OHCHR 23 December 2020

⁴⁷⁹ Paris principles (n

⁴⁸⁰ Domenico Zipoli, 'NHRI Engagement with UN Human Rights Treaty Bodies: A Goal-based Approach', [2019] *Nordic Journal of Human Rights* 259

disabilities by creating linkages with other monitoring mechanisms at the national level ...as well as at the international level'.⁴⁸¹

There is limited literature exploring how NHRI(IMM)s have supported DPOs to engage in other UN monitoring systems beyond the UNCRPD examination process. I found examples of NHRIs assisting DPOs to engage with the UN SR Disability. When the UN SR Disability has conducted country visits a number of NHRIs facilitated and hosted interactive events between the UN SR Disability and DPOs.⁴⁸² NHRIs have included DPOs in consultations relating to the development of their submission to the Universal Periodic Review Process.⁴⁸³ However there is limited evidence of NHRI(IMM)s including DPOs in their reporting across the international human rights system. In my case studies I will explore how NHRI(IMM) have included DPOs in their general monitoring activities.

4.9.4 Domestic monitoring

Through their domestic monitoring a NHRI(IMM) can assist DPOs, firstly by developing new insights into the lived experience of disabled people and secondly by identifying obstacles to the establishment and functioning of DPOs.

The CRPD Committee General Guidelines suggest that NHRI(IMM)s should develop extensive capacity to independently collect and analyse data relating to disabled people. It has been suggested that NHRI(IMM)s should develop independent data collection systems which can be used by DPOs to counter official statistics.⁴⁸⁴ There is limited evidence of NHRIs developing data collection systems that are independent of government. NHRIs who offer advice to the public or receive complaints can collect data and publish reports into trends on the number and form of requests or complaints they have received.⁴⁸⁵ For instance, the Canadian Human Rights Commission ('CHRC'), which is the national equality body, was able through analysis of complaints raised by disabled people to identify several significant obstacles to disabled people exercising the right to work.⁴⁸⁶ In doing so they provided DPOs with statistical data to support their calls for state initiatives to support disabled people into

⁴⁸¹ CRPD and GANHRI, 'Joint Declaration' 19th session Geneva (14 February to 9 March 2018)

⁴⁸² A/HRC/40/54/ADD.1

⁴⁸³ Interview with representative of NZNHRI

⁴⁸⁴ Quinn, Gerard and Crowther, Neil 'Human rights and disability: A Manual for NHRIs' (Asia Pacific Forum 2017)

⁴⁸⁵ Canadian Human Rights Commission 'Annual Report 2018

⁴⁸⁶ Report of the Special Rapporteur on the rights of persons with Disabilities A/HRC/43/41/Add.2 19 December 2019 para 28

employment. In my case studies I will assess whether the EHRC and the IHREC have collected and published data on their complaints handling role.

Whilst the capacity of a NHRI to support DPOs through the production of independent statistics is somewhat limited, a NHRI can potentially support DPOs through developing new forms of analysis of existing statistics. A number of features of a NHRI make them well placed to develop new forms of statistical analysis. They are likely to have statutory powers to access information that is not open to DPOs or other CSOs. NHRIs have a ‘temporal advantage’ over DPOs in being permanent bodies.⁴⁸⁷ This allows NHRIs to analyse trends over time and track progression or decline; highlighting trends that government may wish to obscure.⁴⁸⁸ Priestley and Lawson have highlighted the value of DPOs having access to ‘concurrent multinational evidence to identify examples of promising practices or poor performance that could shape their lobbying efforts and policy change’.⁴⁸⁹ NHRI(IMM)s who are included in both regional and international networks can compare and contrast domestic trends with regional or international trends. In doing so a NHRI(IMM) can identify where a state is falling behind neighbouring states. This evidence can be of value in convincing states to adopt policies or practices that have been proven to be effective in other jurisdictions. In my case studies I will consider whether the IHREC and the EHRC have developed new forms of statistical analysis to support the advocacy activities of DPOs.

As set out in my legal analysis, the CRPD places new and unique obligations on the state to respect, protect and fulfil the rights of disabled people to form together in representative organisations.⁴⁹⁰ In my analysis of published literature and of monitoring reports developed by NHRI(IMM) I found limited evidence of NHRIs expanding their monitoring activities to include an assessment of state measures to support the development and growth of DPOs. NHRI(IMM) interviewed for this research tended to emphasise that other organisations exist which monitor the development of civil society, including DPOs.⁴⁹¹ For instance, the DIHR noted that the Danish Disabled Peoples Council keeps under review obstacles to the establishment of DPOs and monitors the availability of funding to DPOs.⁴⁹² The GIHR

⁴⁸⁷ Alison Corkery, National Human Rights Institutions as Monitors of Economic, Social and Cultural Rights, Centre for Economic and Social Rights 2012 https://www.cesr.org/sites/default/files/NHRIs_as_Monitors_of_ESC_Rights.pdf (Accessed on 2 January 2023)

⁴⁸⁸ A. Lawson and M. Priestley, ‘Potential, Principle and Pragmatism in Concurrent Multinational Monitoring: Disability Rights in the European Union’, [2023] *The International Journal of Human Rights* 739, p. 752

⁴⁸⁹ *ibid*

⁴⁹⁰ Quinn (n. 4)

⁴⁹¹ Interview with representative of SHRC 18 March 2021

⁴⁹² Interview with representative of DIHR 4 January 2021

emphasised that they had not been resourced to take on a role in monitoring the provision of support to DPOs, noting ‘If we do that, we can’t, you know, observe or monitor the law-making processes. We can’t really monitor administrative practice and stuff.’.⁴⁹³ In my case studies I will explore whether the EHRC or the IHREC have expanded their monitoring activities to include critically assessing systems for the registration of DPO and the funding available to support their activities.

4.9.5 Provision of advice on law reform proposals

The Paris Principles require that NHRI(IMM)s be imbued with power to offer advice ‘on any matters concerning the promotion and protection of human rights’. Through their advice function a NHRI(IMM) can enrich discourse on domestic disability law and policy.⁴⁹⁴ As discussed above many of the articles of the CRPD are not ‘sharply defined’ and are somewhat ambiguous.⁴⁹⁵ The approach of the CRPD Committee to addressing these ambiguities has been to put forward expansive interpretations that reflect the paradigm shift in disability policy that it is hoped the CRPD will bring about.⁴⁹⁶ A representative of the OHCHR interviewed for this research noted that there were concerns that NHRIs may be putting forward restrictive interpretations of the provisions of the CRPD as compared to the CRPD Committee’s interpretations.⁴⁹⁷

The CRPD Committee have adopted an expansive interpretation of the right to legal capacity, which requires the abolition of all forms of substitute decision making and their replacement with supported decision-making frameworks.⁴⁹⁸ This interpretation goes significantly further than the established jurisprudence of the European Court of Human Rights (ECt.HR). The ECt.HR have held that a deprivation of legal capacity constitutes a serious interference with a right to a person’s private life.⁴⁹⁹ However, this interference may be justified in circumstances in which an individual is ‘unable to adequately understand the significance and the implications of the specific decision’ and where stringent procedural safeguards are put in place.⁵⁰⁰ Whilst

⁴⁹³ Interview with representative of GIHR 28 January 2021

⁴⁹⁴ Interview with representative of the office of the UN Special Rapporteur on Disabilities 30 November 2020

⁴⁹⁵ Gerard Quinn, ‘The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability’ [2009] *Texas Journal on Civil Liberties & Civil Rights* 33 p. 39

⁴⁹⁶ [Series, Lucy](#) and Nilsson, Anna 2018. *Article 12 CRPD: Equal recognition before the law*. In: Bantekas, Ilias, Stein, Michael Ashley and Anastasiou, Dimitris eds. *The UN Convention on the Rights of Persons with Disabilities: A Commentary*, Oxford: Oxford University Press, pp. 339-382 p. 363

⁴⁹⁷ Interview with representative of the OHCHR 23 December 2020

⁴⁹⁸ CRPD Committee (n. 62) para 32

⁴⁹⁹ *Salontaji Drobnjak v Serbia*, App no 36500/ 05, 13 October 2009

⁵⁰⁰ *European Court on Human Rights. AM-V v Finland. ECHR 273, 2017.*

the ECt.HR has emphasized that ‘deprivation, even partial, of legal capacity should be a measure of last resort’, in accepting that a deprivation of legal capacity may be justifiable the ECt.HR permits a situation which the CRPD Committee consider is a breach of Article 12 of the CRPD.⁵⁰¹

These distinctions in approaches have led to the UNCRPD Committee publicly criticizing decisions of the ECt.HR.⁵⁰² The more expansive interpretation put forward by the UNCRPD Committee have been broadly welcomed by the DPM.⁵⁰³ However for European NHRIs, who are required to advise on compliance with the European Convention on Human Rights, (‘ECHR’) the novel approach of the CRPD presents a challenge.⁵⁰⁴

A number of NHRI(IMM)s have been criticised by DPOs for not fully reflecting the UNCRPD Committee’s GC on Article 12 when providing advice to Government.⁵⁰⁵ In 2008 the Northern Ireland Assembly sought the advice of the NIHRC on the compatibility of the Mental Capacity (NI) Bill with human rights law. The Bill included provisions to allow for substitute decision making on the basis of a functional assessment.⁵⁰⁶ In its advice the NIHRC suggested that there were ‘a number of disparities and contradictions in the standards set down by the ECt.HR and the standard set by the UNCRPD Committee’.⁵⁰⁷ Disability scholars have correctly clarified that the standards set by the UNCRPD do not in fact contradict the jurisprudence of the ECt.HR.⁵⁰⁸ The NIHRC’s advice was criticised for failing to ‘challenge the central assumption that functional assessments of mental capacity which result in the removal of legal capacity are contrary to Article 12’.⁵⁰⁹ Similarly a representative of the AHRC interviewed for this research highlighted that DPOs have been critical of the AHRC for acknowledging that under Australian law the CRPD Committee’s GCs only have persuasive authority.⁵¹⁰ This suggests that the issue of legal capacity may be an issue on which DPOs and NHRIs have adopted different interpretations on how to reconcile the positions of different treaty bodies. In my case studies

⁵⁰¹ *Ivinović v Croatia*, App no 13006/13, 18 September 2014, para 44, See for discussion Oliver Lewis ‘Council of Europe’ in Lisa Waddington and Anna Lawson (eds.), *The UN Convention on the Rights of Persons with Disabilities in Practice: A Comparative Analysis of the Role of Courts* (2018 Oxford University Press)

⁵⁰² OHCHR Press Release, UN experts urge European Court of Human Rights to rethink vote ban for those with cognitive disabilities 1 March 2021 Available at: <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=26821&LangID=E> (Accessed 19 October 2021)

⁵⁰³ Interview with representative of OHCHR (23 December 2020)

⁵⁰⁴ UKIM ‘Submission to CRPD Committee consultation on a general comment relating to Article 12’ available at:

⁵⁰⁵ Interview with representative of the SHRC (18 March 2021)

⁵⁰⁶ Mental Capacity Act (Northern Ireland) 2016

⁵⁰⁷ Independent Mechanism NI, Response to Consultation on proposals for new mental capacity legislation, (NIHRC 2014)

⁵⁰⁸ Jovičić, S. ECHR v. UNCRPD: ending restrictions on voting rights of persons with disabilities. *ERA Forum* 22, 699–715 (2021), p. 713

⁵⁰⁹ Eilíonoir Flynn, Mental (in)Capacity or Legal Capacity: A Human Rights Analysis of the Proposed Fusion of Mental Health and Mental Capacity Law in Northern Ireland, [2013] N. IR. LEGAL Q 485, p.501

⁵¹⁰ Interview with representative of Australian Human Rights Commission 26 November 2021

I will consider in more detail whether the DPM consider the EHRC and the IHREC are appropriately reflecting the CRPD in their advice.

Processes for developing advice

In my legal analysis I explained how an analysis of the requirements of the CRPD needed to be informed by domestic circumstances.⁵¹¹ Advising on measures to bring about compliance with the standards of the CRPD requires extensive knowledge of the domestic policy context and the circumstances of disabled people. The key sources of information on the circumstances of disabled people are disabled people themselves and their representative groups.⁵¹² Therefore NHRI(IMM)s clearly have a strategic need to ensure that their advice on the UNCRPD is informed by the lived experience of disabled people.⁵¹³

NHRIs interviewed for this research tended not to consult with civil society when developing their statutory advice. Some NHRI(IMM)s have developed their internal structures to incorporate elements of civil society, for instance the SHRC established a ‘Lived Experience Leadership Group’ to ensure that their advice is informed by the lived experience of rights holders including disabled people.⁵¹⁴ A number of NHRI(IMM) office holders interviewed for this research were cautious of involving DPOs in developing their advice. These interviewees tended to emphasise that their role is not to reiterate the views of CSOs.⁵¹⁵ However a number of staff members did report that they maintained informal contacts with the staff of CSOs and sought their views on policy issues when developing their institution’s response. These connections may be classed as what Peter Haas refers to as an ‘epistemic community’, composed of organisations considered to have valuable evidence and views which a NHRI can draw on when developing their advice.⁵¹⁶ In my case studies I will consider whether the EHRC and the IHREC have included DPOs in either formal structures or informal communities to assist in the development of their advice.

⁵¹¹ Gerard Quinn, ‘The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability’ [2009] *Texas Journal on Civil Liberties & Civil Rights* 33 p. 39

⁵¹² Laufey Love, Rannveig Traustadottie & James Rice, *Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People's Organizations in Securing a Seat at the Table*, [2019] *Laws* 1

⁵¹³ M. Howlett, ‘Policy analytical capacity: The supply and demand for policy analysis in government’ [2015] *Policy and Society* 173, p. 177

⁵¹⁴ Interview with representative of Scottish Human Rights Commission 18 March 2021

⁵¹⁵ *ibid*

⁵¹⁶ Peter Haas, *Introduction: epistemic communities and international policy coordination* (Cambridge University Press, 2009)

Providing advice on statistics

For the first time in a human rights treaty, Article 31 of the CRPD requires that ‘states parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention’.⁵¹⁷ Article 31 is an innovative provision and a necessary one.⁵¹⁸

The development of Article 31 was influenced by the need to reform data collection systems which tended to focus on the measurement of impairment, rather than the identification and measurement of disabling barriers.⁵¹⁹ Article 31 is central to the development of rational policies necessary for the effective implementation of the UNCRPD.⁵²⁰ The CRPD Committee have encouraged states to develop data collection processes which identify previously hidden impediments to the full participation of disabled people in society.⁵²¹ The implementation of Article 31 is crucial to ensure that NHRI(IMM)s have access to substantive evidence in order to monitor implementation of the UNCRPD.⁵²²

Data collection systems will have to be modified to ensure that they are fully accessible and that they capture the lived experience of disabled people.⁵²³ The reform of data collection systems requires ‘collective, coordinated and continuous efforts’ by NHRI(IMM), state bodies and DPOs.⁵²⁴ A NHRI can play a key role in providing advice and guidance on the development of data collection systems.⁵²⁵ The OHCHR has emphasised that a NHRI(IMM) can play a key and continuous role in providing advice to government on steps required to ensure compliance with article 31, in particular, through developing a memorandum of understanding with National Statistics Offices (NSO).⁵²⁶

I identified that there are several examples of NHRIs working with NSOs to adjust their data collection processes.⁵²⁷ The AHRC persuaded the Australian NSO to amend the questions

⁵¹⁷ UNGA (n1) Article 31.

⁵¹⁸ Quinn, ‘Resisting the “Temptation of Elegance”’: Can the Convention on the Rights of Persons with Disabilities Socialize States to Right Behaviour?’ in Oddny M Arnardóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Person with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009), p. 227

⁵¹⁹ Article 31

⁵²⁰ Quinn, (n. 518) p.254

⁵²¹ CRPD Committee, ‘Concluding Observations on the Initial Report of Paraguay’ UN Doc CRPD/C/PRY/CO/1 (15 May 2013) para 72.

⁵²² Lawson and Priestley, (n. 488) p. 730

⁵²³ Normand Boucher and David Fiset ‘Monitoring Individual Experiences’ in Rioux, M.H., Pinto, P.C., & Parekh, G., Eds. *Disability, Rights Monitoring, and Social Change: Building Power out of Evidence*. (Canadian Scholars Press 2015), p.128

⁵²⁴ CRPD Committee (n.) para 36

⁵²⁵ OHCHR ‘The United Nations Human Rights Treaty System,’ Fact Sheet No 30 Rev 1 (2012) 19

⁵²⁶ OHCHR Press Release ‘Counting groups left behind: a stellar step for inclusion in Kenya’ 28 November 2018

⁵²⁷ OHCHR, Statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities 28 December 2021 A/HRC/49/60

included within the national survey of disability, ageing and carers to ensure it collected data relating to the employment experiences of disabled people. The AHRC were able to utilise data gathered through the survey to inform its monitoring work relating to the right to employment.⁵²⁸

The AHRC has sought to develop a new partnership across government to ensure an effective data monitoring systems. In April 2020 the Australian Government announced the commencement of the national disability data asset (NDDA). The NDDA seeks to link data collected across government relating to disabled people and to introduce new data collection approaches to develop ‘a complete picture of the life experiences and life outcomes’ of disabled people.⁵²⁹ The pilot is guided by a disability advisory committee which is chaired by the AHRC and which includes a number of DPOs. In advising Government on the development of this initiative the AHRC has sought to ensure the inclusion of DPOs and disabled people. From my evidence gathering this seems to be a promising example of a NHRI(IMM) working in partnership with state bodies to develop innovative approaches to evidence gathering. Rather than focusing on developing their own evidence gathering approaches the AHRC has worked with Government to adapt official evidence gathering approaches. In doing so the NHRI is creating opportunities for disabled people and DPOs to inform evidence gathering processes and involving them in the reform of these processes to ensure they are accessible to disabled people.

NHRI(IMM) are increasingly engaging with NSOs in order to ensure that national surveys and censuses fully record the number of disabled people within a jurisdiction. For instance, the Kenyan NHRI, with the support of the OHCHR, worked with the Kenyan NSO to ensure that the national census included a range of questions relating to albinism.⁵³⁰

These examples suggest that rather than developing an alternative independent approach to monitoring implementation NHRI(IMM) are prioritising engaging with government agencies to ensure official data collection processes are in line with the Article 31. In my case studies I

⁵²⁸ Australian Human Rights Commission, ‘Willing to Work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability’ (Australian Human Rights Commission 2016), available at: <<http://www.humanrights.gov.au/our-work/disability-rights/publications/willing-work-national-inquiry-employment-discrimination>>. (accessed 30 March 2022)

⁵²⁹ Government of Australia, ‘National Disability Data Asset’ 2020, available at: <https://www.dss.gov.au/sites/default/files/documents/06_2020/dss-ndda-web-page-input_1.pdf> (accessed 30 March 2022)

⁵³⁰ OHCHR ‘Statistics and Data’ (n. 479)

will consider whether either the IHREC or the EHRC have advised government and engaged with their NSO to broaden and reform the state's evidence gathering approaches.

Advising on Policies

Those involved in negotiating the CRPD were conscious of the need to develop domestic plans to ensure the articles of the CRPD were developed into workable policy solutions. During the negotiation of the CRPD, the Australian NHRI proposed the incorporation of an obligation to develop a National Disability Action Plan (NDAP) on implementation of the CRPD.⁵³¹ Whilst this proposal was not adopted, interest in NDAPs remains and they have become an important tool for translating the provisions of the CRPD and the Committee's concluding observations into 'operationalizable' policy goals.⁵³²

Within an NDAP, broad recommendations can be broken down into 'challenging yet feasible' targets.⁵³³ NHRIs, with their insider knowledge of the mechanics of government, have developed extensive experience in advising on the development of domestic policies to implement treaty body recommendations and are uniquely placed to propose targets for inclusion within a NDAP.⁵³⁴

The NZHRC developed the first New Zealand National Human Rights Action Plan. This involved consultation with CSOs, including DPOs, in the identification of 100 actions, supported by 232 indicators, to bring about the implementation of recommendations from the international human rights system, including the UN CRPD Committee.⁵³⁵ Informed by this experience, the NZHRC in conjunction with the New Zealand DPO Coalition played a key role in influencing the development of the New Zealand Disability Strategy 2016–2026. Under this strategy, the DPO Coalition plays a central role in monitoring delivery of the strategy, and the NZHRC supports them in doing so.⁵³⁶

⁵³¹ Michael Stein and Janet Lord, *Monitoring the Convention on the Rights of Persons with Disabilities: Innovations, Lost Opportunities, and Future Potential* (2010) 32 *Human Rights Quarterly* 689, 702–703

⁵³² *Ibid*

⁵³³ Jerome Bickenbach, 'Monitoring the United Nation's Convention on the Rights of Persons with Disabilities: data and the International Classification of Functioning, Disability and Health, (2011) *BMC Public Health* 1, 5

⁵³⁴ Michael Mintrom, 'The Policy Analysis Movement', in Laurent Dobuzinskis, David H. Laycock and Michael Howlett (eds) *Policy Analysis in Canada: The State of the Art* (University of Toronto Press 2005) 145, p. 146

⁵³⁵ New Zealand Human Rights Commission 'National Plan of Action' available at: <https://npa.hrc.co.nz/overview> (Accessed 30 March 2022)

⁵³⁶ New Zealand Government, *Disability Action Plan 2019–2023 Putting the New Zealand Disability Strategy into action*, (November 2019)

The CRPD Committee emphasises the use of indicators to assess the implementation of the UNCRPD.⁵³⁷ The formulation and application of indicators is considered central to the effective implementation of human rights standards.⁵³⁸

The use of indicators is a common feature of public policy implementation; indeed political commentators often refer to the development of an ‘indicator industry’.⁵³⁹ In recent years the utilisation of indicators in human rights monitoring has come to prominence and the OHCHR has played a central role in developing a guide on the use of human rights based indicators.⁵⁴⁰ Human rights based indicators are defined as ‘...piece[s] of information used in measuring the extent to which a legal right is being fulfilled or enjoyed in a given situation,’.⁵⁴¹ Building on this experience, in 2021 the OHCHR published a specific set of UN CRPD based indicators, informed by the Sustainable Development Goals. The OHCHR see NHRIs as playing a central role in promoting and advising on the application of the indicators.⁵⁴² It is hoped that NHRIs who have agreed memorandum of understandings with NSOs will be able to promote the use of indicators.⁵⁴³

Through utilising indicators issues can be mainstreamed in political discussions. Sally Merry Engle highlights that ‘numerical measures make visible forms of violation and inequality that are otherwise obscured’.⁵⁴⁴ Indicators have become particularly prominent in monitoring the delivery of economic and social rights.⁵⁴⁵ The adoption of indicators to monitor human rights both creates opportunities and presents challenges. Indicators ‘frame problems – [and] aspects of its solution’.⁵⁴⁶ There is a risk that government may attempt to ‘manipulate or ‘game’ indicators’.⁵⁴⁷ Government will inevitably seek to develop indicators that will assist them in

⁵³⁷ CRPD Committee, ‘Concluding Observations on the Initial Report of Tunisia’ UN Doc CRPD/C/TUN/CO/1 (13 May 2011) para 37

⁵³⁸ Sally Engle Merry and Summer Wood ‘Quantification and the Paradox of Measurement: Translating Children’s Rights in Tanzania’ [2015] *Current Anthropology* 205, p. 207

⁵³⁹ Markku Lehtonen, ‘Indicators: tools for informing, monitoring or controlling?’ in Jordan, A and Turnpenny J (eds.) *The Tools of Policy Formulation: Actors, Capacities, Venues and Effects*. New Horizons in Public Policy . (Edward Elgar 2015), p. 80

⁵⁴⁰ OHCHR Report on Indicators for Monitoring Compliance with International Human Rights Instruments, May 11, 2006, UN Doc. HRI/MC/2006/7, para. 2

⁵⁴¹ Maria Green, ‘What We Talk About When We Talk About Indicators: Current Approaches to Human Rights Measurement’ [2001] *Human Rights Quarterly* 1062, p.1065

⁵⁴² OHCHR Human Rights indicators on the Convention on the Rights of Persons with Disabilities in support of a disability inclusive 2030 Agenda for Sustainable Development , available at: <https://www.ohchr.org/EN/Issues/Disability/Pages/SDG-CRPDindicators.aspx> (Accessed 19 October 2021)

⁵⁴³ Interview with representative of the OHCHR 23 December 2020

⁵⁴⁴ Engle Merry and Wood (n. 538) p. 84

⁵⁴⁵ Philip Alston and Gerard Quinn ‘The Nature and Scope of States Parties’ Obligations under the International Covenant on Economic, Social and Cultural Rights’ *Human Rights Quarterly* Vol. 9, No. 2 (May, 1987), pp. 156-229 pg 172

⁵⁴⁶ Davis, K. E., Kingsbury, B., & Merry, S. E. (2012). Indicators as a Technology of Global Governance. *Law & Society Review*, 46(1), 71–104.

⁵⁴⁷ Nelken D, ‘Conclusion: Contesting Global Indicators’ in Merry S et al. (eds) *The quiet power of indicators: Measuring development, corruption, and the rule of law* (Cambridge University Press 2015), p. 326

presenting a positive image of their performance.⁵⁴⁸ NHRI(IMM) need to develop their skills to ensure they are able to counter government attempts to manipulate indicators. NHRI(IMM)s through sharing their technical insights can also play a role in ensuring DPOs are not excluded from processes for adopting and applying indicators.⁵⁴⁹

The DIHR has developed the disability indicator index which monitors how the Danish state is implementing the CRPD in ten key areas. The index was developed through advisory groups composed of public authorities, public officials, statisticians and DPOs.⁵⁵⁰ In establishing the advisory groups, the DIHR sought to ensure that the voices of DPOs which had been excluded from formal engagement structures were represented.⁵⁵¹ A representative of DIHR emphasised that due to resource constraints the DIHR would not be able to fully apply the indicator index in the long-term. The DIHR have been attempting to convince the Danish Government to incorporate the disability indicator index into their monitoring activities. However, the Danish Government have been unwilling to agree to this. Whilst the DIHR have developed an innovative approach the unwillingness of the Danish Government to adopt and apply the indicators underscores the risk that indicator sets developed by NHRIs may remain in ‘the conceptual sphere’ unless the support of government can be secured.⁵⁵²

In my case studies I will assess the extent to which the EHRC and the IHREC have enhanced their expertise to ensure they are well placed to thwart attempts by state actors to manipulate the processes for developing and applying an indicator.⁵⁵³

4.9.6 Public awareness raising

The Paris Principles require NHRIs to publicize and promote human rights, including through making use of the press.⁵⁵⁴ This has been described by De Beco and Murray as ‘one of the more ambiguous functions’ of a NHRI.⁵⁵⁵ Neither the Paris Principles nor the SCA General Observations have clearly addressed the relationship between the responsibilities of the NHRI

⁵⁴⁸ *ibid*

⁵⁴⁹ Bengt Jacobsson, “Standardization and Expert Knowledge,” in Nils Brunsson et al. (eds), *A World of Standards* (Oxford and New York: Oxford University Press, 2000), 40. p.46.

⁵⁵⁰ DIHR, The disability index, available at: <<https://www.humanrights.dk/our-work/disability/disability-index>> (Accessed 30 March 2022)

⁵⁵¹ Interview with representative of the DIHR 4 January 2021

⁵⁵² Gauthier de Beco, ‘Human Rights Indicators: From Theoretical Debate to Practical Application’ [2013] *Journal of Human Rights Practice* 380

⁵⁵³ Interview with representative of the OHCHR 23 December 2020

⁵⁵⁴ Paris Principles

⁵⁵⁵ De Beco and Murray, (n.) p.64

to promote human rights and the responsibilities of states to promote the rights enshrined within the treaties which it has ratified.

NHRIs tend to focus on raising awareness amongst the general public of the ways in which they can access their rights.⁵⁵⁶ However some NHRIs have played a role in countering societal trends which undermine the protection of human rights.⁵⁵⁷ The potential for an NHRI to embark on awareness raising activities is dependent upon the availability of funding. In my case studies I will consider this function in more detail.

4.9.7 Training the public sector

A number of NHRIs have developed training programmes to raise awareness of human rights obligations and promote professional development within the public sector.⁵⁵⁸ The OHCHR has emphasised the role of an NHRI in providing training to public bodies and professionals, ‘to ensure that human rights standards are respected in their day-to-day work, including through their specific operating procedures’.⁵⁵⁹ A number of NHRIs have developed training programmes to assist in the professional development of policy professionals within domestic public bureaucracies.⁵⁶⁰

The NIHRC has developed a bespoke training program for public servants in NI. In addition to seeking to develop knowledge on human rights laws and processes, the training seeks to address predominant cultures within the civil service. In the words of a representative of the NIHRC, ‘...building that kind of human rights consciousness into policy and legal development’.⁵⁶¹

The SHRC has developed a training program for public servants on adopting human rights-based approaches to policy development. This methodology is based around five key principles, the first amongst which is participation. The training materials include some guidance on designing a participative process, but do not contain specific guidance concerning

⁵⁵⁶ Fateh S. Azzam, ‘The Palestinian Independent Commission for Citizens’ Rights Palestinian Commission’ [1998] *Human Rights Quarterly* 338, p.347

⁵⁵⁷ *ibid*

⁵⁵⁸ See chapter 6 on the work of IHREC

⁵⁵⁹ OHCHR ‘professional training’ (n.)

⁵⁶⁰ Lucas Glusac, ‘National Human Rights Institutions and Oversight of the Security Services’ [2018] *Journal of Human Rights Practice* 58, p. 78

⁵⁶¹ Interview with representative of NIHRC 27 November 2020

disabled people and their organisations. Furthermore, the materials do not consider the issues of representativeness.⁵⁶²

The ratification of the CRPD creates new and specific training needs within the public sector. In particular, public servants need to develop their capacity and skills in developing and delivering policy development processes which are accessible to and inclusive of disabled people.⁵⁶³ To effectively exercise its functions a NHRI(IMM) must assess whether the public sector has sufficient expertise and capacity to meet its obligations under the CRPD. In my case studies I will consider whether the EHRC and IHREC have engaged with the public sector through the CRPD focal point in identifying and possibly addressing their training needs.

4.9.8 Strategic litigation

NHRIs in practice engage with the courts in three distinct circumstances; funding of cases; bringing forward litigation; and intervening in ongoing cases.

Many NHRIs are imbued with powers to fund or provide legal advice and assistance to individuals in relation to human rights issues. In jurisdictions in which there is a shortage of public funding for litigation, this can be a significant function of an NHRI. NHRI(IMM)s interviewed for this research highlighted that DPOs often bring cases to their attention for prospective funding.⁵⁶⁴ The DPM have at times questioned the value of litigation as a mechanism for advancing their rights.⁵⁶⁵ However, Vanhala has demonstrated how legislative developments have provided legal opportunity structures which offer an opportunity for DPOs to promote the rights of disabled people through strategic litigation.⁵⁶⁶ However disabled people and DPOs often lack resources to fully exploit the potential benefits of strategic litigation.

DPOs may lack the funds or expertise to bring forward litigation and may find that through engagement with an NHRI(IMM) they are able to support or be involved in litigation that would otherwise not be possible.⁵⁶⁷ NHRI commentators highlight the importance of NHRIs

⁵⁶² SHRC 'A Human rights based approach' 2019 Available at: <https://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf> Accessed on 30 March 2022

⁵⁶³ Ruth Lister, 'From object to subject: including marginalised citizens in policy making' [2007] Policy & Politics 437, p. 444

⁵⁶⁴ Interview with representative of the AHRC 26 November 2020

⁵⁶⁵ M. Oliver and C. Barnes, 'Disability politics and the disability movement in Britain: Where did it all go wrong?' [2006] Coalition 1

⁵⁶⁶ Lisa Vanhala, 'Fighting discrimination through litigation in the UK: the social model of disability and the EU anti - discrimination directive [2006] Disability and Society 551

⁵⁶⁷ *ibid*

being strategic in the identification of cases for funding.⁵⁶⁸ In my case studies I will examine the approach of the IHREC and the EHRC to strategic litigation.

NHRIs may also be imbued with legal powers to bring cases in their own name. Such powers can be particularly valuable in circumstances in which a victim cannot be readily identified or where a victim may find the process of being a party to litigation traumatizing.⁵⁶⁹ Through utilizing its powers to bring cases in its own name, a NHRI can relieve disabled people of the need to engage in costly and stressful litigation to access their rights. However, I have not identified any examples of NHRIs engaging in own motion litigation relating to the rights of disabled people.

NHRIs are also often equipped with powers to make oral or written interventions in legal proceedings to assist courts in their deliberations. Buyse highlights that ‘NHRIs, with both their unique rootedness in national societies and their independence, are in an excellent position to play an assisting role for the Court’.⁵⁷⁰ NHRIs are increasingly utilizing their powers of interventions to raise awareness of the CRPD. For instance, in 2021 the European Network of NHRIs (‘ENNHRI’) intervened in the case of Strøbye v Denmark. This intervention was initiated by the DIHR. The case related to the deprivation of voting rights for those under legal guardianship. In its submission ENNHRI highlighted the need to comply with the CRPD. In addition in its submission ENNHRI provided an account of practices throughout Council of Europe member states highlighting the ‘consensus and common values emerging around the principle that the voting rights of persons with disabilities, including those under regimes that restrict or remove their legal capacity’.⁵⁷¹ In my case studies I will assess in detail how the EHRC and the IHREC have utilised their power to support strategic litigation.

4.9.9 Individual Complaints Handling

The CRPD Committee’s General Guidelines states that they should have ‘complaint handling of individual and group complaints alleging violations of the rights guaranteed under the

⁵⁶⁸ Brice Dickson, *The Protection Role of the Northern Ireland Human Rights Commission* in Ramcharan B (ed.) *The Protection Role of National Human Rights Institutions* (Nijhoff Law Specials 2005), p. 153

⁵⁶⁹ In the matter of an application by the Northern Ireland Human Rights Commission for Judicial Review (Northern Ireland) [2018] UKSC 27

⁵⁷⁰ Buyse A, ‘The Court’s Ears and Arms: National Human Rights Institutions and the European Court of Human Rights’ in Meuwissen, K. and Wouters, J (eds.) *National Human Rights Institutions in Europe: Comparative, European and International Perspectives* Intersentia, 2013 p. 178

⁵⁷¹ ENNHRI Written observations in applications nos. 25802/18 and 27338/18 *Strøbye v. Denmark* and *Rosenlind v. Denmark*

Convention'.⁵⁷² It is notable that when the CRPD Committee consulted on the then draft General Guidelines the GANHRI suggested that the complaints handling function should be an optional rather than necessary feature of an IMM.⁵⁷³ This suggestions was informed by the fact that the Paris Principles do not require that NHRIs be empowered to consider complaints, and as a result NHRIs have often not been empowered to do so.⁵⁷⁴

The CRPD Committee suggests that IMMs should have the power to 'hear and consider' complaints but it does not require that IMMs should have the power to determine complaints. From my analysis of pre-existing literature, there appears to be a lack of exploration into the complaints handling function of a NHRI. Whilst numerous NHRIs operate helplines or offer advice to individuals, only a small number of NHRIs actually have power to determine if a complaint is legitimate.⁵⁷⁵ Carver has warned that empowering NHRIs to make enforceable determinations on complaints is 'contrary to justice, because NHRIs would combine both inquisitorial and quasi-judicial functions'.⁵⁷⁶ Even those NHRIs with formal complaints handling powers rarely offer direct redress and instead NHRIs tend to be empowered to offer a range of mediation and conciliation services relating to specific domestic protections which are ancillary to the courts system.⁵⁷⁷ A number of NHRIs interviewed for this research had worked with complaints handling bodies to ensure that their complaints handling processes were accessible and that decision makers were taking human rights into account when considering complaints.⁵⁷⁸

In my evidence gathering I did not identify any example of NHRIs being specifically empowered to investigate complaints relating to the CRPD. A representative of the AHRC, which has a complaints handling function, noted that the designation of the AHRC as the IMM did not lead to reforms of its complaints handling functions.⁵⁷⁹ In Canada, the designation of CHRC as the IMM occurred simultaneous to a significant extension of the CHRC's complaints handling powers, following the enactment of the Accessible Canada Act 2019.⁵⁸⁰ During my

⁵⁷² CRPD Committee (n.) para 5

⁵⁷³ GANHRI 'Submission' (n.)

⁵⁷⁴ Pegram, Thomas 'National human rights institutions in Latin America: politics and institutionalization' in Goodman, Ryan and Pegram, Thomas (eds) Human rights, state compliance and social change: assessing national human rights institutions Cambridge University Press, NY USA, 2012

⁵⁷⁵ Dickson (n. 519)

⁵⁷⁶ Carver R, Assessing the Effectiveness of National Human Rights Institutions International (Council on Human Rights Policy 2005) 20-21

⁵⁷⁷ Uggl, Fredrik 'Through Pressure or Persuasion?: Explaining Compliance with the Resolutions of the Bolivian Defensor del Pueblo' in Goodman, Ryan and Pegram, Thomas (eds) Human rights, state compliance and social change: assessing national human rights institutions (Cambridge University Press 2012)

⁵⁷⁸ Interview with representative of NIHRC 27 November 2020

⁵⁷⁹ Interview with representative of AHRC 26 November 2020

⁵⁸⁰ S.C. 2019, c. 10

evidence gathering the CHRC was in the process of consulting with DPOs, to determine how their role as a IMM may be reflected in their complaints handling functions.⁵⁸¹ The experience of the CHRC may lead to the development of good practice guidance amongst NHRI(IMM)s relating to the complaints handling functions.

For the purposes of this enquiry, it is notable that the role of a NHRI(IMM) in investigating and determining complaints is not fully understood in the existing literature.⁵⁸² Of broader relevance to this enquiry, it is notable that empowering a NHRI(IMM) with a complaint handling or advise function provides them with a direct link to disabled people and their representative groups. It connects the NHRI with the lived experience of rights holders and provides an important source of data to inform strategic decision making across the other functions of a NHRI(IMM).⁵⁸³ In my case study I will consider the role of the IHREC and the EHRC in providing advice.

4.9.10 Investigation and Inquiries

The CRPD Committee General Guidelines provide that IMM should have the power to conduct inquiries.⁵⁸⁴ The Paris Principles require that NHRIs are empowered to issue reports on '[a]ny situation of violation of human rights which it decides to take up'.⁵⁸⁵ To inform such a report an NHRI must have capacity to carry out an investigation or inquiry to determine whether violations of human rights have taken place.⁵⁸⁶

Human rights abuses against disabled people, in particular those in institutions, often go unreported or are not investigated by official channels.⁵⁸⁷ Through utilizing their inquiry powers a NHRI(IMM) can raise awareness of abuses that would otherwise go unnoticed. In addition to potentially providing an avenue for redress, an inquiry can provide a platform for disabled people to share their lived experiences. In recent years NHRI(IMM)s have sought to ensure that inquiry processes are open and accessible to rights holders.⁵⁸⁸ By incorporating a public hearing element to an investigation or inquiry process, an NHRI(IMM) can provide a mechanism for disabled people to provide an account of their experiences. For instance, during

⁵⁸¹ Canadian Human Rights Commission, Submission to the CRPD Committee general comment on the right to work 2020

⁵⁸² Uggla (n. 577) p.289

⁵⁸³ Ibid

⁵⁸⁴ CRPD Committee (n.) para 11

⁵⁸⁵ Paris Principles

⁵⁸⁶ SCA (n.) para1.2

⁵⁸⁷ Theresia Degener, Disability in a Human Rights Context [2016] Laws 14, p. 35

⁵⁸⁸ Asia Pacific Forum 'Conducting Effective National Inquiries' 2012

the NIHRC inquiry into accident and emergency services, the chairman of a local DPO gave a detailed account of his own experience of accessing health care.⁵⁸⁹ This put on the public record experiences of disabled people that may otherwise have gone unreported.

Through their inquiries NHRIs can support interactions between DPOs and public authorities.⁵⁹⁰ NHRI(IMM)s have included DPOs and disabled people within advisory committees on inquiries.⁵⁹¹ An inquiry by the Indian NHRI into the right to health saw the NHRI collaborate with a coalition of several hundred health related NGOs and DPOs. Brodie notes that this inquiry performed a significant educational role, encouraging disabled people to appreciate that they had a right to health and an understanding of how to hold the government to account.⁵⁹²

As set out in my legal analysis, the CRPD requires a change in thought processes within decision makers. Through their investigations NHRIs have raised awareness of human rights violations and provided new insights into the inequalities experienced by numerous groups. For instance, the AHRC's inquiry into the employment of disabled people provided new insights into the obstacles to accessing employment for disabled people.⁵⁹³ Through utilizing public inquiries the AHRC was able to provide a forum for civil society and government to come together and seek to identify human rights compliant solutions in a non-adversarial environment.⁵⁹⁴

In my case study analysis, I will consider how the EHRC and IHREC has engaged with disabled people and DPOs throughout their inquiry processes.

4.11 Conclusions

In this chapter I have charted the growth and development of NHRIs. I have set out how a NHRI is simultaneously seen as a key partner of the international system and as part of a state's national protection system for the protection of human rights.

⁵⁸⁹ NIHRC 'Human Rights Inquiry Emergency Health Care' (NIHRC Belfast) 2014

⁵⁹⁰ Meg Brodie, 'Uncomfortable Truths: Protecting the Independence of National Human Rights Institutions to Inquire' [2015] UNSW Law Journal 1215, p. 1223

⁵⁹¹ Interview with representative of Australian Human Rights Commission 26 November 2020

⁵⁹² Brodie (n. 590) p. 1242

⁵⁹³ Australian Human Rights Commission, 'Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families' (April 1997)

⁵⁹⁴ Quinn, Gerard and Neil Crowther 'Human rights and disability: A Manual for NHRIs' (Asia Pacific Forum 2017)

Civil society have played a key role in encouraging states to develop a NHRI. However, there is a lack of analysis as to how a NHRI should relate to civil society once it is established. Academic literature and practitioners have not fully explored how NHRIs and CSOs can work together to develop a shared understanding of the role which a NHRI should perform. Much of the literature presupposes that a NHRI will fail to meet the expectations of CSOs without considering approaches a NHRI could take to manage civil society's expectations. The fact that civil society have not been encouraged to participate in the accreditation processes has in my view prevented important discussions of what is and is not achievable by a NHRI in the domestic context.

NHRIs have clearly become the preferred partner of the international human rights system.⁵⁹⁵ The international system has sought to develop NHRIs, granting them both access to the system itself and access to training programmes intended to develop their expertise. The GANHRI and individual NHRIs have proven themselves to be effective at securing funding and new responsibilities for NHRIs. Indeed, the inclusion of a reference to the Paris Principles within Article 33(2) is considered the result of effective lobbying by the AHRC.⁵⁹⁶ The inclusion of this reference has led to a significant number of NHRIs being designated as an IMM for the purposes of Article 33(2).

As I have set out, disability advocates considered that once designated as IMMs NHRIs would exert their influence to ensure that the rights of disabled people were appropriately prioritised in the domestic policy making process.⁵⁹⁷ My analysis of literature and pre-existing research relating to NHRIs demonstrates that it cannot be taken for granted that they will be influential. Drawing on the writings of political scientists relating to the policy influencing process in my case studies I will explore how the IHREC and the EHRC have sought to exert influence and how successful they have been.

The CRPD Committee in its General Guidelines has set out an expansive range of functions which a NHRI designated as a IMM should perform. To perform these functions effectively a NHRI needs to be given new legal powers and resources. It will also need to expand its monitoring programmes. However, in my analysis of published literature and documentation

⁵⁹⁵ Sidoti, Chris, 'National Human Rights Institutions and the International Human Rights System' in Ryan Goodman and Thomas Pegram (eds) *Human Rights, State Compliance and Social Change* (Cambridge University Press 2012), p. 93

⁵⁹⁶ Melish, T J, 'An Eye Toward Effective Enforcement: A Technical-Comparative Approach to the Drafting Negotiations.' in Maya Sabatello and Marianne Schulze (eds), *Human rights and disability advocacy* (University of Pennsylvania Press 2014)

⁵⁹⁷ Byrnes, Andrew 'The Role of National Human Rights Institutions' in Sabatello, M and Schulze, M (eds), *Human rights and disability advocacy* (University of Pennsylvania Press 2014), p. 224

I have found that states have rarely resourced or expanded the powers of a NHRI to ensure they are able to perform their functions as a IMM effectively. In my case studies I will consider the process of designating the IHREC and the EHRC as IMM for the CRPD.

Whilst the range of functions which a NHRI(IMM) should perform are vast and diverse, for the purposes of this enquiry I am broadly focused on the role a NHRI in advocating for reforms to ensure the inclusion of disabled people and DPOs in the policy making process and in supporting disabled people and DPOs to take advantage of these opportunities. In my case studies I will explore in detail how the IHREC and EHRC have adapted their functions to reflect their role as IMM.

Chapter 5: UK Case Study: Equality and Human Rights Commission

5.1 Introduction

In my introduction chapter I explained the rationale for selecting the EHRC as a case study for this research. In this chapter I will set out more detail on my interview strategy for the UK. I will provide a brief overview of the human rights framework in the UK and will then discuss the development of the DPM in the UK and some of its key features. I will structure my findings section in line with the functions performed by the EHRC. I will then set out my overarching conclusions relating to this case study.

I began my analysis of the EHRC by conducting a thorough review of available corporate documentation including strategic plans, annual reports, minutes of the EHRC Board and Committees. To inform my analysis of the Commission's activities I critically assessed EHRC submissions to consultation exercises, court proceedings and UN bodies. In addition, I extensively reviewed the EHRC website, its press releases, and its research reports. My analysis covered the full lifetime of the EHRC and included events up to 15 March 2022. My interviews were principally conducted during the spring and early summer of 2021. Due to the coronavirus pandemic my interviews were conducted online.

I conducted structured interviews with the lead staff member responsible for disability, a former EHRC Commissioner and with a member of the EHRC Disability Advisory Committee (EHRC-DAC). I conducted structured interviews with three former senior staff members of the EHRC who had gone on to take up positions in DPOs. In addition, I carried out structured interviews with a representative of the NIHR and a representative of the SHRC who are designated alongside the EHRC as the UK's Independent Monitoring Mechanism (UKIMM).

I interviewed representatives of three categories of CSO. Namely Disabled People's Organisations (DPOs), Organisations for Disabled People (OfDP) and human rights NGOs. To identify relevant CSOs I first contacted all organisations who had made a submission to the UNCRPD Committee during the Committee's examination of the UK.⁵⁹⁸ To augment this list, I reviewed relevant parliamentary inquiries and relevant websites to identify additional CSOs.

⁵⁹⁸ Interview with DPO (IS) 28 April 2021

I conducted structured interviews with 9 UK based DPOs and one EU wide DPO. I interviewed five representatives of OfDP. Two of whom are members of the Disability Charities Consortium. The Disability Charities Consortium is the representative body for the nine largest disability charities in the UK.⁵⁹⁹ In addition I interviewed representatives of 3 UK human rights NGOs.

As set out in my introductory chapter I analyzed the transcripts of my interview drawing from a grounded theory approach.

5.2 Human rights framework in the UK

The UK is a parliamentary democracy with an unwritten constitution, the central feature of which is that the UK Parliament is sovereign. The Parliament has developed a Joint Committee for Human Rights ('JCHR') which takes on a key role in scrutinizing compliance with international human rights obligations and tends to play a central role in human rights discourse.⁶⁰⁰

The UK is a dualist state and as such, as a rule, the Government is not bound by unincorporated international treaties.⁶⁰¹ UK courts may draw on international treaties in certain tightly prescribed circumstances.⁶⁰² UK courts have at times questioned the value of the CRPD as an aid to interpreting provisions of UK domestic law, describing its articles as providing 'broad and basic principles'.⁶⁰³

The ECHR was incorporated into UK law by way of the Human Rights Act 1998 ('HRA'). The HRA is considered a constitutional act.⁶⁰⁴ Human rights discourse in the UK tends to focus on the HRA and on compliance with the ECHR.⁶⁰⁵ The incorporation of the ECHR opens up the potential for the UNCRPD to have an indirect effect on the UK legal system. As Lady Hale

⁵⁹⁹ Disability Charity Consortium webpage available at : <<https://www.mencap.org.uk/get-involved/campaign-mencap/our-work-parliament/disability-charities-consortium>> Accessed on 30 March 2022

⁶⁰⁰ House of Parliament, Terms of Reference for Human Rights Joint Committee available at: <https://committees.parliament.uk/committee/93/human-rights-joint-committee/> (Accessed on 30 March 2022)

⁶⁰¹ *JH Rayner (Mincing Lane) Ltd v Department of Trade and Industry* [1990] 2 AC 418, per Lord Oliver at 499

⁶⁰² A Series and A Lawson, United Kingdom, in Lisa Waddington and Anna Lawson *The UN Convention on the Rights of Persons with Disabilities in Practice: A Comparative Analysis of the Role of Courts* (2018 Oxford University Press) p. 420

⁶⁰³ *Hainsworth v MOD* [2014] EWCA Civ 763, para 61

⁶⁰⁴ Gordon Anthony, *Judicial Review in Northern Ireland*, (2014 Hart Publishing) p. 20

⁶⁰⁵ Hiebert J, *Legislative Rights Review: Addressing the Gap between Ideals and Constraints in Murray Hunt, Hayley Hooper and Paul Yowell (eds) Parliaments and Human Rights Redressing the Democratic Deficit* (Bloomsbury 2015) p. 41

has set out, ‘the guarantees contained in the ECHR should be interpreted in the light of other relevant international human rights instruments’.⁶⁰⁶

The UK has tended to adopt a legalistic approach towards the enforcement of human rights and equality protections. Francesca Klug notes that the potential for rights to become values underpinning the state and society more generally has ‘gone largely uncharted in the UK’.⁶⁰⁷ It is notable that equality and human rights protections are contained in separate legal instruments in the UK. Equality protections for Great Britain are largely contained within the Equality Act 2006. Whereas equality protections in Northern Ireland are included in a number of separate legal instruments.⁶⁰⁸

Discussion on disability rights and protections tend to focus on equality protections rather than human rights protections. Spencer notes ‘international [human rights] dimension had very little impact on the development of the UK’s own anti-discrimination legislation’.⁶⁰⁹ In addition, key commentators highlight that the HRA has had limited impact on disability rights in the UK.⁶¹⁰ This context creates specific challenges to the implementation of the UNCRPD, a human rights convention which pivots on the axis of equality.⁶¹¹

5.3 The UK Disabled People’s Movement

In keeping with established literature, I will use the term UK Disabled People’s Movement (UKDPM). Some contributors to this research questioned whether it was accurate to refer to a UK wide movement of disabled people or whether it could be considered that there were four separate DPMs for each of the constituent parts of the UK.⁶¹² However as the HRA applies to the whole of the UK and as DPOs throughout the UK have tended to come together in reporting to the CRPD Committee I consider that the term UKDPM is most appropriate. I will refer to

⁶⁰⁶ In the matter of an application by the NIHR for Judicial Review [2018] UKSC 27, para 31 Lady Hale

⁶⁰⁷ Francesca Klug *Values for a Godless Age: the story of the UK’s New Bill of Rights* Penguin 2000, p.65

⁶⁰⁸ Meehan, E, ‘Policy Learning: Equality and Human Rights in Northern Ireland, Ireland and Great Britain’ [2012] *Regional & Federal Studies* 323 p. 333

⁶⁰⁹ Spencer, S. (2004). ‘Partner rediscovered: Human rights and equality in the UK’ in Colin Harvey (ed) *The Community: Rights As Agents for Change* (Bloomsbury Publishing Plc 2005), p. 30

⁶¹⁰ Lawson, A *The Human Rights Act 1998 and Disabled People: A Right to be Human?* Human Rights in Colin Harvey (ed) *The Community: Rights As Agents for Change* (Bloomsbury Publishing Plc 2005), p. 152

⁶¹¹ Gerard Quinn, ‘The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability’ [2009] *Texas Journal on Civil Liberties & Civil Rights* 33 p. 51

⁶¹² Interview with DPO (Man) 11 May 2021

the UKDPM as including disabled people and those organisations which meet the definition of a DPO as adopted by the CRPD Committee.⁶¹³

5.3.1 Early Development 1970 – 2005

The UKDPM rose to prominence in the late 21st century. Campbell and Oliver note that in the 1960s ‘many disabled people were faced with the choice of managing with little or no service input or being shut away in a geriatric ward’.⁶¹⁴ A number of key individuals sought to cultivate the growth of a collective disability identity in order to oppose their limited life choices.⁶¹⁵ As an early advocate of the social model Hunt highlighted, ‘the problem of disability lies not only in the impairment of function and its effects on us individually, but also, more importantly, in the area of our relationship with ‘normal’ people’.⁶¹⁶ Hunt, working in conjunction with Finkelstein formed the Union of the Physically Impaired Against Segregation (‘UPIAS’) to ‘mobilise and get disabled people involved in their own emancipation’.⁶¹⁷ In 1975, UPIAS published the ‘Fundamental Principles of Disability’ which made clear that it is society which disables people, outlining the analysis that would develop into the social model of disability.⁶¹⁸

At the beginning of the 1980s, the organisation of events around the UN International Year of Disability provided a basis for the development of grass roots DPOs.⁶¹⁹ The UPIAS in conjunction with grass roots DPOs held a conference in 1981 with the aim of developing a pan disability organization and the British Council of Organisations of Disabled People (‘BCODP’) was established.⁶²⁰ The main purpose of the BCODP was to campaign ‘against the institutional discrimination and prejudice that characterised the experience of living with impairment in British society’.⁶²¹ The BCODP continued in existence until 2006.

The UKDPM is broadly seen to have risen in opposition to charitable organisations. Mark Priestley notes ‘the early organisation and campaigning was defined in opposition to (and located within) the organisational structures of large charitable and public welfare

⁶¹³ CRPD Committee (n. 62) para 19

⁶¹⁴ Campbell, J. and Oliver, M. 1996: *Disability Politics: Understanding Our Past, Changing Our Future*. London: Routledge, p. 29

⁶¹⁵ Hunt J, ‘No Limits: The Disabled People’s Movement, (Creative Commons 2019), p. 81

⁶¹⁶ Hunt P, A Critical Condition in Paul Hunt (ed) *The experience of Disability* (Geoffrey Chapman 1966), chapter 12

⁶¹⁷ Finkelstein, A Personal Journey into Disability Politics 2001, p.5 . Available at <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-presentn.pdf> (Accessed 30 March 2022)

⁶¹⁸ Union of the Physically Impaired Against Segregation, *Fundamental Principles of Disability*. (London 1976)

⁶¹⁹ Mark Priestly, *Disability Politics and Community Care* (Kingsley Publishers 1999) p. 63

⁶²⁰ Mike Oliver (2016) *Rewriting history: the case of the Disability Discrimination Act 1995*, *Disability & Society*, 31:7, 966-968, p. 967

⁶²¹ Colin Barnes, *Institutional Discrimination against Disabled People: A Case for Legislation* 2007, p.6 Available at: <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-bcodp.pdf> (Accessed on 30 March 2022)

institutions’.⁶²² Disability activists from an early stage adopted the view that ‘groups which advocated for justice for disabled people should be controlled by, and accountable to, disabled people’.⁶²³ When DPOs in the UK began to emerge to prominence and convinced Government of the importance of disability led organisations, OfPDs sought to retain their control through adopting the language and approach of DPOs.⁶²⁴ Research by Drake into the disability voluntary sector in 1994 found that despite the rhetoric adopted by many traditional OfDPs, disabled people continued to be concentrated in ‘subordinate and powerless’ positions within such organisations.⁶²⁵ The disingenuous attempts to include disabled people within traditional disability charities has further undermined relations between DPOs and OfDPs which do not meet the definition of DPOs.⁶²⁶

The UKDPM prioritized the development of anti-discrimination legislation and embarked on a campaign to make the case for the introduction of legal protections for disabled people. The campaign was realized with the enactment of the Disability Discrimination Act 1995. The success of this campaign is often attributed to the direct action of DPOs. Their actions included road blockages and sit ins, including a protest at Downing Street in which a protestor painted red paint on Number 10 Downing Street.⁶²⁷ However, disabled advocates engaged in a range of outsider and insider tactics to influence Government action. DPOs and OfDPs came together in the Rights Now! Coalition to coordinate the campaign for anti-discrimination legislation. This coalition brought DPOs focused on outsider tactics with organisations focused more specifically on insider tactics such as the Royal Association for Disability and Rehabilitation (‘RADAR’).⁶²⁸ Bert Massie, CEO of RADAR worked closely with the Conservative Minister for Disabilities, William Hague MP to develop an anti-discrimination bill. Indeed RADAR’s legal adviser worked closely with Government legal advisers in preparing the Bill.⁶²⁹

⁶²² Mark Priestly ‘Thesis: Disability Values and Quality’ (Leeds University 1997) p. 90 Available at: https://etheses.whiterose.ac.uk/486/1/uk_bl_ethos_390969.pdf (Accessed on 30 March 2022)

⁶²³ Eilionoir Flynn, Participatory Justice, Deliberation and Representation in Public and Political Life, in (E. Flynn) Participatory Justice, Deliberation and Representation in Public and Political Life 2016 pg 147

⁶²⁴ Barnes, C. and Mercer, G. ‘Independent Futures: Creating User-Led Disability Services in a Disabling Society’ (2006: The Policy Press)

⁶²⁵ Drake, R. F. The exclusion of disabled people from positions of power in British voluntary organisations. [1994] *Disability & Society*, 461, p. 478

⁶²⁶ Ellen Clifford, *The War on Disabled People* (Zed Books 2020)

⁶²⁷ Oliver, M., and C. Barnes. 2006. Disability politics: Where did it all go wrong. In *Coalition*, 8-13. Manchester: Greater Manchester Coalition of Disabled People. Available at: <https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.464.6659&rep=rep1&type=pdf> (Accessed on 2 April 2022)

⁶²⁸ Gareth Millward, ‘Disability and Voluntarism in British Policymaking’, *Voluntary Action History Society Blog* (27 February 2012). Available at: <http://www.vahs.org.uk/2012/02/disability-millward/> (Accessed on 30 March 2022)

⁶²⁹ *ibid*

5.3.2 Reformulation of the Movement

Commenting in the mid 1990s, Colin Barnes suggested that the UKDPM was ‘one of the most potentially potent political forces in contemporary British society’.⁶³⁰ Since the turn of the century the UKDPM has struggled to establish and sustain professional campaigning organisations to provide a voice for disabled people on national policies.⁶³¹ Writing in 2006 along with Mike Oliver, Barnes noted that the movement had become politically isolated and was in a state of decline, with the BCODEP becoming increasingly inactive.⁶³² My analysis of existing literature and published reports has identified a number of factors which have contributed to this decline.

Due to the legal framework regulating the activities of voluntary organisations in the UK, DPOs who engage in service provision often must limit or desist from campaigning activities. DPOs who are awarded public service contracts are prohibited from engaging in political activity as a condition of public tendering.⁶³³ Fenwick et. al highlight that rather than empowering CSOs, public sector contracts in the UK tend to place CSOs in a subsidiary role - they ‘embed hierarchical accountability’ which dampens their capacity to engage in independent advocacy.⁶³⁴ Contracting arrangements have the potential to significantly constrain the UKDPM’s ability to harness the collective capacity of disabled people throughout the UK.

A key feature of disability policy in the UK is the provision of direct payments and budgets to disabled people, empowering them to make their own decisions relating to their care.⁶³⁵ Morris posits that the individualisation of social care provision has undermined the capacity of the UKDPM to engage in collective action.⁶³⁶ Soldatic and Meekosha further argue that neo liberal approaches to care in the UK ‘seek to privatize the right of disabled people to personal support

⁶³⁰ Cambell, J. & Oliver M. (1996) *Disability Politics: Understanding Our Past, Changing Our Future* (London, Routledge). Epilogue

⁶³¹ Rebekah Young, Mathew Reeve, Nathan Grills *The Functions of Disabled People’s Organisations (DPOs) in Low and Middle-income Countries: a Literature Review* [2016] *Disability CBR & Inclusive Development* 45

⁶³² Colin Barnes, *Disability Activism and the Price of Success: A British Experience* *Intersticios* [2007] *Revista Sociológica de Pensamiento Crítico* 15, p.18

⁶³³ Sansome J, ‘The Links Between Models and Theories to Social Changes as Seen and Understood’ in Maria Berghs, et al (eds) *The Routledge Handbook of Disability Activism* (Routledge 2019), p.77

⁶³⁴ John Fenwick, Karen Miller Johnston and Duncan McTavish, ‘Co-governance or meta-bureaucracy? Perspectives of local governance ‘partnerships’ in England and Scotland’ [2012] *Policy & Politics* 405, p. 415

⁶³⁵ Morris, J. (2008), ‘Inside the belly of the beast’, Conference keynote, Disability Studies Association Conference, 3–5 September 2006, Lancaster.

⁶³⁶ *ibid*

assistance, thus absolving the state of its responsibilities to a class of citizens'.⁶³⁷ The result of this is a reduction in broader claims for 'social provisioning measures' by the broader movement.⁶³⁸

The election of a Labour Government in 1997 brought a new emphasis on participatory governance which created new opportunities for individuals and organisations to participate in governance.⁶³⁹ Individuals who had previously been involved in the organisation of DPOs were appointed to Government positions. For instance, Jane Campbell who had been active in the BCODP was appointed as the chair of the Social Care Institute for Excellence. Bert Massie, who led the campaign for anti-discrimination legislation, was appointed to chair the Disability Rights Commission ('DRC') and a number of activists were appointed as independent government advisers.⁶⁴⁰ Much existing literature posits that the appointment of members of the movement to Government positions had a debilitating effect on the movement.⁶⁴¹ However disabled activists interviewed for this research who took up opportunities to participate in governance highlighted that 'You need people who can put pressure on government inside'.⁶⁴² Interviewees tended to consider that whilst opportunities to participate provided by the Labour Government presented genuine opportunities to influence change.⁶⁴³ However offers to participate emerging from the current Conservative Government were more tokenistic.⁶⁴⁴ Baroness Jane Campbell was highlighted as an example of a disabled activist who took up opportunities to participate in governance who continues to be a strong voice for the rights of disabled people in the House of Lords.⁶⁴⁵

5.3.3 Current condition of the Movement

During my evidence gathering I invited participants to provide comments on the strengths and weaknesses of the UKDPM. Overall, interviewees felt that the UKDPM was not as strong or effective as it once was. One DPO leader commented, 'since the demise of the [BCOPD],

⁶³⁷ Soldatic, K., & Meekosha, H. 'Disability and neoliberal state formations' in Nick Watson, Alan Roulstone, and Carol Thomas (Eds.), *Routledge Handbook of Disability Studies* (Routledge 2012)

⁶³⁸ *Ibid.*, p. 205

⁶³⁹ Colin Barnes, 'Disability activism and the struggle for change: disability, policy and politics in the UK' [2007] *Education, Citizenship and Social Justice* 203

⁶⁴⁰ JCHR, *UN Convention on the Rights of Persons with Disabilities: Government response to the Committee's First Report of the Session 2008–09, Sixth Report of Session 2008–09*, para 26

⁶⁴¹ Barnes (n. 632) p. 219

⁶⁴² Interview with DPO (Alf) 26 April 2021 and Interview with disability advocate 19 March 2021

⁶⁴³ Interview with DPO representative 5 May 2021

⁶⁴⁴ Interview with DPO (mh) 22 April 2021

⁶⁴⁵ Interview with disability advocate 19 March 2021, see further: Saba Salman, Disability rights campaigner Jane Campbell: 'In the Lords, I'm still a radical activist' *Guardian* 8 July 2015

which was the figurehead for the movement, things have ever since [become] increasingly fragmented'.⁶⁴⁶ One interviewee felt that the absence of an umbrella organization had facilitated the marginalization of persons with intellectual disabilities within the movement.⁶⁴⁷ This view corresponds with a 2017 study by Petri and others who noted that persons with intellectual disabilities continue to be marginalized within the UKDPM.⁶⁴⁸ In addition one interviewee noted that users and survivors of psychiatry had historically been separate from the UKDPM.⁶⁴⁹ However, users and survivors of psychiatry has largely integrated within the movement through their activism relating to social security reform.

Since the turn of the century the UKDPM has been active in challenging reforms to the social security system.⁶⁵⁰ Successive UK Governments have sought to curb the costs of social security provision in the UK. Morris highlights, ‘..this mind-set is integrally linked to the promulgation of the idea that an increase in the number of people receiving ‘disability’ benefits is a sign of increasing ‘welfare dependency’ rather than a sign of...a society which makes resources available to attempt to create a level playing field..’.⁶⁵¹

In the wake of the global financial crisis the Coalition Government of Conservatives and Liberal Democrats brought forward a raft of social security reforms intended to reduce public expenditure on disability benefits.⁶⁵² The Coalition Government sought to justify these social security reforms through a public relations campaign which portrayed welfare as a life style choice.⁶⁵³ People with depression or stress were in particular portrayed as undeserving recipients.⁶⁵⁴ In response to the reforms and an ‘increasingly hostile press media’, the UKDPM embraced online disability activism.⁶⁵⁵ The UKDPM developed a strong wing of online activists who engaged in ‘from bed activism’ utilising social media and blogs to influence the political agenda.⁶⁵⁶ During the passage of social security reforms through the House of Lords,

⁶⁴⁶ Interview with DPO (gz) 21 April 2021 (Online)

⁶⁴⁷ Interview with DPO (ED) 16 April 2021 (Online)

⁶⁴⁸ Gabor Petri, Julie Beadle-Brown and Jill Bradshaw, “‘More Honoured in the Breach than in the Observance’—Self-Advocacy and Human Rights’ [2017] *Laws* 26, p. 3

⁶⁴⁹ Interview with DPO (mh) 22 April 2021

⁶⁵⁰ *Andy McSmith* ‘Wheelchair warriors target Blair’ *the Guardian* 16 May 1999

⁶⁵¹ Jennifer Morris, *Rethinking Disability Policy* (Joseph Rowntree, 2011), p. 6

⁶⁵² Simon Roberts, Bruce Stafford and Katherine Hill *Diluting Substantive Equality: Why the UK Government doesn’t Know if its Welfare Reforms Promote Equality: 167 – 184 in Inequalities in the David Fée and Anémone Kober-Smith UK New Discourses, Evolutions and Actions*

⁶⁵³ Kayleigh Garthwaite ‘The language of shirkers and scroungers?’ *Talking about illness, disability and coalition welfare reform*, [2011] *Disability & Society* 369, p. 371

⁶⁵⁴ Soorenian, A. ‘Media Disability and Human Rights’ in Michael Gill and Cathy J. Schlund-Vials (eds) *Disability, Human Rights and the Limits of Humanitarianism* (Routledge 2014), p. 49

⁶⁵⁵ Charlotte Pearson and Filippo Trevisan, ‘Disability Activism in the New Media Ecology: Campaigning Strategies in the Digital Era’, [2015] *Disability & Society* 924, p. 925

⁶⁵⁶ Butler, P. 2012. “How the Spartacus Welfare Cuts Campaign Went Viral.” *The Guardian*, 17 January.

social media activists used the hashtag ‘Spartacusreport’ to draw attention to a report highlighting the full impact of the reforms on disabled people. The campaign generated a significant number of retweets by high profile individuals, so much so that a government spokesman took to Twitter to respond. Pearson and Trevisan note that this event signalled a ‘new era of campaigning in disability politics’.⁶⁵⁷ The trend has continued throughout the coronavirus pandemic with online activists successfully utilising social media to challenge the absence of sign language interpretation during Government coronavirus briefings.⁶⁵⁸

The DPO Disabled People against Cuts (‘DPAC’), in particular, has emerged as a coordinator of grass roots activism. DPAC organized street protests during the UK Paralympic games protesting the sponsorship by private contractor Atos, who were involved in the implementation of social security reforms.⁶⁵⁹ McKeown and Spandler note that DPAC ‘present a radical framing of disability politics as protest’.⁶⁶⁰ DPAC and other like-minded organisations have come together in the Reclaiming Our Futures Alliance (‘ROFA’). The members of ROFA call for fundamental reform and have highlighted the ‘limitations of overly focusing on a legislative rights agenda’.⁶⁶¹

A number of interviewees noted that social security reforms have led to many disabled people, in particular those with chronic pain conditions, becoming politicised.⁶⁶² Whilst this increased the number of people involved in disability advocacy and indeed the range of activities, these activists tended to be focused specifically on opposition to social security cuts, rather than the broader goal of the emancipation of disabled people.⁶⁶³

An emphasis on human rights was a consistent feature across the nine UK based DPOs interviewed for this research, all of whom felt that the ratification of the CRPD was a positive development. In the words of one DPO ‘it has given people a crystallisation of the concept, disabled people having rights and particularly human rights’.⁶⁶⁴ DPOs had developed a detailed

657 Pearson and Trevisan (n. 598) p. 928

658 BBC News Covid: Call for briefings to include British Sign Language 4 October 2020

659 S Stuart Braye, ‘You Shall Not Murder’: Atos at the Paralympic Games’, [2017] *Journal of Disability & Religion* 215, p. 217

660 McKeown M and Spandler H, *Solidarity across difference: organising for democratic alliances* in Helen Spandler, Jill Anderson, and Bob Sapey (eds) *Madness, distress and the politics of disablement* (Policy Press 2015) p.272

661 Ellen Clifford, *The War on Disabled People* (Zed Books 2020), p. 306

662 Interview with DPO (mh) 22 April 2021

663 Interview with disability advocate 19 March 2021

664 Interview with DPO representative 5 May 2021

understanding of the CRPD examination process and invested in acquiring knowledge relating to the CRPD.⁶⁶⁵

5.4 Disability Policy: Focal Point Article 33(1)

At the time of ratification of the CRPD, the Office for Disability Issues (ODI) within the Department for Work and Pensions was designated as the CRPD focal point. This body was established in 2005, with a remit focused on ensuring effective joined-up working across government, to improve the life chances of disabled people.⁶⁶⁶ The EHRC appeared to have a good working relationship with the ODI. The Minister for Disabilities reported that the ODI was in regular contact with the EHRC and highlighted that the ODI attended the EHRC Treaty Monitoring Working Group.⁶⁶⁷

The role of the ODI diminished significantly throughout its years of operation as did the number of staff employed within it.⁶⁶⁸ In one of her last acts as Prime Minister, Theresa May announced the development of a new Disability Unit within Cabinet Office to replace the ODI.⁶⁶⁹ The Cabinet Office is the Department which usually takes responsibility for the implementation of strategic cross-departmental aims.⁶⁷⁰ This initiative was welcomed by the EHRC as, ‘a bold statement from the government to tackle these problems and a very welcome move’.⁶⁷¹ The UKDPM similarly welcomed the establishment of the Disability Unit.⁶⁷² The activities of the Disability Unit are analysed below.

5.5 UNCRPD Independent Mechanism

The UK has three systems of law and three devolved administrations.⁶⁷³ Reflecting this situation the UK has three NHRIs. The NIHR, which has responsibility for monitoring the activities of the Westminster Parliament and the NI Assembly in NI. The SHRC, which has

⁶⁶⁵ Ibid

⁶⁶⁶ Prime Minister’s Strategy Unit, ‘Improving the Life Chances of Disabled People’ (London: HMSO. 2005).

⁶⁶⁷ Equality and Human Rights Commission: Recruitment Question for Department for Work and Pensions UIN 42431, tabled on 11 July 2016

⁶⁶⁸ Department for Work and Pensions written question Office for Disability Issues: Staff, – answered on 30th May 2019.HL Deb, 30 May 2019, cW)

⁶⁶⁹ Prime Minister’s Office Press Release, PM launches new drive to tackle barriers faced by disabled people, 25 June 2019 Available at: <https://www.gov.uk/government/news/pm-launches-new-drive-to-tackle-barriers-faced-by-disabled-people> (Accessed on 2 April 2022)

⁶⁷⁰ Mathew Flinders ‘Governance in Whitehall’ (2002) 80 (1) Public Administration 51, 59.

⁶⁷¹ See n. 611

⁶⁷² OHCHR, ‘National Implementation and Monitoring’ UN Doc CRPD/CSP/2014/3 (1 April 2014) para 11(b).

⁶⁷³ A Series and A Lawson, United Kingdom, in Lisa Waddington and Anna Lawson (eds.) The UN Convention on the Rights of Persons with Disabilities in Practice: A Comparative Analysis of the Role of Courts (2018 Oxford University Press) p. 420

responsibility for monitoring the activities of the Scottish Parliament in Scotland. The EHRC, which has responsibility for monitoring the activities of the devolved administrations and the Westminster Parliament throughout Great Britain. The UK ratified the UNCRPD in 2009. Upon ratification the UK appointed the three UK NHRIs and the NI Equality Commission as the UK Independent Mechanism (UKIM).

In 2009, the JCHR reported on the measures required to ensure the UK Government's compliance with its CRPD obligations in the preparation for ratification.⁶⁷⁴ The JCHR recorded broad support for the proposed composition of the UKIM.⁶⁷⁵ It is notable that submissions from DPOs to the JCHR did not refer to the development of an IMF, or to the potential inclusion of civil society within it. Murray and Johnson commented that at the time of ratification, 'it was apparent that the implementation of Article 33 had not yet been fully considered by many of the players, in particular civil society organisations'.⁶⁷⁶

The absence of any discussion of the inclusion of civil society within an IMF is perhaps a reflection of how novel such an arrangement would be in the UK context. Whilst the UK Government has involved CSOs in the provision of services it has rarely developed collaborative approaches to governance which involve the integration of CSOs within the policy making process.⁶⁷⁷

As set out in chapter 4, the publication of GC7 has encouraged a number of NHRI(IMM)s to review their working methods. Amongst CSOs interviewed for this case study there was limited awareness of GC7. Whilst DPOs in NI informed by GC7 have engaged with the NIHRC to successfully advocate for the establishment of a disability forum, neither the EHRC nor the UKIM collectively have sought to adapt their structure to reflect GC 7.⁶⁷⁸ A member of the EHRC-DAC stated 'I have never had any conversation where they specifically referenced GC 7 or how to utilise that to be more participatory or collaborative in their way'.⁶⁷⁹

⁶⁷⁴ JCHR Inquiry The UN Convention on the Rights of Persons with Disabilities 2009 HL Paper 70

⁶⁷⁵ *ibid* para 100

⁶⁷⁶ Murray, R and Johnson K, 'Implementation of Article 33 CRPD in the United Kingdom: The Need to Consolidate Civil Society Engagement' in Gauthier De Beco (ed) *Article 33 of the UN Convention on the Rights of Persons with Disabilities National Structures for the Implementation and Monitoring of the Convention* (Brill 2013) p. 98

⁶⁷⁷ Brandsen T and Johnston K, *Collaborative Governance and the Third Sector: Something Old, Something New* in Edoardo Ongaro, and Sandra Thiel (eds.) *The Palgrave Handbook of Public Administration and Management in Europe* (Palgrave Macmillan 2017)

⁶⁷⁸ Interview with representative of NIHRC

⁶⁷⁹ Interview with member of EHRC Disability Advisory Committee 13 May 2021

Overall, amongst both DPOs and members of UKIM, there appears to be a lack of a clear appreciation as to how DPOs could be included in the monitoring activities of UKIM. One DPO took the view that the EHRC and UKIM should share their statutory powers with the UKDPM to co-produce activities.⁶⁸⁰ Members of UKIM interviewed for this research were concerned that including DPOs or their nominees within UKIM may create governance issues.⁶⁸¹ In addition, there was a concern that it may dilute the ‘very distinctive role, unique role, played nationally and internationally’ by an NHRI.⁶⁸²

5.6 EHRC

5.6.1 Establishment of EHRC

During the campaign to introduce anti-discrimination protections the UKDPM consistently highlighted the need for an enforcement body to initiate proceedings against public and private bodies who fail to meet their obligations.⁶⁸³ This campaign goal was not realized within the DDA, but was realized in 1999 with the establishment of the DRC as a statutory body with specific responsibility for regulating compliance with the DDA.⁶⁸⁴ As set out above the DRC was chaired by Bert Massie who was a key member of the movement.

The Labour Government’s 1997 Command Paper on the incorporation of the ECHR into UK law raised the prospect of establishing a NHRI for GB.⁶⁸⁵ In response the Institute for Public Policy Research published a paper setting out proposals for a GB NHRI which would have responsibility for both human rights and equality.⁶⁸⁶ The JCHR was tasked with carrying out a review of the potential for a GB NHRI which would be an amalgamation of the Equal Opportunities Commission, the DRC and the Commission for Racial Equality.⁶⁸⁷

Disability activists who had developed a good working relationship with the DRC were disappointed at the proposal for its abolition. Spencer notes that the DRC and its supporters

⁶⁸⁰ Interview with DPO (Man) 11 May 2021

⁶⁸¹ Interview with NIHRC Representative 27 November 2020

⁶⁸² Interview with SHRC Representative 11 December 2020

⁶⁸³ BBC Radio 4, The Reunion: Disability Campaigners 10 April 2016. Available at: <https://www.bbc.co.uk/programmes/b0769qsq>

⁶⁸⁴ Disability Rights Commission Act 1999 c. 17

⁶⁸⁵ Home Office UK Rights Brought Home: The Human Rights Bill Cm. 3782 24 October 1997

⁶⁸⁶ Spencer S and I. Bynoe I. A Human Rights Commission: The Options for Britain and Northern Ireland (Institute for Public Policy Research 1998)

⁶⁸⁷ House of Parliament, Human Rights (Joint Committee), Available at <<https://committees.parliament.uk/committee/93/human-rights-joint-committee>> (Accessed on 2 April 2022)

were the greatest obstacles to the establishment of a GB NHRI, seeking to resist, ‘the prospect of the [DRC] being wound up so early in its life’.⁶⁸⁸

Despite this opposition, the JCHR considered the case for a single NHRI for GB to be compelling.⁶⁸⁹ The UK Government agreed considering that a combined human rights and equality body would be better placed to address ‘multiple and intersecting equality considerations’.⁶⁹⁰ The EHRC was established by way of the Equality Act 2006 and opened its doors on 1 October 2007.

5.6.2 EHRC – Compliance with the Paris principles

The EHRC was last assessed by the Global Alliance of NHRI SCA in 2015, who re-awarded it with A status. However, the SCA did express concerns that the UK Government has significant discretion over the allocation of funds to the EHRC and raised concerns relating to the process for appointing Commissioners.⁶⁹¹

The EHRC is a Non-Departmental Public Body (‘NDPB’). This is a common method for establishing arm’s length bodies in the UK. The EHRC’s sponsor Department is the UK Cabinet Office. The EHRC itself has said that ‘... the standard model of NDPB accountability is [not] a sufficiently outward and visible guarantee of independence’.⁶⁹²

The EHRC is composed of a Board of between 10 to 15 Commissioners, who are chaired by a Chief Commissioner.⁶⁹³ The Chief Commissioner and Commissioners are appointed by the Minister for Women and Equalities by means of a public appointment process.⁶⁹⁴ The Minister has broad discretion to make appointments from a list of candidates deemed suitable for appointment. The appointments process is governed by the UK Government’s Governance Code for Public Appointments, which is regulated by the Commissioner for Public Appointments.⁶⁹⁵ A nominated Chief Commissioner is required to attend a hearing before the

⁶⁸⁸ Sarah Spencer, ‘Equality and Human Rights Commission: A Decade in the Making’ [2008] *The Political Quarterly* 1, p. 8

⁶⁸⁹ Joint Committee on Human Rights Sixth Report Session, 2002- 2003, *The Case for a Human Rights Commission*, vols 1 and 2, HL Paper 67.1, HC 489 1.

⁶⁹⁰ UK Government, White Paper ‘Fairness for all: a new Commission for equality and human rights’ 2004

⁶⁹¹ ICC Sub-Committee on Accreditation Report – November 2015

⁶⁹² EHRC Enterprise and Regulatory Reform Bill 2012-13 Report stage and third reading briefing House of Commons October 2012

⁶⁹³ Equality Act 2006 Schedule 1

⁶⁹⁴ *ibid*

⁶⁹⁵ Cabinet Office, *Governance Code on Public Appointments*, 2016

JCHR and the Women and Equalities Committee ('WEC').⁶⁹⁶ A former EHRC Commissioner interviewed for this research considered that involving CSOs including DPOs in the appointment process would perhaps strengthen its credibility.⁶⁹⁷

In recent years concerns have arisen relating to the motivations behind a number of appointments to the EHRC Commission.⁶⁹⁸ This reflects a more general concern that the current Conservative Government are seeking to appoint individuals who are sympathetic to their priorities to NDPBs throughout the UK.⁶⁹⁹ When making appointments to the EHRC the then Minister for Women and Equalities, Liz Truss emphasised the contribution which appointees will make to delivering the Government's priorities rather than emphasising their role in independently monitoring or holding the Government to account.⁷⁰⁰ The EHRC in responding to criticism of recent appointments have highlighted that 'All appointments to our non-executive and executive roles are made through a fair, open and transparent recruitment process' and that has 'not changed since the commission was established.'⁷⁰¹ In November 2021 the Committee on Standards in Public Life highlighted that the UK public appointments system 'is highly dependent on informal mechanisms, including the willingness of the minister to act with restraint'.⁷⁰² This comment highlights that due to the informal nature of the appointments process a change in approach by an appointing Minister can undermine the integrity of the appointments process.

Controversial appointments to the EHRC have contributed to a fracturing of relations between the EHRC and significant sections of the civil society in the UK. In April 2021 the Runnymede Trust, the UK's leading think tank on race equality matters in an open letter to the Prime Minister highlighted the 'eroded independence' of the EHRC due to the 'political nature' of recent appointments.⁷⁰³

⁶⁹⁶ JCHR 'Appointment of the Chair of the Equality and Human Rights Commission' 2020 Available at:

<https://publications.parliament.uk/pa/jt5801/jtselect/jtrights/180/18005.htm>

⁶⁹⁷ Interview with EHRC Commissioner 9 March 2021

⁶⁹⁸ Amelia Gentleman, Equalities campaigners criticise senior EHRC appointment, 13 November 2020 (The Guardian, London)

⁶⁹⁹ Robert Booth, Tory intrusion 'chilling' independence of national bodies, critics claim, 7 November 2021 (The Guardian, London)

⁷⁰⁰ Liz Truss, 'Deliver the Government's Equality Agenda' (Twitter 11 November 2020) Available at

<https://twitter.com/trussliz/status/1326485053287915520> Accessed on 11 April 2022

⁷⁰¹ Josh Parry, Rights watchdog 'should lose status' over trans row, 11 February 2022 (BBC News London)

⁷⁰² Committee on Standards in Public Life, Upholding Standards in Public Life: Final report of the Standards Matter 2021

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1029944/Upholding_Standards_in_Public_Life_-_Web_Accessible.pdf

⁷⁰³ EHRC, Open letter to the Prime Minister from Runnymede Trust: Our letter to Dr Halima Begum 12 Apr 2021 Available at:

<https://www.equalityhumanrights.com/en/our-work/news/open-letter-prime-minister-runnymede-trust-our-letter-dr-halima-begum>

Leaders of trans and LGBTQ+ organisations have written an open letter to the EHRC highlighting that it ‘has driven forward very little for our communities in recent years’.⁷⁰⁴ A larger dispute has emerged in relation to advice submitted by the EHRC to the Scottish Parliament relating to reforms to the law relating to gender recognition.⁷⁰⁵ This led to a coalition of CSOs co-ordinated by the LGBT charity Stonewall requesting that the GANHRI SCA conduct a review of the EHRC’s compliance with the Paris principles.⁷⁰⁶ The SCA decided not to undertake a special review but instead will consider the matters raised in the complaints within the next periodic review of the EHRC in October 2022.⁷⁰⁷ Whilst this dispute occurred following the conclusion of my evidence gathering, the developments support my finding that the EHRC’s approach to managing its relationship with civil society is ineffective.

Only one of the nine DPOs interviewed for this research felt that the EHRC was independent of Government. A number of interviewees highlighted that the Government had made appointments to the EHRC which appeared to be political and that individual Commissioners who were critical of Government policies tended not to be re-appointed.⁷⁰⁸ A number of DPOs, OfPDs and two of the three human rights NGOs interviewed suggested that the EHRC was often reluctant to make statements or exercise their powers in ways that would be viewed unfavorably by the Government lest it result in a reduction in their budget.⁷⁰⁹

The budget of the EHRC has reduced significantly since it was first established. It is currently £17 million.⁷¹⁰ Almost all organisations interviewed for this research acknowledged that the budget of the EHRC had been significantly reduced and that this had impacted on the range of activities they engage in.⁷¹¹

The EA 2006 provides that the Commission’s Board is its decision-making body with responsibility for setting and overseeing the strategic plan of the Commission.⁷¹² Evidence

⁷⁰⁴ Consortium for stronger LGBT+ Communities, Correspondence to EHRC, 2021 Available at: <<https://www.consortium.lgbt/ehrc-open-letter/>> Accessed on 11 April 2022

⁷⁰⁵ EHRC Correspondence to the Cabinet Secretary for Social Justice, Housing and Local Government, 4 February 2022 Available at: <https://www.parliament.scot/chamber-and-committees/committees/current-and-previous-committees/session-6-equalities-human-rights-and-civil-justice-committee/correspondence/2022/reform-of-the-gender-recognition-act-2004> Accessed on 11 April 2022

⁷⁰⁶ Hayley Dixon, ‘Stonewall attempts to have equalities watchdog stripped of independent status’ 11 February 2022 (London, The Telegraph)

⁷⁰⁷ *ibid*

⁷⁰⁸ Interview with Human Rights NGO (AI) 19 March 2021

⁷⁰⁹ Interview with DPO 11 May 2021

⁷¹⁰ EHRC ‘Annual report and accounts: 1 April 2020 to 31 March 2021’ 19 Jul 2021, HC 525

⁷¹¹ Interview with OfDP 28 April 2021

⁷¹² Equality Act section 9

from current and former staff members within the EHRC indicates that in practice many key decisions are being taken by the Chief Executive and the Executive Team alone.⁷¹³

Five of the nine DPOs interviewed for this research considered that there was a lack of transparency around how decisions are taken by the EHRC, and this has contributed to a lack of trust.⁷¹⁴ As set out below interviewees highlighted a lack of transparency around decisions relating to strategic litigation and the exercise of inquiry powers.

5.6.3 Role of EHRC – influencing change?

Throughout the history of the EHRC a question has consistently arisen over the extent to which it should be an organisation which seeks to advocate for change to bring about human rights compliance. In 2018, a government appointed independent review of the EHRC recommended that the EHRC ‘reset its vision to focus on the use of its unique powers as an enforcer and regulator of equality law’.⁷¹⁵ The review placed limited emphasis on the role of the EHRC in advocating for reforms to meet its international human rights obligations. A number of DPOs welcomed this recommendation as they hoped it would lead to higher levels of compliance with domestic equality provisions.⁷¹⁶ However, a disability advocate highlighted that the recommendation reflected a ‘political shift of saying to the EHRC you are there to regulate the laws made by Parliament and no more’.⁷¹⁷

I invited interviewees to provide their views on the level of influence exerted by the EHRC. A former EHRC Commissioner surprisingly noted that he felt that a CSO which he previously chaired had a greater degree of influence over Government than the EHRC, stating ‘perversely I had better dealings with government when I was chair of a [CSO] than I did as [a Commissioner in] the HRC and I often you know wonder why that is’.⁷¹⁸ The former Commissioner went on to note that there was a lack of clarity within Government as to the role which the EHRC should perform.

⁷¹³ Interview with former EHRC Commissioner 9 March 2021

⁷¹⁴ Interview with DPO 28 April 2021

⁷¹⁵ Government Equalities Office, Tailored Review of the Equality and Human Rights Commission (UK Gov 2018) p. 13

⁷¹⁶ Interview with DPO 17 March 2021

⁷¹⁷ Interview with Disability Advocate 19 March 2021

⁷¹⁸ Interview with former EHRC Commissioner 9 March 2021

The views of DPOs were more mixed but the majority of DPOs and three NGOs interviewed for this research felt that by virtue of the EHRC's unique powers to initiate legal proceedings and inquiries the EHRC could potentially level significant influence.⁷¹⁹ A lack of common understanding on the level of influence which NHRIs can exert arose consistently throughout my evidence gathering and is addressed in my concluding chapter.

5.6.4 Inclusion of disabled people in the structures of the EHRC

As set out above in section 5.6.1 the UKPM were concerned at the prospect that the amalgamation of the DRC with the Equal Opportunities Commission and the Commission for Racial Equality would lead to the marginalization of disability issues. In light of this concern the UKDPM engaged in significant lobbying with the Westminster Government and Parliament to address this risk.⁷²⁰ In doing so they collaborated closely with Commissioners and staff members within the DRC.⁷²¹

The Government White paper proposing the establishment of the EHRC made provision for the establishment of a Disability Committee. The Government suggested this was required as a ‘..recognition that ‘reasonable adjustments’ are often needed to deliver equal opportunities for disabled people – some specific arrangements and expertise will be required’.⁷²² The Equality Act 2006 provided for a Disability Committee and required that at least one EHRC Commissioner have a disability.⁷²³ The EHRC developed a practice of designating one Commissioner as the Disability Commissioner.

An individual interviewed for this research, who was employed by the DRC at the time of the merger, highlighted that the inclusion of a requirement to establish a Disability Committee and the designation of a Disability Commissioner were considered to be important safeguards to ensure that disability issues would receive appropriate attention.⁷²⁴ It was considered that by the House of Lords Select Committee that these features gave the EHRC ‘a slight but perceptible leaning towards disability interests’.⁷²⁵ Notably the requirement to establish a

⁷¹⁹ Interview with DPO (IS) 28 April 2021

⁷²⁰ Interview with DPO (Sp) 21 April 2021

⁷²¹ Ibid

⁷²² UK Government White Paper ‘Fairness for all: a new Commission for equality and human rights’ 2004

⁷²³ Schedule 1 para 3

⁷²⁴ Interview with DPO (Sp) 21 April 2021

⁷²⁵ House of Lord Select Committee on the Equality Act 2010 and Disability, The Equality Act 2010: the impact on disabled people, 2016 HL Paper 117

committee composed of disabled people and to appoint a disabled commissioner was unique. There were no requirements to appoint committees or commissioners to ensure representation from other minority groups.

Disability Committee

The 2006 Act provided that the Disability Committee would be a decision-making body and provided for the delegation of powers relating to ‘disability matters’.⁷²⁶ The Act provided for an independent review of the Disability Committee which was conducted in 2013.⁷²⁷ The Independent Reviewer undertook extensive engagement with stakeholders including disabled people and noted that 61 percent of individuals and organisations believed the Committee should be retained. The Reviewer noted that the Committee had a number of achievements but that it had not been ‘hard-wired in’ to the Commission.⁷²⁸ To address this the Reviewer made numerous recommendations for the recruitment of new members and for new operating procedures.⁷²⁹ Somewhat surprisingly in responding to the review, the EHRC set out plans to abolish the Disability Committee and replace it with a strategic advisory committee.⁷³⁰ This decision was not supported by the UKDPM and continues to be cited as evidence of the marginalisation of disability issues within the EHRC.⁷³¹ Bert Massie who in addition to chairing the DRC, had been a Commissioner within the EHRC commenting at the time stated, ‘I can’t but be suspicious about the motivation because there is no honourable motivation I can see’.⁷³²

Following this decision, the EHRC-DAC was established. The terms of reference for the EHRC-DAC made clear that its role was to ‘inform and advise’ the EHRC. DPOs considered that its role was much diminished from that of the previous Disability Committee.⁷³³ However, DPO interviewees did acknowledge that the EHRC-DAC included a number of disabled activists, including a number who hold senior positions in DPOs. A former Commissioner interviewed for this research indicated that the EHRC-DAC had been ‘hugely successful’ and

⁷²⁶ Schedule 1 Part 5

⁷²⁷ *ibid*

⁷²⁸ Agnes Fletcher, Independent Reviewer, *Independent Review of the Equality and Human Rights Commission’s Statutory Disability Committee*, June 2013, p. 53

http://www.equalityhumanrights.com/sites/default/files/publication_pdf/independent_review_report_final_for_web.pdf (Accessed on 2 April 2022)

⁷²⁹ *Ibid* p. 41

⁷³⁰ Equality Act 2006 (Dissolution of the Disability Committee) Order 2014 (SI No.406)

⁷³¹ Interview with DPO (IS) 28 April 2021

⁷³² John Pring Equality watchdog to scrap vital disability committee Disability News Service 19 July 2013

⁷³³ EHRC Disability Advisory Committee Terms of Reference April 2017

performed a very useful role. Minutes of the November 2020 Commission meeting indicate that the Commission considered that the EHRC-DAC was ‘positive, informative and engaging’.⁷³⁴ However, the terms of reference for the EHRC-DAC indicated that it would cease operating in March 2022 at which point the EHRC will adopt a new approach for stakeholder engagement.

In its 2019-2022 strategic plan the EHRC set out plans to review its stakeholder engagement mechanisms ‘with a view to ensuring that they are accessible’.⁷³⁵ Throughout my data gathering the EHRC was conducting this review.⁷³⁶ A terms of reference for this review has not been published and the EHRC were unable to furnish a copy upon request.⁷³⁷ Given that the continued existence of the EHRC-DAC was considered as part of this review it is surprising that DPOs and OfPD had limited awareness of the review. One DPO stated, ‘No. I don't know who they have approached. I mean nobody has mentioned it’.⁷³⁸

In August 2021 the EHRC published a draft strategic plan for 2022-25.⁷³⁹ The draft plan did not set out detail on the proposed abolition of the EHRC-DAC. However, in March 2022 the EHRC issued a statement confirming that the EHRC-DAC would be abolished with its last meeting taking place in early March 2022. In response to this 20 DPOs signed a letter prepared by ROFA to the EHRC which stated that the abolition of the EHRC-DAC ‘places insufficient weight on the particular expertise that Deaf and Disabled People's Organisations can bring and the importance of engagement specifically with organisations of, not for, Deaf and Disabled people within the implementation of the UN Convention on the Rights of Disabled People’.⁷⁴⁰ DPOs highlighted that the rationale informing the decision was unclear. In responding an EHRC spokesperson stated ‘Disability, to date, has been the only protected characteristic with this dedicated advisory function. Stakeholder engagement with other representative groups has taken place via less formal structures’.⁷⁴¹ The lack of consultation with DPOs and disabled people more generally is surprising and in my view does not reflect the spirit of Article 33(3). Furthermore, the abolition of this participative mechanism appears

⁷³⁴ EHRC Minutes of the Board Meeting of the EHRC November 2020

⁷³⁵ EHRC ‘Strategic plan: 2019 to 2022’ 2019 Available at: <https://www.equalityhumanrights.com/sites/default/files/strategic-plan-2019-22.pdf> (Accessed on 2 April 2022)

⁷³⁶ EHRC ‘Response to Tailored review of the Equality and Human Rights Commission’ 2018

⁷³⁷ Correspondence on record with the author

⁷³⁸ Interview with DPO (DPA) 12 May 2021

⁷³⁹ EHRC (n. 665)

⁷⁴⁰ Correspondence from ROFA to the Chair of the EHRC 16th March 2022 Available at <<https://mailchi.mp/0071c34cbabb/rofa-disability-advisory-committee>> Accessed on 2 April 2022

⁷⁴¹ John Pring, New concerns over equality watchdog as it scraps disability committee 3rd March 2022 <https://www.disabilitynewsservice.com/new-concerns-over-equality-watchdog-as-it-scraps-disability-committee/>

to run contrary to the UNCRPD Committee's GC 7 and its recommendation that NHRI(Imm)s established formal structures of engagement with disabled people and their representative groups.

Disability Commissioner

The EHRC 2019-2022 strategic plan prioritised the development of an intersectional approach.⁷⁴² The plan is informed by a measurement framework which monitors progress on equality and human rights in the UK across six domains. Namely education; work; living standards; health; justice; and participation. The EHRC asserts that adopting this approach allows it to 'strategically address the impact of the law, policy or practices in particular areas of life on people who share a protected characteristic or who have multiple protected characteristics and identities'.⁷⁴³ In preparing to adopt this approach the EHRC ceased the practice of designating a Disability Commissioner in 2018. This decision was not welcomed by disabled people, in particular Lord Shinkin, who secured a debate in the House of Lords on the issue.⁷⁴⁴ In seeking to justify the decision the EHRC suggested that designating a Disability Commissioner 'led to work on disability being seen as the responsibility of specific individuals in the Commission rather than the collective responsibility of the Board and organisation as a whole'.⁷⁴⁵ DPOs interviewed for this research generally did not fully appreciate the EHRC's intersectional approach and a number felt that the EHRC had removed disability specific features without clear justification.⁷⁴⁶ One DPO representative noted '...there were enormous anxieties, ... when the responsibility for disabled people's rights was transferred to an overall body ... I do feel that that concern has been justified ever since'.⁷⁴⁷

The EHRC acknowledged that the move towards an intersectional approach had not been fully explained to DPOs. A former EHRC Commissioner noted, 'Yeah and it's complicated isn't it, that domain-based approach, it's great in theory but if you're a disabled person who's feeling frustrated and your universal credit payments are not coming through, it's quite theoretical'.⁷⁴⁸

⁷⁴² EHRC (n. 113)

⁷⁴³ EHRC, Briefing Question for short debate - Lord Shinkin' 10 May 2018

⁷⁴⁴ Lord Shinkin, Equality and Human Rights Commission: Disability Commissioner, Hansard Volume 791, 10 May 2018

⁷⁴⁵ *ibid*

⁷⁴⁶ Interview with DPO (Ber) 22 April 2021

⁷⁴⁷ *Ibid*

⁷⁴⁸ Interview with former EHRC Commissioner 9 March 2021

The decision to cease designating a Disability Commissioner and the abolition of both the Disability Committee and the EHRC-DAC stand in contrast to efforts by NHRIs in other jurisdictions to enhance the involvement of DPOs in their work in light of the publication of GC 7. Overall, the approach of the EHRC-DAC displays a lack of appreciation for how structural reforms will be perceived by the DPM and an unwillingness to explain its decision making to generate support.

5.7 Collaboration between the EHRC and DPOs

5.7.1 Access to EHRC

When it was first established the Commission operated a helpline providing advice to the public on human rights and equality matters. Following a review of the EHRC in 2011, the UK Government announced that due to concerns regarding the effectiveness and value for money of EHRC's programmes, the EHRC would no longer have responsibility for the helpline.⁷⁴⁹ A number of interviewees considered that the removal of the helpline from the EHRC had a significant damaging effect on the Commission.⁷⁵⁰ This is considered to have impacted on the connectivity with rights holders including disabled people. A human rights NGO noted 'if you are running an advice line or a helpline it informs your wider policy work so effectively and so crucially that I do think it was a massive mistake to take that away from the Commission'.⁷⁵¹ A OfPD highlighted that removing responsibility for the helpline had the effect of 'removing [the EHRC's] access to data and real lived experiences'.⁷⁵²

I explored if the EHRC has developed alternative mechanisms for capturing the lived experiences of disabled people. The EHRC does not have a formal structure for engaging with DPOs. I sought to determine if the DPOs were included in any informal networks established by EHRC staff to gain insights into the lived experience of rights holders. I asked a number of DPOs how they would go about making contact with the EHRC. For some DPOs who had pre-existing contacts this was relatively straightforward.⁷⁵³ However for others who did not have contacts, they reported that they had struggled to make contact.⁷⁵⁴ Furthermore three DPOs

⁷⁴⁹ HM Government, Building a Fairer Britain: Reform of the Equality and Human Rights Commission (HM Government, 2011).

⁷⁵⁰ Interview with Human Rights NGO (Lib) 24 March 2021

⁷⁵¹ *ibid*

⁷⁵² Interview with OfDP (Ph) 23 March 2021

⁷⁵³ Interview with DPO 22 March 2021

⁷⁵⁴ Interview with DPO 22 April 2021

reported negative experiences when they had sought to share experiences and evidence with the EHRC.⁷⁵⁵ One DPO reported, ‘We and other [DPOs] went to one meeting with them about three years ago and there was supposed to be follow up meetings but there never has been. Obviously this could easily be improved by them actually organizing some meetings or sending out a survey to organizations and groups to fill in’.⁷⁵⁶

DPOs highlighted that the absence of a designated disability unit within the EHRC had removed an obvious access point for DPOs.⁷⁵⁷ However it was acknowledged that EHRC staff working on disability had become more visible due to a number of engagement events relating to the EHRC human rights tracker, discussed below.⁷⁵⁸

A member of the EHRC-DAC interviewed for this research highlighted a concern that EHRC staff often considered that seeking the views of the EHRC-DAC as an alternative to engagement with the broader DPM.⁷⁵⁹ The minutes of the EHRC-DAC indicate that members have emphasised the need for the EHRC to engage with DPOs and include them in strategic gathering events.⁷⁶⁰ They have also, at times, emphasised the need to ensure that engagement with DPOs is meaningful.⁷⁶¹ A member of the EHRC-DAC interviewed for this research highlighted that the EHRC needed to develop ‘a clear understanding’ of their relationship with the DPM.⁷⁶²

5.7.2 Supporting the development of DPOs

The EHRC has a general statutory responsibility to promote awareness and understanding of human rights.⁷⁶³ It does not have a specific responsibility to support civil society.

⁷⁵⁵ Interview with DPO 12 May 2021

⁷⁵⁶ Ibid

⁷⁵⁷ DPO Written Submission 1

⁷⁵⁸ Correspondence on file with the author 19.03.2021

⁷⁵⁹ Interview with member of EHRC Disability Advisory Committee 13 May 2021

⁷⁶⁰ EHRC Disability Advisory Committee minutes of meeting on 31 May 2018

⁷⁶¹ EHRC Disability Advisory Committee minutes of meeting on 16 July 2020

⁷⁶² Interview with member of EHRC Disability Advisory Committee 13 May 2021

⁷⁶³ Equality Act 2006 section 9

Funding

When first established the EHRC operated a funding programme for CSOs concerned with promoting equality, diversity, good relations and human rights.⁷⁶⁴ Following a strategic review of the EHRC in 2011 this programme was brought to an end.⁷⁶⁵ A former EHRC Commissioner interviewed for this research considered that the programme gave the EHRC ‘a kind of traction with civil society’.⁷⁶⁶ Due to budgetary constraints the EHRC has limited capacity to provide funding to CSOs. However, the EHRC provided funding for a number of DPOs to attend the UNCRPD examination and one DPO interviewed for this research had received specific funding to develop legal fact sheets for disabled people.⁷⁶⁷

Training

The EHRC does not offer formal training to DPOs or other CSOs. In my evidence gathering I sought to explore the extent to which through its activities the EHRC were providing informal learning opportunities for DPOs.

I identified some examples of the EHRC involving disabled people and DPOs in informal ‘policy-oriented learning’ activities.⁷⁶⁸ In their approach to the UNCRPD examination the EHRC clearly attempted to share their expertise and strengthen the capacity of the UKDPM to engage in the examination process through involving DPOs in the drafting process and hosting engagement events. However, in the domestic context the EHRC representatives tended not to consider that they had a role in meeting the training needs of DPOs. EHRC representatives tended to consider that it supported DPOs through producing high quality research and analysis which DPOs could use to inform their own advocacy.⁷⁶⁹ The suitability of this approach was not clearly demonstrated. One DPO representative highlighted that DPOs often needed the support of the EHRC to ‘actually seek real change’.⁷⁷⁰

⁷⁶⁴ Section 17

⁷⁶⁵ IFF Research, ‘The Strategic Funding Programme: An Evaluation’ 07 March 2016 EHRC

⁷⁶⁶ Interview with former EHRC Commissioner 9 March 2021

⁷⁶⁷ Interview with DPO (IL) 22 March 2021

⁷⁶⁸ See discussion Chapter 4

⁷⁶⁹ Interview with former EHRC Commissioner 9 March 2021

⁷⁷⁰ Interview with DPO (IS) 28 April 2021

A member of the EHRC-DAC did highlight that participation in the EHRC-DAC provided individuals with personal development opportunities.⁷⁷¹ A number of members of the EHRC-DAC hold leadership positions within DPOs and their participation may therefore indirectly contribute to the capacity of their organisation. However as set out above the EHRC-DAC ceased operating in March 2022.

5.7.3 Steering the State: Formal participative structures

The UK Government has developed numerous participative mechanisms since ratification of the UNCRPD. In 2014 the ODI established a forum including DPOs and OfDPs. This forum was linked to the then UK disability strategy.⁷⁷² Interestingly, at the suggestion of members, the EHRC was included as an observer member of the forum.⁷⁷³ The forum met on a sporadic basis, meeting for the seventh and final time in November 2016.⁷⁷⁴ The failure to sustain the forum was considered to reflect a lack of commitment to the development of disability based policies and processes in the UK.⁷⁷⁵ The EHRC were not publicly vocal on the need to establish a replacement.

In July 2020, the Disability Unit established the Disabled People's Organisations Forum ('the Forum'). The Forum is intended to place the 'expertise of disabled people into the heart of government policy making'.⁷⁷⁶ The Forum is composed of DPOs and representatives from eight regional stakeholder networks, which the Unit also administers.⁷⁷⁷

It is notable that the Disability Unit does not appear to have sought the advice of the EHRC when developing the Forum. The EHRC are not included as an observer within the Forum. During my evidence gathering a number of DPOs who had been included in the Forum expressed concerns about its ways of working and indicated that they had disengaged from the Forum.⁷⁷⁸ DPOs highlighted that the Disability Unit had not made reasonable adjustments to

⁷⁷¹ Interview with member of the EHRC-DAC 4 May 2021

⁷⁷² Department for Works and Pensions, Fulfilling Potential: improving the lives of disabled people 2011

⁷⁷³ Office for Disability Issues, Minutes of the 4th Fulfilling Potential Forum 4 March 2015

⁷⁷⁴ Office for Disability Issues, Minutes of the 7th Fulfilling Potential Forum 2 November 2016

⁷⁷⁵ John Pring, Network neglect leaves government 'closer to coercion than co-production' 12th April 2018

⁷⁷⁶ Disability Unit, 'Disabled People's Organisations (DPOs) Forum Launches this Month' (20 July 2020)

<www.gov.uk/government/news/disabled-peoples-organisations-dpos-forum-launches-this-month> accessed 30 March 2021.

⁷⁷⁷ Disability Unit, 'Regional Stakeholder Network to Give Disabled People a Stronger Voice' (2 April 2020)

<www.gov.uk/government/news/regional-stakeholder-network-to-give-disabled-people-a-stronger-voice> accessed 30 March 2021.

⁷⁷⁸ Interview with DPO (IL) 22 March 2021

ensure that the meetings and information provided were accessible.⁷⁷⁹ Fazilet Hadi of the DPO DRUK highlighted that when addressing the Forum the Minister for Disabilities was in ‘broadcast mode’, presenting proposals in a finalised form rather than seeking views.⁷⁸⁰ Due to concerns relating to the Forum its operations were suspended in the spring of 2021.

The EHRC did not publicly raise concerns following the suspension of the Forum. In its advice on the then draft Disability Strategy, the EHRC highlighted concerns relating to the Disability Unit’s engagement activities. However, in their submission they do not offer advice on possible refinements to the Forum.⁷⁸¹ Notably, DPO leaders who disengaged from the Forum did not seek the support or assistance of the EHRC.⁷⁸² Overall it is notable that the EHRC has not been involved in advising on the design of the Forum and has not played a role in addressing concerns relating to its operation. Furthermore, DPO leaders have not requested the assistance of the EHRC in addressing their concerns relating to the Forum.

The UK Government published its Disability Strategy in July 2021, it is notable that the strategy does not acknowledge the role of the EHRC as an Independent Monitor. Furthermore, it does not make provision for the involvement of disabled people or DPOs in monitoring the strategy.⁷⁸³ Whilst DPOs have been critical of the final strategy the EHRC has not made public comments relating to the strategy.⁷⁸⁴

5.7.4 Steering the State: Informal Structures

Consistent with published literature eight of the nine DPOs interviewed for this case study felt that the main obstacle to them developing a constructive relationship with Government was the role of OfDPs, who continued to present themselves as the authentic voices of disabled people.⁷⁸⁵

My interviews with OfDPs broadly confirmed the view that they continued to be the preferred partners of Government. One OfDP reported that, ‘a lot of our engagement around the disability

⁷⁷⁹ Side Event: 13th Conference of States Parties to the CRPD-Independent Monitoring Mechanisms: How to establish them inclusively. Comments by Dr Ruth Warwick IDA

⁷⁸⁰ WEC Committee, Fourth report: Unequal impact? Coronavirus, disability and access to services 2020 HC 1050

⁷⁸¹ EHRC Briefing on Disability Strategy 2021 para 21

⁷⁸² Interview with DPO (DPA) 12 May 2021

⁷⁸³ Department of Works and Pensions, National Disability Strategy 2021 CP 512

⁷⁸⁴ John Pring, ‘Outrage over ‘rehashed’ strategy that is ‘not fit for purpose’ 30th July 2021 Disability News Service

<https://www.disabilitynewsservice.com/national-disability-strategy-outrage-over-rehashed-strategy-that-is-not-fit-for-purpose/>

⁷⁸⁵ Interview with DPO (Ber) 22 April 2021

strategy is actually taking place through the Minister for Disabled People and senior officials'.⁷⁸⁶ The interviewee highlighted that the Disabilities Charity Consortium provided a collective voice for OfDPs that facilitated engagement with Government.⁷⁸⁷ The Minister for Disabilities in statements to Parliament regularly highlights engagement with the Disabilities Charity Consortium.⁷⁸⁸ It is notable that outsider tactics, in particular, protests organized by DPOs appear to have actually reinforced the position of OfDP. For instance, one OfDP noted that protests by DPOs relating to social security reforms had led the Government to seek the advice of the Disabilities Charity Consortium rather than engage with the DPOs organizing the protests.⁷⁸⁹

In my evidence gathering I sought to determine if the EHRC was highlighting that DPOs are the authentic voice of disabled people. Three of the nine DPOs interviewed indicated that the EHRC was playing a role in promoting engagement with DPOs over OfDPs. One DPO stated, 'They are trying to get us a place at the table when kind of we ask them'.⁷⁹⁰ Four of the nine DPOs interviewed for this research strongly felt that the EHRC should be more outspoken in challenging attempts by OfDPs to speak on behalf of disabled people. In the words of one DPO leader, 'the very nature of the way that [OfDPs] operate contradicts the UNCRPD. So, therefore the EHRC do have a duty to intervene, really and truly'.⁷⁹¹ A former EHRC Commissioner interviewed for this research was reluctant for the EHRC to take on such a role, highlighting that civil society is inevitably a very contested space.⁷⁹² A member of the EHRC-DAC stated, 'I don't think it's the role of the NHRI to say categorically, that [organisation] doesn't speak for disabled people, because I think that gets into a messy and distracting platform of, how do you represent the views of the disabled people's community'.⁷⁹³ Given that the UNCRPD makes clear that priority should be given to organisations who are truly representative of disabled people the approach of the EHRC is not consistent with their responsibility to reflect international human rights standards.

⁷⁸⁶ Interview with OfDP 28 April 2021

⁷⁸⁷ *ibid*

⁷⁸⁸ Minister for Disabilities, Correspondence to Social Security Advisory Committee 5 January 2021

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/985165/minister-response-ssac-occasional-paper-25-how-dwp-involves-disabled-people-when-developing-or-evaluating-programmes-that-affect-them.pdf (Accessed on 2 June 2022)

⁷⁸⁹ Interview with OfDP 21 April 2021

⁷⁹⁰ Interview with DPO (IL) 22 March 2021

⁷⁹¹ Interview with DPO (Alf) 26 April 2021

⁷⁹² Interview with member of EHRC Disability Advisory Committee 15 February 2021

⁷⁹³ Interview with former EHRC Commissioner 9 March 2021

5.7.5 Convening Role

Whilst reluctant to become involved in a role critiquing or denouncing CSOs, EHRC representatives emphasised the potential ‘convening power’ of the EHRC.⁷⁹⁴ This is not a statutory power. A convening power is a rather open-ended concept, which is broadly defined as the power to create a space which brings people together to have a dialogue and reach understanding.⁷⁹⁵ The EHRC has in the past used its ‘convening power’ to bring together polarised segments of civil society.⁷⁹⁶ It was considered that the EHRC could bring CSOs ‘together forcing a space to discuss issues’.⁷⁹⁷

I explored with interviewees whether the EHRC could potentially play a role in bringing together OfDPs and DPOs. The two OfDP who were members of the Disability Charity Consortium emphasised that they would welcome an attempt by the EHRC to convene or develop a meeting space for DPOs and OfDPs. OfDP representatives highlighted that they had made significant efforts to increase the involvement of disabled people in the management and control of their organisations and suggested that many of the characterisations of OfDPs were outdated.⁷⁹⁸ The views of DPOs were mixed. Overall, DPOs felt that divisions between DPOs and OfDPs are deep, and that attempts to convene the two groupings were unlikely to bear fruit.⁷⁹⁹ One DPO felt that the EHRC would have to develop its own credibility before embarking on this activity.⁸⁰⁰

A number of DPOs highlighted disputes within the movement over tactics had led to divisions amongst DPOs. Ellen Clifford, a disability activist associated with ROFA has been critical of DPOs engaging with the current Conservative UK Government suggesting such DPOs have ‘clearly failed to grasp the nature of the government’.⁸⁰¹ DPOs who engage in insider tactics noted that they were often criticized by members of ROFA and it was broadly considered that there was a need for a coordinated collaboration within the movement.⁸⁰² A member of the EHRC-DAC suggested that the EHRC could potentially play a role in bringing together DPOs

⁷⁹⁴ *ibid*

⁷⁹⁵ UN Press Release, United Nations Convening Power Unites People, Its Impartiality Bridges Deep Divides, Says Secretary-General on International Day of Democracy 16 September 2009

⁷⁹⁶ Interview with former EHRC Commissioner 9 March 2021

⁷⁹⁷ Interview with member of EHRC Disability Advisory Committee 15 February 2021

⁷⁹⁸ Interview with Disability Charity (men) 28 April 2021

⁷⁹⁹ Interview with DPO (Ma)

⁸⁰⁰ Interview with DPO (DA)

⁸⁰¹ Ellen Clifford, *The War on Disabled People* (Zed Books 2020), p. 275

⁸⁰² Interview with DPO (DA)

and in highlighting the legitimacy of DPOs engaging in a range of influencing tactics.⁸⁰³ DPOs again were sceptical of the potential for the EHRC to play a convening role in bringing together DPOs with different perspectives. DPOs generally felt that the DPM needed to resolve its conflicts itself.⁸⁰⁴ Indeed I note that in June 2021 a new coalition of DPOs emerged inclusive of DPOs who shared a range of views on engagement approaches.⁸⁰⁵ The EHRC were not involved in this initiative. However, through providing funding for activities relating to the UNCRPD Committee examination process the EHRC potentially facilitated the growth of connections between DPOs who have gone on to form the coalition.

In my evidence gathering I observed that DPOs who had chosen to prioritise outsider tactics and had ceased engaging with the Government, continued to engage with the EHRC. In fact, every DPO interviewed for this research wished for more engagement with the EHRC. Therefore, it appears that the EHRC continues to provide a bridge to engagement in the policy making process to those DPOs who have chosen not to engage with Government. This will be explored in my concluding chapter.

5.7.6 Monitoring support for DPOs

In my evidence gathering I sought to determine if the EHRC was monitoring whether funding and policy frameworks were enabling the development of DPOs.

The UK Government Civil Society strategy provides that the Government seeks to provide ‘civil society significant opportunities to achieve policy change’.⁸⁰⁶ In this strategy the UK Government emphasise that it creates opportunities for CSOs to engage in the policy making process, but it does suggest that Government will support CSOs to participate in the policy making process through the provision of funding or capacity building.⁸⁰⁷ The UK Government responded to the UNCRPD Committee’s call for evidence on draft GC 7. In its submission the Government suggested that the Committee qualify their suggestion that the state provide funding to DPOs as ‘state resources are not unlimited’.⁸⁰⁸ In contrast to corporatist states the

⁸⁰³ Interview with member of EHRC Disability Advisory Committee 15 February 2021

⁸⁰⁴ Interview with DPO representative (Alf) 26 April 2021

⁸⁰⁵ John Pring, DPOs take control after Tomlinson ‘shuts down his own forum’ 3 June 2021, Available at: <https://www.disabilitynewsservice.com/dpos-take-control-after-tomlinson-shuts-down-his-own-forum/> (Accessed on 2 June 2022)

⁸⁰⁶ UK Government Civil Society Strategy: building a future that works for everyone August 2018

⁸⁰⁷ UK, National Action Plan for Open Government 2019-2021 12 June 2019

⁸⁰⁸ UK Government, ‘Comments of the Government of the United Kingdom of Great Britain and Northern Ireland Draft General Comment No.7 on Articles 4.3 and 33.3’ 2018, Available at < <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no7-article-43-and-333-participation>> (Accessed on 2 April 2022)

UK Government are strongly of the view that the state should not provide funding to assist CSOs to engage in advocacy activities.

DPOs consistently highlighted the lack of funding to support national advocacy or campaigning activities. One DPO stated ‘you can’t apply for funding if you’re a campaigning organisation. So, there’s lots of criteria that restrict disabled people’s voices’.⁸⁰⁹ Organisations involved in the provision of services under contract reported that contracting arrangements continued to restrict them from engaging in advocacy.⁸¹⁰ One DPO involved in the provision of services who chose not to participate in this research highlighted that they had to limit their involvement in rights advocacy.⁸¹¹ The absence of funding undermines the capacity of DPOs to advocate for the normative reforms necessary to bring about compliance with the UNCRPD, for example concerning inclusive education.⁸¹² One DPO highlighted that the UK’s exit from the EU has removed an important source of funding for DPOs.⁸¹³

Charitable trusts are often a source of funding for the advocacy and campaigning activities of CSOs in the UK.⁸¹⁴ Whilst I identified some examples of DPOs successfully obtaining funding from charitable trusts, DPOs in general reported that they found their funding programmes inaccessible.⁸¹⁵ In contrast, OfDPs reported that whilst the process of applying for funding from charitable trusts was complex, they were often successful. One CEO of a OfDP, who had recently secured funding, set out the factors behind the successful funding application, noting, ‘Partly I was able to get into the room because I was at [a large OfDP] and they had forged this relationship with the Foundation. Could disabled people organisations do it? A lot of it is word of mouth and so it is about gradually building your reputation’.⁸¹⁶ It therefore appears that OfDPs are at a significant advantage when it comes to competing with DPOs to gain access to a main source of funding for advocacy activities in the UK. DPOs tended to report that charitable foundations in the UK did not seek to prioritise the funding of advocacy by DPOs over OfDPs.⁸¹⁷

⁸⁰⁹ Interview with DPO (Alf) 26 April 2021

⁸¹⁰ Interview with OfDP 23 March 2021

⁸¹¹ Correspondence on file with the author

⁸¹² Interview with DPO (AL) 26 April 2021

⁸¹³ Interview with DPO (DA) 5 May 2021

⁸¹⁴ Interview with Human Rights NGO (AI) 19 March 2021

⁸¹⁵ Interview with DPO (DA) 5 May 2021

⁸¹⁶ Interview with Disability Charity (stra) 30 April 2021

⁸¹⁷ Interview with DPO (mh) 22 April 2021 and Interview with DPO (DA) 5 May 2021

There is limited evidence of the EHRC or UKIM monitoring or critically assessing the availability of funding to support DPO's advocacy activities. The EHRC has commissioned research identifying the impact of the loss of EU funding on civil society, including DPOs.⁸¹⁸ However, overall, the EHRC has not adopted a systematic approach to monitoring the availability of public funding or charitable funding to support the advocacy efforts of DPOs. For instance, it is notable that funding issues were not highlighted in the EHRC's briefing on the disability strategy or within its human rights tracker.⁸¹⁹ UKIM representatives highlighted that other bodies existed in the UK which reviewed funding available to civil society and spoke on their behalf, in particular the National Council for Voluntary Organisation.⁸²⁰

In relation to the policy framework two of the nine DPOs interviewed raised concerns that the Lobbying Act 2014 had constrained the ability of DPOs to engage in lobbying, as it had other charitable organisations.⁸²¹ The EHRC has not publicly raised concerns relating to the impact of the Lobbying Act. During my evidence gathering a Bill was progressing through Parliament imposing limitations on the right to protest. The EHRC has raised concerns at the impact of proposed restrictions on the right to protest.⁸²² However, it has not sought to engage with DPOs and other CSOs who engage in protests, whose activities will be curtailed as a result of the legislation.⁸²³

5.7.7 Supporting participation in the international human rights international system

In 2013 DPAC, amongst others, petitioned the UNCRPD Committee to conduct an inquiry into the impact of social security reforms in the UK on the rights of disabled people.⁸²⁴ The Committee launched an inquiry in 2015 finding that the reforms cumulatively amounted to 'grave and systemic violations'.⁸²⁵ The inquiry involved a visit to the UK during which DPOs throughout the UK met with the UNCRPD Committee.

⁸¹⁸ Interview with DPO (ED) 16 April 2021

⁸¹⁹ EHRC, Briefing on Development of National Disability Strategy 12 February 2021

⁸²⁰ Interview with SHRC Representatives 18 March 2021

⁸²¹ Interview with DPO (DA) 5 May 2021

⁸²² EHRC Briefing Police, Crime, Sentencing and Courts Bill July 2021

⁸²³ Interview with DPO (DPA) 12 May 2021

⁸²⁴ Crowther N., Sayce L, Was Ratification of the CRPD the High Watermark for United Kingdom Disability Rights? Ten Years of Monitoring Implementation of the CRPD. in Emily Kakoullis and Kelly Johnson (eds) *Recognising Human Rights in Different Cultural Contexts*. (Palgrave Macmillan 2020), p. 43

⁸²⁵ Committee on the Rights of Persons with Disabilities, Inquiry concerning the UK, 2016, CRPD/C/15/R.2/Rev.1 2016, par. 5, 13

As the Committee conducted its inquiry, it engaged with the UKIM and received numerous briefings. The UKIM supported the Committee's visit to the UK and facilitated their engagement with DPOs and civil society. The UNCRPD Committee in their inquiry report thanked the EHRC for their assistance throughout the inquiry.⁸²⁶ A member of the UNCRPD Committee secretariat interviewed for this research highlighted that the support provided by UKIM was valuable and assisted the Committee in connecting with key DPOs.⁸²⁷ One DPO interviewed for this research pointed out that a meeting space provided by the EHRC for engagement between DPOs and the Committee was not fully accessible. However, DPOs in general were complimentary of the EHRC's approach to the inquiry.⁸²⁸ The inquiry report of the UNCRPD Committee was clearly informed by the submissions from the EHRC, with extensive reference to the EHRC research relating to cumulative impact assessments.⁸²⁹ UKIM has highlighted the need for the UK Government to address the report recommendations.⁸³⁰

The UNCRPD Committee examined the UK's initial report on compliance with the UNCRPD in 2017. As part of UKIM the EHRC coordinated its engagement with the other UK Commissions. In preparing its report for the examination the EHRC held stakeholder engagement events in Wales, Scotland and England.⁸³¹ The purpose of these events was to share approaches and also to assist DPOs who were developing their own submissions. The EHRC funded a DPO coalition to produce an independent report for the UNCRPD Committee pre-sessional working group in March 2017.⁸³²

DPOs interviewed for this research were generally complimentary of the EHRC's approach to the UNCRPD examination. It is noted that an early attempt by DPOs to come together and agree a disability wide submission was unsuccessful.⁸³³ The provision of funding by the EHRC provided an incentive for DPOs to come together and agree a joint submission. One of the recipients of the funding, highlighted that the process of developing a shadow report provided an opportunity for the movement to discuss key issues of concern.⁸³⁴ The development of a

⁸²⁶ Ibid

⁸²⁷ Interview with CRPD Committee Representative 26 November 2020

⁸²⁸ Correspondence on file with the author

⁸²⁹ CRPPD Committee 'Inquiry Report' (n. 777) para 86

⁸³⁰ UKIM, Key concerns of the UK Independent Mechanism following the release of the CRPD Committee's inquiry (EHRC 2017)

⁸³¹ UK Independent Mechanism, Updated submission to the UN Committee on the Rights of Persons with Disabilities in advance of the public examination of the UK's implementation of the UN CRPD, 2017

⁸³² Disability Rights UK and Disability Wales (2017), 'Implementation of the UN CRPD in England and Wales shadow report'..]

⁸³³ Interview with Disability Advocate 19 March 2021

⁸³⁴ Interview with DPO 28 April 2021

joint submission was considered a positive measure, which was unlikely to have happened without the intervention by the EHRC.⁸³⁵

The EHRC also provided funding to a number of DPOs to facilitate their attendance at the State Dialogue. Perhaps unsurprisingly recipients of this funding were generally complimentary of the provision of funding by EHRC.⁸³⁶ In addition, DPOs were generally complimentary of the EHRC's approach to the state dialogue. Indeed, at a side event to the 2020 Conference of State Parties the approach of UKIM to the state dialogue was highlighted as an example of good practice by the International Disability Alliance.⁸³⁷ Following the publication of the UNCRPD Committee concluding observations on the UK the EHRC published an easy read version, making the recommendations more accessible to disabled people and DPOs.⁸³⁸

A human rights NGO interviewed for this research highlighted that in preparation for treaty body examination processes the EHRC had established itself as 'a centre point for engagement' for civil society.⁸³⁹ The EHRC have taken some measures to ensure the participation of DPOs in international human rights examinations beyond the UNCRPD. For instance, providing funding for DPOs to attend the Convention on the Elimination of Discrimination Against Women ('CEDAW') examination.⁸⁴⁰ However the EHRC has not developed a systematic approach to supporting DPOs to participate across the UN system.

In 2019, the EHRC launched an online tracker recording the UK's compliance with recommendations from the international human rights system.⁸⁴¹ The tracker was designed as a 'means of assessing what the gaps between our international commitments were and domestic legislation'.⁸⁴² Building on treaty body recommendations the tracker provides more detail on policy developments required to bring about human rights compliance. The tracker was specifically designed to provide a resource for civil society. The EHRC has provided briefings to civil society, including DPOs on utilizing the tracker.⁸⁴³ DPOs were aware of the tracker and

⁸³⁵ Ibid

⁸³⁶ Correspondence on file with the author

⁸³⁷ IDA (n. 119)

⁸³⁸ EHRC, 'How is the UK performing on disability rights' 2017. Available at:

https://www.equalityhumanrights.com/sites/default/files/ehrc_un_crpd_report.pdf (Accessed 27 May 2021)

⁸³⁹ Interview with Human Rights NGO (AI) 19 March 2021

⁸⁴⁰ Correspondence on file with the author

⁸⁴¹ EHRC, 'First ever UK human rights tracker' available at: <https://www.equalityhumanrights.com/en/our-work/news/first-ever-uk-human-rights-tracker-launched> (Accessed on 2 April 2022)

⁸⁴² Interview with former EHRC Commissioner 9 March 2021

⁸⁴³ DPO Email Submission 2

were broadly complimentary of the initiative.⁸⁴⁴ However, I note that DPOs and others CSOs were not invited to contribute to the assessments contained in the tracker. Whilst this is a welcome resource the lack of involvement of DPOs in making the assessments seems to be a missed opportunity. This will be discussed in my concluding chapter.

5.7.8 Provision of Advice on law reform proposals

I explored with DPOs whether they were content with the advice provided by the EHRC. A number of interviewees suggested that the EHRC was not fully reflecting the UNCRPD in its advice documents.⁸⁴⁵ To inform my analysis I critically assessed policy advice relating to disability rights produced by the EHRC over the past ten years. I found that the EHRC has often failed to provide comment on important policy discussions relating to the rights of disabled people. For instance, the EHRC did not provide advice to a Parliamentary Committee established to scrutinize the operation of the Mental Capacity Act 2006.⁸⁴⁶ Where the EHRC has provided advice on policy issues relating to disabled people's rights I found that there was often a need for the EHRC to provide specific advice on reforms required to bring about compliance with the UNCRPD. For instance, in its submission to a Parliamentary Committee inquiry relating to the introduction of additional safeguards when an individual with a mental health condition is deprived of their liberty deprivation, the EHRC simply set out relevant provisions of the UNCRPD without exploring how they could be operationalized within the proposed reforms.⁸⁴⁷ In responding to this inquiry, the EHRC did not appear to have coordinated their engagement with the Parliamentary Committee with DPOs.

All DPOs interviewed for this research expressed a desire to collaborate more with the EHRC when engaging in domestic policy discussions and consultation processes. Two of the nine DPOs interviewed suggested that they had attempted to engage with the EHRC to discuss proposed reforms and found them either unresponsive or unhelpful.⁸⁴⁸ When developing its advice or policy submissions the EHRC does not tend to seek input from CSOs. In relation to disability policy whilst the EHRC policy staff often sought inputs from the EHRC-DAC they

⁸⁴⁴ Interview with DPO (IS) 28 April 2021

⁸⁴⁵ Interview with Human Rights NGO (Lib) 24 March 2021, Interview with Alfie

⁸⁴⁶ House of Lords Select Committee, Mental Capacity Act 2005: post-legislative scrutiny 2014, HL Paper 139

⁸⁴⁷ See for example EHRC 'Response to the Select Committee Inquiry the Right to Freedom and Safety: Reform of the Deprivation of Liberty Safeguards' March 2018, paras 11-21

⁸⁴⁸ Interview with member of EHRC Disability Advisory Committee 13 May 2021

do not routinely seek inputs from DPOs.⁸⁴⁹ However, the EHRC does seek to make their advice readily available to DPOs. For instance, the EHRC publicized its advice on the draft Disability Strategy in the hope that their analysis would inform submissions by DPOs and others. One DPO highlighted that the EHRC briefing provided useful insights.⁸⁵⁰

I found that the EHRC were more willing to adopt participative approaches when developing proposals for law reform. In 2020 the EHRC with reference to recommendations from the UNCRPD Committee determined that there was sustained or severe regression in the enjoyment of the right to independent living.⁸⁵¹ To address this, in July 2020 the EHRC submitted a briefing to the JCHR setting out initial draft proposals for the right to independent living to be enshrined in UK law.⁸⁵² These proposals were developed by the EHRC in conjunction with a number of DPOs and disability advocates.⁸⁵³ This appears to be a positive example of the EHRC sharing its expertise and resources to develop proposals for the implementation of the UNCRPD. However, an interviewee involved in this project voiced concern that whilst the EHRC had invested in the development of the proposal it appeared to be reluctant to collaborate with DPOs and OfDPs in advocating strongly for the proposal to be adopted.⁸⁵⁴

5.7.9 Research

The EHRC engages in a range of research activities. On a periodic basis the EHRC publishes a wide-ranging report tracking progress on human rights and equality matters against an equality and human rights framework.⁸⁵⁵ The report brings together a range of relevant statistics to identify trends in the enjoyment of human rights.⁸⁵⁶ For instance, the report analyses statistics on the number of disabled people appointed to public bodies. The 2018 report raised concern regarding the scarcity of primary quantitative data to inform their analysis in several areas.⁸⁵⁷ The EHRC research reports are often utilised by DPOs and OfDP to inform

⁸⁴⁹ *ibid*

⁸⁵⁰ EHRC 'Briefing on Disability Strategy' February 2021

⁸⁵¹ EHRC 'Tracker Home' available at: <https://humanrightstracker.com/en/progress-assessment/independent-living-uk-government-assessment/> (accessed 27 May 2021)

⁸⁵² EHRC, 'Evidence to the Joint Committee on Human Rights inquiry on the Government's response to Covid-19: human rights implications Adult social care and the right to independent living' 13 July 2020

⁸⁵³ Interview with Human Rights NGO (Lib) 24 March 2021

⁸⁵⁴ Interview with Disability Advocate 19 March 2021

⁸⁵⁵ Jean Candler, Holly Holder, Sanchita Hosali, Anne Maree Payne, Tiffany Tsang and Polly Vizard, Human Rights Measurement Framework: Prototype panels, indicator set and evidence (EHRC 2011)

⁸⁵⁶ EHRC 'Is Britain Fairer? The state of equality and human rights' (EHRC 2018)

⁸⁵⁷ *Ibid* p. 199

their submissions and reports.⁸⁵⁸ DPOs were generally complimentary of the EHRC's research reports.⁸⁵⁹

The EHRC has also collaborated with DPOs in developing new approaches to data analysis. In 2012, DPOs called on the Government to conduct a cumulative impact assessment into the impact of social security cuts on disabled people.⁸⁶⁰ The UK Government responded to this call by suggesting that it was not possible to accurately conduct cumulative impact assessments and noted that 'external organisations have not produced this either'.⁸⁶¹ DPOs raised this issue with the EHRC, who funded a research project which developed a methodology for conducting cumulative impact assessments.⁸⁶² The EHRC, in conjunction with DPOs, promoted this methodology both to Government and the UNCRPD Committee.⁸⁶³ This methodology was shared with other members of the UKIM who replicated the project in Northern Ireland.

This research project was highlighted by three DPOs as a positive example of the EHRC developing a new methodology of statistical analysis which provided new insights on the impact of public policies on disabled people.⁸⁶⁴ A representative of UKIM highlighted that by utilizing contacts within Government and within academia the EHRC and UKIM were able to add value and validate the claims of DPOs.⁸⁶⁵ This analysis authoritatively recorded that disparities between disabled people and the non-disabled were increasing and demonstrated the feasibility of cumulative impact assessments.⁸⁶⁶ Utilizing the EHRC research, DPOs engaged with Parliamentarians to secure a further debate on the impact of social security reforms on disabled people.⁸⁶⁷

In my evidence gathering, I sought to discover whether the EHRC is supporting the development of new approaches to primary data collection in line with Article 31. I discovered that at times the EHRC has worked with the Office of National Statistics to improve its

⁸⁵⁸ Inclusion London, 'Response to the EHRC's draft strategic plan 2019-2022' (Inclusion London 2019)

⁸⁵⁹ Interview with DPO (IL) 22 March 2021

⁸⁶⁰ Disability Support— in the House of Commons at 6:54 pm on 19th December 2018. HC Deb, 19 December 2018, c907

⁸⁶¹ Ibid

⁸⁶² EHRC 'Submission to Welfare Reform Bill Public Bill Committee', Session 2010-12 (WR50)

⁸⁶³ Jed Meers, 'The 'cumulative impact' problem in social welfare: some legal, policy and theoretical solutions' [2022 *Journal of Social Welfare and Family Law*] 42, p. 50

⁸⁶⁴ Interview with DPO (IL) 22 March 2021

⁸⁶⁵ Interview with NIHR UKIM Member 12 January 2021

⁸⁶⁶ EHRC 'Is Britain Fairer? The state of equality and human rights' 25 Oct 2018

⁸⁶⁷ Disability Support— in the House of Commons at 6:54 pm on 19th December 2018. HC Deb, 19 December 2018, c907

processes for developing primary quantitative data.⁸⁶⁸ However, the EHRC has not been included in important discussions relating to disability evidence gathering.

One of the objectives of the Disability Unit is to improve the quality of evidence and data to support policymaking. In furtherance of this objective the Disability Unit has commissioned Leeds University and the DPO Disability Rights UK to conduct research into the lived experience of disabled people in the UK.⁸⁶⁹ The EHRC has not been involved in this initiative. Whilst the EHRC engaged with the ODI on the development of data collection processes, the EHRC has not collaborated with the Disability Unit in improving disability data collection.⁸⁷⁰ If the EHRC is not well placed to shape data collection systems this may limit its capacity to monitor compliance with the UNCRPD.

During my evidence gathering the EHRC was in the process of developing a new strategic plan. During a Commission Board meeting it was agreed that, ‘the Commission should gather evidence and data then fill in the gaps with lived experience, but be mindful that when the evidence/data is not available, lived experience should be considered as subjective data’.⁸⁷¹ The view of the EHRC on the value of lived experience may pose a challenge to collaboration with DPOs.⁸⁷² This comment reflects a broader change in strategic direction within the EHRC which is considered to place less emphasis on the views of CSOs which it has previously collaborated with.⁸⁷³ This strategic re-direction is considered to have contributed to deteriorating relations between the EHRC and a number of CSOs who have raised their concerns with GANHRI, discussed above.

5.7.10 Equality Regulator – Policy Making process

The role of the EHRC as an equality regulator is broad ranging, in this section I will consider its role in line with the relevant provisions of the Equality Act 2010.

⁸⁶⁸ Sylvia Walby, Jo Armstrong, Les Humphreys ‘Research Report No. 1 Review of equality statistics’ (EHRC 2008)

⁸⁶⁹ UK Government Procurement Office ‘Provision of a Systematic Review of the Lived Experience of Disabled People in the UK’ CCZZ21A07 (4 March 2021)

⁸⁷⁰ Presentation by Marc Verlot to DARE Public Event, ‘Engaging Disability Research for Policy Reform’, 29 October 2020 <<https://www.youtube.com/watch?v=UXmypsF08Cg&feature=youtu.be>> Accessed 9 November 2020.

⁸⁷¹ EHRC, Minutes of the 94th meeting of the Board of the EHRC, 2021

⁸⁷² CRPD Committee (n. 62) para 9

⁸⁷³ Harroon Sidique, ‘EHRC undermined by pressure to support No 10 agenda, says ex-chair’, (London Guardian) 18 January 2021

Reasonable Adjustment : Funding litigation

The duty to make reasonable adjustments for disabled people is now contained in section 20 of the Equality Act 2010. When campaigning for the right to reasonable adjustments the UKDPM consistently highlighted the need for an enforcement mechanism to ensure that rights are realised in practice. The EHRC has unique powers to apply to the court to obtain an order stating that an individual has failed to make reasonable adjustments. As an alternative it may enter into legal agreements with such individuals who undertake not to commit unlawful acts and refrain from specified acts.⁸⁷⁴

The effectiveness of the EHRC as an equality regulator is often a subject of discussion, with a number of Parliamentary inquiries considering this matter.⁸⁷⁵ Three of the nine DPOs and one of the human rights NGOs interviewed for this research felt that the EHRC is not sufficiently proactive in its role as a regulator.⁸⁷⁶ A number of DPO representatives suggested that there was a lack of appreciation across the public sector, in particular at local authority level, of the role of the EHRC as an equality regulator.⁸⁷⁷ DPOs consistently suggested that there was a need for the EHRC to address discriminatory acts through court action. One DPO representative stated ‘because they don’t enforce anything people don’t carry out their equality duties’.⁸⁷⁸

An EHRC representative highlighted that a focus on the number of cases brought was unhelpful as the EHRC sought to resolve disputes without recourse to the courts.⁸⁷⁹ In my analysis of the EHRC’s use of its regulatory powers I identified several examples of the EHRC entering into legal agreements with public and private sector bodies to address discriminatory action against disabled people. For instance, in January 2021 the EHRC entered into a legal agreement with Network Rail to make reasonable adjustments for disabled passenger using Manchester Victoria station.⁸⁸⁰ A representative of a Human Rights NGO with experience of litigation highlighted that the EHRC has often engaged in constructive follow up work where litigation has settled.⁸⁸¹

⁸⁷⁴ Equality Act 2010 section 23

⁸⁷⁵ House of Lords, Select Committee on the Equality Act 2010 and Disability ‘The Equality Act 2010: the impact on disabled people’ Report of Session 2015-16 - published 24 March 2016 - HL Paper 117

⁸⁷⁶ Interview with DPO (HC) 17 March 2021

⁸⁷⁷ Interview with DPO (Man) 11 May 2021

⁸⁷⁸ Interview with DPO (HC) 17 March 2021

⁸⁷⁹ Interview with former EHRC Commissioner 9 March 2021

⁸⁸⁰ EHRC Press Release Network Rail signs agreement to prevent discrimination against disabled people (14 January 2021)

⁸⁸¹ Interview with Human Rights NGO (Lib) 24 March 2021

The EHRC may assist an individual bringing legal proceedings relating to the 2010 Act, including in proceedings in which they allege that an individual or organisation has failed to meet their obligation to make reasonable adjustments.⁸⁸² The EHRC litigation policy provides that only individuals who have initiated proceedings and who are legally represented can apply for support.⁸⁸³ A number of DPO representatives were critical of this approach highlighting that only a small number of ‘privileged people’ had the capacity to initiate litigation.⁸⁸⁴ One DPO highlighted that the EHRC’s approach did little to shield disabled people from the emotional and financial pressure of seeking recourse through the courts.⁸⁸⁵ Despite this criticism, in my evidence gathering I identified a number of examples of the EHRC funding strategic cases which had led to important legal precedents broadening existing protections for disabled people, in particular in relation to the participation of deaf jurors.⁸⁸⁶

On being appointed Chair of the EHRC in 2017, David Isaac announced his intention to transform the EHRC into a ‘more muscular regulator’.⁸⁸⁷ As part of this new approach the EHRC launched a litigation support project to support individuals to bring litigation.⁸⁸⁸ When initially established the fund prioritised supporting disabled people, providing support in 94 cases. The project now focuses on supporting victims of racial harassment and discrimination to bring litigation.⁸⁸⁹ The EHRC’s need to prioritise certain areas of law reflects the lack of funding available to the EHRC.

The EHRC has lobbied Government and Parliament to increase its funding and to strengthen its powers as a regulator to make it more effective.⁸⁹⁰ These attempts have proven ineffective. It is notable that the EHRC has not sought to engage with DPOs and other CSOs to explain the challenges and seek their support in engaging with Government and Parliament on their regulatory powers and funding.

⁸⁸² Equality Act 2010 section 28

⁸⁸³ EHRC, Our litigation and enforcement policy 2019 to 2022 (EHRC 2019)

⁸⁸⁴ Interview with DPO (IL) 22 March 2021

⁸⁸⁵ Interview with DPO (Ber) 22 April 2021

⁸⁸⁶ John Pring, Deaf campaigner takes court action over BSL jury ban Disability News Service 23rd August 2018

⁸⁸⁷ David Isaac ‘Prioritising our legal work’ 12 April 2017 (London EHRC) <<https://www.equalityhumanrights.com/en/our-work/blogs/prioritising-our-legal-work>> (Accessed 21 February 2022)

⁸⁸⁸ EHRC Legal support scheme <<https://www.equalityhumanrights.com/en/gwaith-achos-cyfreithiol/legal-support-project-helping-people-get-legal-assistance>> (Accessed 21 February 2022)

⁸⁸⁹ *ibid*

⁸⁹⁰ WEC ‘Enforcing the Equality Act: The law and the role of the EHRC’ (HC 1470) 2019

Reasonable Adjustment: Code of Practice

One of the EHRC's unique powers as a regulator is its ability to issue a code of practice relating to any matter under the Equality Act 2010.⁸⁹¹ In 2017, DPOs and OfDPs influenced a House of Lords Committee which recommended that the EHRC prepare a specific Code of Practice on reasonable adjustments to supplement the existing Equality Act Codes.⁸⁹² The minutes of the EHRC-DAC indicate its support for this recommendation.⁸⁹³ However, the EHRC wrote to the House of Lords rejecting this recommendation citing the existence of general guidance.⁸⁹⁴

The need for specific guidance on the reasonable adjustment duty has risen to prominence with respect to access to retail premises for disabled people during the Coronavirus pandemic. In light of concerns raised by disabled people, the EHRC issued new guidance on the responsibility of food retailers to make reasonable adjustments on 3 September 2020.⁸⁹⁵ Whilst the guidance was grounded in the context of the coronavirus pandemic, much of it is generic. The need for completely new guidance largely vindicates the view of DPOs and the EHRC-DAC that further guidance relating to reasonable adjustments was necessary. A member of EHRC-DAC interviewed for this research suggested that the incident demonstrated the need for the EHRC to be more receptive to the views of DPOs and the EHRC-DAC when exercising their regulatory powers.⁸⁹⁶

Public Sector Equality Duty

The Equality Act 2010 places an obligation on public authorities in the UK to have 'due regard' to the need to eliminate discrimination, advance equality of opportunity and to foster good relations between persons who share a relevant protected characteristic, including disabled people.⁸⁹⁷ The EHRC may investigate the extent to which a public authority has complied with the Public Sector Equality Duty ('PSED'). Based on which it may issue a compliance notice requiring action.⁸⁹⁸

⁸⁹¹ Section 14(1)

⁸⁹² House of Lords Select Committee, Report on the Equality Act 2010's impact on disabled people, (HL 117) 2017, para 231

⁸⁹³ EHRC Disability Advisory Committee meeting minutes July 2018, para 9.3

⁸⁹⁴ Ibid

⁸⁹⁵ EHRC Press Release, 'New guidance calls for retailers to do more to help disabled customers' (3 September 2020)

⁸⁹⁶ Interview with DPO (DPA) 12 May 2021

⁸⁹⁷ Equality Act 2010 Section 149

⁸⁹⁸ Equality Act 2006 Section 32

In 2012, the Government reviewed the PSED as part of the ‘Red Tape Challenge’ which sought to reform or remove bureaucratic burdens on government and business.⁸⁹⁹ Whilst it was originally anticipated that this review may result in the abolition of the PSED, a NGO representative interviewed for this research highlighted that public sector policy makers in responding to the review were of the view that the PSED encouraged them to ‘genuinely focus our minds in the way it was intended which is before you implement a policy or before you finalise a decision you look forward at the adverse impact on people with protected characteristics’.⁹⁰⁰ Whilst the PSED was not abolished during the Red Tape Challenge, many DPOs felt that following the review Government Departments have become less officious in the execution of the duty.⁹⁰¹ A number of DPOs felt that the EHRC were not active in countering the narrative put forward by the Government which sought to portray the duty as bureaucratic and burdensome.⁹⁰²

In my data analysis I sought to determine if the EHRC was utilising the PSED to promote and support the participation of DPOs. It appears that whilst the EHRC has produced guidance for public authorities on engaging with civil society to ensure compliance with the PSED, it has not actively promoted this guidance and there was limited awareness of the guidance amongst DPOs interviewed for this research.⁹⁰³ DPOs in general did not suggest that they were routinely raising concerns with the EHRC when they encountered policy making processes that are not accessible and potentially in breach of the PSED.⁹⁰⁴

In January 2021, the Disability Unit launched a survey on a draft Disability Strategy.⁹⁰⁵ The press release made clear that only responses received within 6 weeks of the launch of the survey would influence the development of the strategy. The publication of the survey provoked outrage amongst disabled people and DPOs. Three DPOs interviewed for this research indicated that they were in the process of initiating a judicial review of the decision to conduct the survey, arguing that the short period of consultation amounted to a breach of the PSED and of human rights protections.⁹⁰⁶ None of the DPOs involved in these proceedings indicated that they had engaged with the EHRC on the issue. When asked why one DPO stated, ‘I think it’s

⁸⁹⁹ Cabinet Office Press Release, ‘Press release: Red Tape Challenge’ 7 April 2011

⁹⁰⁰ Interview with Human Rights NGO (Lib) 24 March 2021

⁹⁰¹ Interview with DPO (IL) 22 March 2021=

⁹⁰² Interview with DPO (Man) 11 May 2021

⁹⁰³ EHRC, *Engagement and the Equality Duty: A Guide for Public Authorities* (London 2019)

⁹⁰⁴ Interview with DPO (Man) 11 May 2021

⁹⁰⁵ Disability Unit, ‘National Strategy for Disabled People Survey’ 15 January 2021, Available at:

<<https://www.gov.uk/government/news/citizen-space-survey-national-strategy-for-disabled-people>> (Accessed on 2 April 2022)

⁹⁰⁶ Interview with DPO (IL) 22 March 2021

probably because we don't automatically think about going to the EHRC because we don't feel they will do anything'.⁹⁰⁷ It is notable therefore that at a time when DPOs were considering the merits of litigation they did not seek the views or assistance of the EHRC. In their submissions the claimants argued that 'nothing about us without us' was a 'vital principle for the disabled people's movement'.⁹⁰⁸ The litigation was successful with the High Court ruling that the process of developing the Disability Strategy was unlawful.⁹⁰⁹

A number of DPOs felt that the EHRC could be doing more to promote the transformative potential of the PSED.⁹¹⁰ However others questioned whether the EHRC had sufficient credibility to do so. One DPO specifically highlighted that the way in which the EHRC had addressed a human resource matter relating to disabled employees had impacted on the potential for the EHRC to present examples of good practice.⁹¹¹ This issue was raised as a concern by the WEC which stated that the EHRC 'should not be following the minimum required, it should be setting the standard for others to follow'.⁹¹²

5.7.11 Engagement with the public sector

I sought to determine if the EHRC had established itself as a source of expertise on the development of participative policy making initiatives within the public sector. During my evidence gathering the Social Security Advisory Committee published a report into how the Department for Works and Pensions is involving disabled people when developing or evaluating programmes which affect them.⁹¹³ It is notable that when preparing the report, the Committee did not engage with the EHRC and do not refer to any guidance produced by the EHRC in their report. In my analysis of the EHRC's strategic plans and activities I identified limited evidence of the EHRC seeking to effect culture change within the Government bureaucracy.

⁹⁰⁷ Interview with DPO (DPA) 12 May 2021

⁹⁰⁸ John Pring 'Government must rewrite its National Disability Strategy, court is told' Disability News Service 4 November 2021

⁹⁰⁹ John Pring, 'Disability strategy delayed again as government consultation faces high court challenge' Disability News Service 22 July 2021, Available at: <https://www.disabilitynewsservice.com/government-must-rewrite-its-national-disability-strategy-court-is-told/>

⁹¹⁰ Interview with DPO (Man) 11 May 2021

⁹¹¹ Email Submission from DPO

⁹¹² WEC 'Enforcing the Equality Act: the law and the role of the EHRC' 30 July 2019, para 95

⁹¹³ Social Security Advisory Committee 'How DWP involves disabled people when developing or evaluating programmes that affect them' Occasional Paper No. 25 December 2020

The EHRC has sought to establish itself as a source of advice and guidance on international examination processes.⁹¹⁴ Establishing a Treaty Body Working Group that includes representatives of various departments. This Working Group tends to focus on compliance with reporting obligations rather than on implementation or compliance.

5.7.12 Engagement with other regulators

In my evidence gathering I found that the EHRC was seeking to change cultures and approaches within other public sector regulators. The EHRC chairs a regulator, inspectorate and ombudsmen forum to consider how to further the integration of human rights and equality within the regulatory approaches of members.⁹¹⁵ The EHRC has specifically sought to influence the work of the Care Quality Commission (CQC), the independent regulator of health and social care services. In 2014 the EHRC funded a training programme delivered by the British Institute for Human Rights to develop the capacity of the CQC.⁹¹⁶ Following on from this initiative, the EHRC and CQC issued joint guidance for CQC regulators on integrating equality and human rights into their investigations. During my evidence gathering EHRC and CQC published a memorandum of understanding setting out a framework for future engagement.⁹¹⁷ This measure and the general approach of the EHRC was welcomed by DPOs and OfDPs.⁹¹⁸ The development of sector specific guidance was seen as a very effective way to promote human rights and equality compliance.

5.7.13 Legal Powers – Bringing cases in its own name

A number of DPOs interviewed for this research felt that the ability of the EHRC to bring legal proceedings in its own name is a significant unique power which gives it the capacity to effect strategic change in ways not available to CSOs.⁹¹⁹ I found examples of the EHRC utilising this power to effect change for disabled people. In 2018, following campaigning by DPOs and disability activist Fleur Perry, the EHRC issued a judicial review pre-action letter to 13 Clinical Commissioning Groups regarding caps in funding packages to support disabled people to live

⁹¹⁴ Interview with former EHRC Commissioner

⁹¹⁵ EHRC Our Strategic Plan 2009–2012 (EHRC, 2009) p 22

⁹¹⁶ EHRC ‘New guidance for inspectors and assessors’ (EHRC, 28 April 2014)

⁹¹⁷ EHRC, ‘New agreement between CQC and Equality and Human Rights Commission’ (EHRC, 9 March 2021)

⁹¹⁸ Interview with OfDP 23 March 2021

⁹¹⁹ Interview with DPO (IS) 28 April 2021

in the community.⁹²⁰ Through publicising this action the EHRC was able to secure an agreement with Commissioning Groups to review their policies. A number of DPOs flagged this as a good example of collaboration, a DPO representative stated, ‘I think that was a good kind of example of when we brought an issue to them and they took some active role to try and kind of use their legal team to [bring litigation]... without us having to find them claimants’.⁹²¹

In February 2020, the EHRC announced that it had dispatched a pre-action letter to the Department of Health relating to the disproportionate number of people with autism being detained in secure hospitals.⁹²² A number of interviewees welcomed this initiative, but in April 2021 an interviewee expressed concern that it appeared that this legal action would not proceed.⁹²³ The interviewee expressed disappointment and some confusion as to why and how the decision had been arrived at. An analysis of the minutes of the EHRC Commission meeting in January 2021 indicate that these proceedings will not be brought. Noting that the Government was developing the new mental health policy, the minutes suggest reconsideration to determine ‘whether [the litigation] would be an effective use of public money’.⁹²⁴ This decision led to a perception by the interviewee that the Commission chose not to embark on the litigation as it may damage the Commission’s relationship with the Government. At the time of writing the EHRC has not publicly commented on whether litigation will be pursued on this issue.

5.7.14 Legal Powers: Interventions

The EHRC is empowered to intervene in proceedings to assist the court in clarifying the law. DPOs interviewed for this research were generally quite complimentary of the EHRC’s interventions in legal cases. One DPO stated, ‘They intervene in very few court cases although when they do it is obviously helpful’.⁹²⁵

The EHRC current litigation and enforcement policy makes clear it will use its ‘power to intervene only if we are satisfied that we will add value to the proceedings and assist the court

⁹²⁰ EHRC ‘NHS u-turns on discriminatory policies’ (EHRC 31 May 2018), See twitter account for Fluer Perry https://twitter.com/perry_fleur?ref_src=twsrc%5Egoogle%7Ctwcamp%5Eserp%7Ctwgr%5Eauthor (accessed 2 May 2021)

⁹²¹ Ibid

⁹²² EHRC Press Release, ‘Health Secretary faces legal challenge for failing patients with learning disabilities and autism’ 21 February 2020

⁹²³ Interview with Disability Charity (stra) 30 April 2021

⁹²⁴ EHRC Board Minutes of 93rd meeting on 13 January 2011

⁹²⁵ Interview with DPO (DPA) 12 May 2021

in its determination'.⁹²⁶ The UK courts have highlighted that the role of an intervener is to assist the court, the courts have at times been critical of interventions by NHRIs which do not provide additional knowledge or arguments for the court to consider.⁹²⁷

Whilst conscious of this criticism the EHRC has intervened in a number of strategic cases relating to disability rights. In doing so, the EHRC has drawn extensively on the UNCRPD. In its intervention to the Court of Appeal in the case of Burnip, the EHRC presented clear argument highlighting the relevance of the UNCRPD to the Court's interpretation of the ECHR. This intervention appears to have influenced the Court's decision to refer to the UNCRPD in determining the scope of the protections provided by the ECHR.⁹²⁸ In the case of Bracking, the EHRC intervened providing guidance for the court on the correct legal approach to the PSED.⁹²⁹ Again this appears to have influenced the outcome of the case and facilitated the development of a precedent clarifying that compliance with the PSED requires 'a conscious consideration of the criteria which the law requires'.⁹³⁰

Through its interventions, the EHRC are therefore strengthening the legal framework governing the PSED. Whilst DPOs may wish to see the EHRC intervening in a greater number of cases and being more supportive of the arguments advanced by disabled litigants, to adopt such an approach may lead to criticism by the courts and undermine the credibility of the EHRC. Devising litigation strategies to advance social causes is a complex exercise.⁹³¹ As the UK is a dualist state there is a risk that legal interventions which overemphasise the relevance of unincorporated international human rights treaties may be unhelpful or lead to unintended consequences. For instance, in the case of SC the UK Supreme Court responded to an argument that reforms to child tax credits were in breach of the United Nations Convention on Children's Rights ('UNCRC') by making clear that unincorporated treaties do not form part of UK law.⁹³² This established a precedent which may undermine attempts to argue for the relevance of the UNCRPD and other unincorporated treaties. The EHRC therefore need to be strategic in determining which cases to intervene in and in developing arguments to put forward. In light

⁹²⁶ EHRC 'Our litigation and enforcement policy 2019-22' 2019 p. 8

⁹²⁷ *In re E (a child) (AP) (Appellant) (Northern Ireland)* [2008] UKHL 66 para 3

⁹²⁸ *Burnip v Birmingham City Council & Anor* [2012] EWCA Civ 629 (15 May 2012)

⁹²⁹ *Stuart Bracking & Ors v Secretary of State for Work and Pensions* [2013] EWCA Civ 1345 (06 November 2013)

⁹³⁰ *Ibid*

⁹³¹ János Fiala-Butora, Matthew S. Smith, & Michael Ashley Stein, 'Disability Cause Lawyering at the European Court of Human Rights' 2022 (awaiting publication)

⁹³² *R (on the application of SC, CB and 8 children) (Appellants) v Secretary of State for Work and Pensions and others (Respondents)* [2021] UKSC 26, para 77

of their unique powers the EHRC could potentially play a co-ordinating role, sharing their own strategic calculations when making decisions relating to strategic litigation.

5.7.15 Inquiries

In addition to having specific investigatory powers relating to breaches of the Equality Act, the EHRC has a specific power to carry out an inquiry into any matter relating to equality and human rights under its remit.⁹³³

DPOs interviewed for this research were generally complimentary of the inquiries which the EHRC has undertaken. The 2010 inquiry into disability hate crime was, in particular, held up as an example of an inquiry which had captured the lived experience of disabled people and positively influenced public discourse.⁹³⁴ The 2010 disability hate crime report was detailed and wide ranging. Importantly the EHRC invested significant resources in promoting implementation of its recommendations.⁹³⁵ DPOs felt that the ability of the EHRC to undertake an inquiry is a significant power and whilst it cannot compel implementation of its recommendations the publicity generated by an inquiry can effect change.⁹³⁶

DPOs who had experience of collaborating with the EHRC during its inquiries were generally complimentary of its approach. During my evidence gathering the EHRC was conducting an inquiry into the use of restraint in schools.⁹³⁷ One DPO highlighted that the EHRC had approached them to contribute to the inquiry and reported that they found the discussions to be constructive.⁹³⁸

There was a general view amongst DPOs that the EHRC is underusing its power to conduct an inquiry.⁹³⁹ Three DPOs suggested that they had presented credible evidence to the EHRC of human rights violations relating to social security reform but this did not lead to the EHRC conducting an inquiry.⁹⁴⁰ One DPO in commenting on this stated, ‘I mean you’ve got proof that disabled people have literally been killed by the policies that government have put in place

⁹³³ Equality Act 2006 section 16

⁹³⁴ EHRC ‘Disability Related Hate Crime’ (EHRC 2011)

⁹³⁵ EHRC ‘Tackling disability-related harassment: Final progress report’ (EHRC 2017)

⁹³⁶ Interview with DPO (Scot) 17 March 2021

⁹³⁷ EHRC ‘Restraint in schools inquiry: using meaningful data to protect children's rights’ (EHRC 2021)

⁹³⁸ Interview with DPO (Alf) 26 April 2021

⁹³⁹ Email Submission DPO 6 March 2021

⁹⁴⁰ Interview with DPO (IL) 22 March 2021

and the EHRC are sort of saying well yeah well, we're not really going to bother pursuing this'.⁹⁴¹ There seemed to be a lack of understanding within UKDPM as to why the EHRC had not initiated an inquiry into social security reform.⁹⁴² The lack of a clear decision was a source of frustration amongst DPOs and appeared to have a damaging impact on relations between the EHRC and a number of significant DPOs.⁹⁴³ A member of the EHRC-DAC acknowledged, 'there has been a lack of detail from the EHRC as to why they haven't done an inquiry or what measures they're taking to do that and on one level you can understand because it is such a complex issue but at the same time having very minimal information given to the civil society harms it's relationship'.⁹⁴⁴

During my evidence gathering the EHRC reported that it would launch an inquiry into the social care system.⁹⁴⁵ This was welcomed by a DPO interviewed for this research, who considered it an opportunity to embed the human rights lens into ongoing social care reform.⁹⁴⁶ However, no public statement was issued relating to the request for an inquiry into social security reforms. The DPO coalition ROFA has raised the issue with the UNCRPD Committee.⁹⁴⁷

5.8 Conclusions

In my concluding chapter I will set out overall conclusions informed by reflections on both of my case studies and of the existing literature. Here I will make three specific conclusions relating to the EHRC.

The EHRC do not have a statutory responsibility to support the development of human rights capacities in DPOs or civil society generally. The powers and functions of the EHRC relate to the provision of advice and assistance to state bodies, including the Government, the Parliament and the courts. This statutory framework has influenced an approach by the EHRC which sees support to civil society as ancillary to its core functions.

⁹⁴¹ Interview with DPO (AC) 12 May 2021

⁹⁴² Interview with DPO (Man) 11 May 2021

⁹⁴³ John Pring, Anger after watchdog appears to back away from inquiry into DWP deaths 29 April 2021

⁹⁴⁴ Interview with member of EHRC Disability Advisory Committee 15 February 2021

⁹⁴⁵ John Pring 'Watchdog's 'invaluable' inquiry set to expose 'fragility' of social care system' Disability News Service 29 April 2021

⁹⁴⁶ *ibid*

⁹⁴⁷ Interview with DPO (IL) 22 March 2021

The EHRC has sought to support the development of DPOs to facilitate engagement in the UNCRPD examination. At a domestic level, the EHRC focuses on supporting civil society through the production of authoritative research and analysis which DPOs can utilize and integrate into their advocacy activities. This research suggests that this approach is ineffective. In addition to authoritative analysis, DPOs often need support and guidance to ensure they are able to effectively engage with Government and Parliament.

The EHRC has an extensive range of statutory powers and responsibilities. Its budget is not commensurate to its statutory responsibilities which has meant that it must be strategic when deciding whether to exercise its powers to undertake an inquiry or engage in litigation. The UKDPM in general consider the EHRC has not appropriately prioritized the rights of disabled people and have found the EHRC to be unresponsive when they have asked the EHRC to exercise their statutory powers. There appears to be a lack of transparency around decision making within the EHRC. This lack of transparency has contributed to a perception within the UKDPM that the EHRC do not value their views. When faced with criticism from the UKDPM the EHRC has often been unduly defensive and unwilling to provide reasons for their decisions.

The original design features of EHRC to ensure a discernable emphasis on the rights of disabled people have diminished in significance due to the decision of the EHRC to prioritize the development of an intersectional approach. This change in approach has not been well understood by the UKDPM and has largely been perceived as an attempt to marginalize disability issues. DPOs expressed a clear preference for the establishment or maintenance of disability specific features, whether that be a Disability Commissioner, a disability unit or a Disability Committee. The EHRC has not engaged in effective consultation with disabled people when making decisions relating to its engagement structures. There has been an absence of consideration for how the EHRC can reflect the principle of nothing about us without us.

Chapter 6 Case Study Ireland – Irish Human Rights and Equality Commission

6.1 Introduction

In this chapter, I will set out my critical analysis of the relationship between the Irish Human Rights and Equality Commission (IHREC) and the Irish disabled people’s movement (‘IDPM’). First, I will explain my interview and document review strategy, I will then provide a brief overview of the human rights framework in Ireland and the IDPM. Lastly, I will set out in detail the relationship between the IHREC and the DPM using the powers of the IHREC to structure my analysis.

In order to gather evidence, I conducted eleven structured interviews with representatives of seven Irish DPOs and two human rights NGOs. In addition to this, for each of these DPOs I reviewed their websites and relevant published documents and resources. I also observed a meeting of Irish DPOs and OfDPs who had come together to develop a draft UNCRPD shadow report.⁹⁴⁸

In order to inform my assessment of the IHREC, I conducted a legal analysis of its founding statute and critically assessed relevant corporate documentation, including strategic plans, business plans and annual reports. I conducted structured interviews with current and former senior staff within the IHREC, with a Commissioner with experience of disability activism, and with members of the IHREC Disability Advisory Committee (IHREC-DAC). Furthermore, I critically assessed relevant publications of the IHREC relating to the rights of disabled people, including legislative observations, written interventions to relevant court cases, submissions to international committees and guidance documents.

I reviewed the activities of the IHREC from its establishment to 1 March 2022. I also reviewed the activities of Ireland’s first NHRI the Irish Human Rights Commission (IHRC) which was amalgamated with the Equality Authority to become the IHREC. Whilst this enquiry is principally focused on the activities of the IHREC I expanded my analysis to include certain activities of IHRC at the suggestion of a number of DPO leaders and activists.

⁹⁴⁸ CDLP, Contributing to a shadow report for Ireland, 10 December 2019

6.2 Irish Human Rights Framework

Ireland is a dualist state. Article 29.6 of the Irish Constitution provides that ‘No international agreement shall be part of the domestic law of the State save as may be determined by the Oireachtas’. All ratified international agreements are, in practice, laid before Dáil Éireann. The Irish Government, in general, ensure that all necessary legislative provisions and administrative arrangements are put in place before ratification.⁹⁴⁹

The Irish Government signed the UNCRPD in 2007, but did not ratify the UNCRPD until 2018. In the intervening years, the Irish Government brought forward a number of legislative measures to bring about compliance with the UNCRPD.⁹⁵⁰ The Irish Government has indicated that the IHREC will be designated as the independent monitoring mechanism for the purposes of Article 33(2).⁹⁵¹ This will be provided for by way of the Assisted Decision Making (Capacity Amendment) Bill 2021.

The Irish Government has not yet ratified the Optional Protocol to the UNCRPD.

6.3 The Irish Disabled People’s Movement

To inform a critical assessment of the relationship between the IHREC and the IDPM, in this section I provide a brief overview of the IDPM and the history of its development. In doing so I will identify a number of specific challenges the IDPM have faced.

There is a small body of published literature chronicling the activities and development of the IDPM.⁹⁵² In developing my analysis of the IDPM I have drawn on a range of academic articles, newspaper reports and interviews with members of the movement.

Prior to the 1980s, activism by disabled people tended to be ‘organized at the local, constituency scale’.⁹⁵³ The UN Decade of Disabled Persons encouraged reflection amongst disabled activists in Ireland on the need for collective action. In 1990 the Forum of People with Disabilities, a grass roots advocacy organisation was formed (‘FDP’).⁹⁵⁴ The FDP highlighted the need for the fundamental reforms to address the obstacles to disabled people participating

⁹⁴⁹ Law Reform Commission, Discussion Paper: Domestic Implementation of International Obligations 2020, p 130

⁹⁵⁰ Department of Justice, ‘Roadmap to Ratification of the United Nations Convention on the Rights of Persons with Disabilities’ 2014

⁹⁵¹ Ireland, ‘Initial Report under the Convention on the Rights of Persons with Disabilities’ 2020, para 39

⁹⁵² See for instance Pauline Conroy, ‘A Bit Different: Disability in Ireland’ (Orpen Press 2019)

⁹⁵³ Rob Kitchin and Robert Wilton, ‘Disability activism and the politics of scale’ [2003] Canadian Geographer 97

⁹⁵⁴ Flynn E, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2011) pp. 352–355.

in society. In responding to advocacy by disabled people, in 1993 the Irish Government established the Commission on the Status of People with Disabilities to examine the situation of disabled people, and the organisation and adequacy of existing services.⁹⁵⁵ The Commission had significant representation from disabled people.

In conducting its review, the Commission embarked on an extensive engagement programme with disabled people throughout Ireland. The Commission made recommendations for reforms to practice, policy and laws to address obstacles to disabled people. Flynn described the report from the Commission as a ‘turning point in Irish law and policy on disability’.⁹⁵⁶ The approach of the Commission on the Status of People with Disabilities was highlighted by interviewees as an example of good practice that has rarely been emulated by Government Departments in Ireland.⁹⁵⁷ Representatives from the IDPM interviewed for this research consistently highlighted the continued relevance of the report and its findings.

In its report the Commission acknowledged the importance of developing the capacity of disabled people to advocate for themselves.⁹⁵⁸ The Commission recommended the establishment of a state body to coordinate implementation of the Commission’s recommendations and the establishment of a council of people with disabilities, to provide a voice to disabled people.

Following on from the publication of the Commission’s report, disability activists highlighted the need for enforceable legal protections against discrimination.⁹⁵⁹ In responding to these demands the Irish Government developed a draft Disability Bill in 2001. The Bill was rejected by the IDPM due to the inclusion of a provision expressly providing that the rights provided within the Bill would be non-justiciable.⁹⁶⁰ In developing a new Disability Bill, the Irish Government established a Disability Legislation Consultation Group (‘DLCG’), which included key disability activists, the Forum on People with Disabilities and OfDP representatives. The purpose of the DLCG was to report on the preferred content of the Bill.⁹⁶¹ The DLCG made clear that the Bill should provide that disabled people have a legal right to access services. Upon publication of the new Bill, three members of the DLCG including the

⁹⁵⁵ Commission on the Status of People with Disabilities 2006, *A Strategy for Equality*, Dublin: Stationery Office. 1996

⁹⁵⁶ Flynn E, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2011) p. 289

⁹⁵⁷ Interview with DPO representative 16 July 2021

⁹⁵⁸ Commission (n 955) p. 95

⁹⁵⁹ Interview with DPO representative 1 July 2021 (DA)

⁹⁶⁰ Flynn E, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2011) p. 302

⁹⁶¹ Disability Legislation Consultation Group ‘Equal Citizens: Proposals for Core Elements of Disability Legislation’ (Dublin: DLCG).

Forum resigned from the group raising concerns that the Bill did not make provision for a legal right of redress.⁹⁶²

In 2004 the Irish Government referred the draft Disability Bill to the IHRC for advice. In its advice the IHRC set out how the inclusion of a right to redress within the Bill would be consistent with the state's international human rights obligations.⁹⁶³ When the Disability Bill was published without including a right to redress, the IHRC in conjunction with the IDPM developed ten key proposed changes to the Bill.⁹⁶⁴ The FDP collaborated closely with the IHRC in lobbying for amendments to the Bill as it progressed.⁹⁶⁵ Flynn noted that engagement relating to the Disability Act 2005 was a 'valuable learning experience' for the movement.⁹⁶⁶ It appears that lobbying on the Bill also provided disabled activists with an insight into the value of collaborating with the NHRI and the benefits that could accrue from this.

In line with the recommendation from the Commission, the Department of Justice, Equality and Law Reform provided funding for the establishment of the Council of People with Disabilities in 1996. The Council was composed of 28 members who were either disabled people or their advocates.⁹⁶⁷ Early in its operation internal difficulties emerged between the Council members and the Chief Executive.⁹⁶⁸ An audit of the Council in 1998 reported concerns that funds had been misappropriated and found little evidence that the Council had engaged with disabled groups.⁹⁶⁹ In 2000, the Council was replaced by the People with Disabilities in Ireland Ltd.⁹⁷⁰ People with Disabilities in Ireland Ltd was composed of a board of directors. Whilst it was intended to provide a voice for disabled people in the policy making process People with Disabilities in Ireland Ltd were largely absent from relevant policy discussions.⁹⁷¹ In 2011, the Irish Government conducted a value of money review of the organisation and found that the 'annual budget was spent on the operation of its office

⁹⁶² Namhi (now inclusion Ireland) and the National Parents and Siblings Association also resigned, See Flynn E, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2011), p. 324

⁹⁶³ Irish Human Rights Commission Observations on the Disability Bill 2004 (2004)

⁹⁶⁴ *Irish Times*, Major changes to disability legislation urged 9 February 2005 <https://www.irishtimes.com/news/major-changes-to-disability-legislation-urged-1.413318>

⁹⁶⁵ *ibid*

⁹⁶⁶ Flynn E, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2011) p. 324

⁹⁶⁷ Irish Independent, Minister intervenes in row at group for disabled, February 27 1998, Available at <https://www.independent.ie/irish-news/minister-intervenes-in-row-at-group-for-disabled-26197582.html>

⁹⁶⁸ Colm Keena, Acting head of council for the disabled dismissed after 2 months, 9 October 1998 (Dublin Irish Times) <https://www.irishtimes.com/news/acting-head-of-council-for-the-disabled-dismissed-after-2-months-1.201709>

⁹⁶⁹ Irish Times, Uncomfortable reading for some civil servants 9 October 1999 available at: <https://www.irishtimes.com/news/uncomfortable-reading-for-some-civil-servants-1.236636>

⁹⁷⁰ Jurgen De Wispelaere and Judy Walsh, 'Disability Rights in Ireland: Chronicle of a Missed Opportunity' [2007] *Irish Political Studies* 517

⁹⁷¹ Department of Justice, Written Answers Equality and Law Reform UN Conventions [16336/04] 1 June 2004

headquarters and on administration rather than on the creation of projects which would directly benefit people with disabilities'.⁹⁷² The organisation ceased operating in 2012.⁹⁷³

Neither body was considered by the IDPM to truly represent them.⁹⁷⁴ Interviewees for this research highlighted that the activities of the People with Disabilities in Ireland Ltd often happened in parallel to but not in collaboration with the IDPM.⁹⁷⁵ Jacquie Brown, who was a member of the Commission on the Status of People with Disabilities, has stated that the organisation was '...foisted upon us rather than [emerging from] grass roots ...the model was always wrong from the start because it was a top down approach, we were given a CEO who was an employee of the Department of Justice'.⁹⁷⁶ The approach of the Irish Government reflects what Acheson and others consider to be a general trend for the Irish state to take on a role '...in structuring the civic space in which voluntary action occurs'.⁹⁷⁷ The Irish state prioritised the establishment of bodies which it could control rather than providing funding to support and foster the growth of independent DPOs. One interviewee noted that despite the fact that People with Disabilities in Ireland Ltd was designed by the Irish state, public officials have cited its mismanagement of public funds as a failure of the IDPM.⁹⁷⁸

The Forum of People with Disabilities was active from 1990 to 2006. It received funding from the European Union and from Atlantic Philanthropies.⁹⁷⁹ Chaired by Donal Toolan, the Forum effectively campaigned on a number of issues relating to the rights of disabled people.⁹⁸⁰ The Forum also regularly highlighted the need for the introduction of accountability mechanisms for those responsible for the provision of disability services.⁹⁸¹ The Forum often worked in conjunction with activists involved in the Centres for Independent Living in Ireland, most notably Martin Naughton.⁹⁸²

⁹⁷² Kathleen Lynch, Minister of State for Disability, Equality, 'Mental Health and Older People Statement in relation to People with disabilities in Ireland' 25 November 2011, Available at: <https://www.justice.ie/en/JELR/Pages/PR11000237> (Accessed on 2 April 2022)

⁹⁷³ Nicky McFadden TD, 'Disability Support Service' Written answers Tuesday, 13 December 2011 [39668/11]

⁹⁷⁴ Interview with representative of DPO 7 October 2021 (KM)

⁹⁷⁵ Interview with DPO representative 16 July 2021 (VI)

⁹⁷⁶ ILMI Episode Four: Recorded 20th May 2020, Jacqui Brown joins us in Conversations About Activism and change, Available at <https://ilmi.ie/ilmi-podcasts/> (Accessed on 2 April 2022)

⁹⁷⁷ Acheson, N Harvey, B Kearney, J and Williamson, A, 'Two Paths, One Purpose: Voluntary Action in Ireland, North and South' (Institute of Public Administration 2004), p. 197

⁹⁷⁸ Interview with representative of DPO 7 October 2021 (KM)

⁹⁷⁹ Pauline Conroy, 'A Bit Different: Disability in Ireland' (Orpen Press 2019)

⁹⁸⁰ Rosaleen McDonagh, 'Travellers and people with disabilities must use their vote for change' Irish Times 24 April 2019 <https://www.irishtimes.com/life-and-style/health-family/travellers-and-people-with-disabilities-must-use-their-vote-for-change-1.3860951>

⁹⁸¹ Carl O'Brien, 'Call for more accountability on use of disability funding' 13 November 2007 <https://www.irishtimes.com/news/call-for-more-accountability-on-use-of-disability-funding-1.981555>

⁹⁸² Mark Hilliard, 'Noted disability campaigner Martin Naughton dies at 62' 13 October 2016 <https://www.irishtimes.com/news/social-affairs/noted-disability-campaigner-martin-naughton-dies-at-62-1.2828751>

The closure of the Forum was considered to have restricted the capacity of the IDPM to substantively contribute to the policy making process.⁹⁸³ However, members of the movement remained visible and the movement retained capacity to attract media attention.⁹⁸⁴ Notably the movement coordinated a sit out at the Houses of the Oireachtas in 2012 highlighting the impact of planned cuts to disability services.⁹⁸⁵ However, the absence of professional organisations hampered the ability of the movement to build on individual successes.⁹⁸⁶

Interviewees noted that throughout the 2000s, participation in formal structures of engagement relating to the development of a national disability strategy detracted members of the movement from influencing policy priorities and proved to be ‘massively exhausting activities .. with very ... little result’.⁹⁸⁷ Interviewees highlighted that in the early 2010s many key activists experienced burn out and became unable to ‘contribute sustained time to [advocacy] activities’.⁹⁸⁸

Discussions relating to the ratification of the UNCRPD sparked ‘renewed interest in disability policy development’ within the IDPM.⁹⁸⁹ In recent years a number of DPOs have formed, for example the organisation Disabled Women of Ireland was established to provide a voice for disabled women in May 2018. In 2022 the grass roots DPO, Disability Power Ireland (‘DPI’) was established.⁹⁹⁰ DPI aim is to ‘celebrate and connect the disabled community and normalise disability as a natural and beautiful part of human diversity’.⁹⁹¹ Throughout July 2022 DPI organised a number events to celebrate Disability Pride Month.⁹⁹² The emergence of DPOs has taken place at a time at which there is reduced funding available to support the growth of advocacy organisations in Ireland.⁹⁹³ As a result many DPOs have struggled to secure funding. For instance, the National Platform of Self Advocates (NPSA) a DPO which seeks to provide a voice for people with intellectual disabilities in the policy making process campaigned for state funding to facilitate their continued operation from

⁹⁸³ Interview with representative of DPO 7 October 2021 (KM)

⁹⁸⁴ Interview with representative of DPO 21 January 2022

⁹⁸⁵ Aine McMahon, Protest at cuts to disability payments, Irish Times 22 November 2021

⁹⁸⁶ Interview with representative of Human Rights NGO 19 January 2022

⁹⁸⁷ Interview with IHREC staff member 19 May 2021 (I)

⁹⁸⁸ Interview with Commissioner of IHREC 16 August 2021

⁹⁸⁹ Flynn E, From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities (Cambridge University Press, 2011) p. 325

⁹⁹⁰ Conor Capplis, ‘New grassroots organisation aims to change perceptions of disability with ‘radical’ events’ Irish Examiner 29 June 2022

⁹⁹¹ Ibid

⁹⁹² DPI ‘Disability and Pride Festival’ Available at: <http://disabilitypride.ie> (Accessed on 18 July 2022)

⁹⁹³ Deaglan De Breadun, ‘Protesters’ disability becomes their greatest strength’ 8 September 2012, Available at:

<https://www.irishtimes.com/opinion/protesters-disability-becomes-their-greatest-strength-1.527088> (Accessed on 2 August 2022)

2018-2021.⁹⁹⁴ Whilst the NPSA receiving funding in 2021, its lengthy campaign highlights the exclusion of DPOs from public funding streams.

The establishment of new DPOs has encouraged reflection within the movement on the need to develop coherence, in particular through the establishment of umbrella organisations or networks. In the late 2010s, Suzy Byrne coordinated the development of Disabled People of Ireland which was intended to act as an umbrella organisation open to DPOs and disabled people.⁹⁹⁵ However this initiative was unable to secure funding and support.⁹⁹⁶

Separate to this initiative, in 2017 a committee composed of disabled people, chaired by Eileen Day, began meeting to reflect on the need for a cross impairment DPO.⁹⁹⁷ The group, going by the name 'By Us With Us', held a memorial event for twelve prominent disabled campaigners in September 2017.⁹⁹⁸ The discussions emerging from this event led to the launch of a new DPO, named the Independent Living Movement of Ireland ('ILMI'). The ILMI was launched in 2018 and is funded through the Department of Health.⁹⁹⁹

Representatives of ILMI interviewed for this research were clear in their goal that ILMI could and should become a pan disability umbrella organisation providing a voice for the broader movement. As part of this strategy, ILMI has received EU funding for a project seeking to develop grass roots DPOs throughout Ireland.¹⁰⁰⁰ However, representatives of other DPOs interviewed for this research were less supportive of the view that ILMI should take on this central role. A number of interviewees were concerned that this initiative was not fully inclusive of the broader movement.¹⁰⁰¹ Their views reflected concerns that an emphasis on independent living leads to a focus on those with physical disabilities over other impairment groups, such as those with intellectual impairments.¹⁰⁰²

The ratification of the UNCRPD and the need to develop a shadow report has acted as a further impetus for the movement to come together. In 2020, the Centre for Disability Law and Policy

⁹⁹⁴ Inclusion Europe – Irish self-advocacy organisation closing down for lack of funding: “This is truly unacceptable!” 4 December 2019 Available at: <https://www.inclusion-europe.eu/irish-self-advocacy-organisation-shutting-down-for-lack-of-funding-this-is-truly-unacceptable/> (Accessed on 2 August 2022)

⁹⁹⁵ The Journal, 'Disability advocate says 'it's time to put up or shut up' as she joins board of Irish Rail' 3 August 2018 available at: <https://www.thejournal.ie/disability-state-boards-4163500-Aug2018/> (Accessed on 2 June 2022)

⁹⁹⁶ Interview with representative of DPO 17 January 2022

⁹⁹⁷ Eileen Day, 'New Horizons – Re-energizing the Disability Movement in Ireland' 23 September 2017 Available at: <https://www.ahead.ie/journal/New-Horizons-Re-energizing-the-Disability-Movement-in-Ireland> (Accessed on 2 June 2022)

⁹⁹⁸ Ibid

⁹⁹⁹ Interview with representative of DPO 7 October 2021 (KM)

¹⁰⁰⁰ Interview with representative of DPO 7 October 2021 (KM)

¹⁰⁰¹ Interview with representative of DPO 17 January 2022

¹⁰⁰² McGettrick G, Health services and disability in Suzanne Quin and Bairdre Redmond (eds) 'Disability & Social Policy in Ireland' (UCD Press 2003) p. 79

at NUI Galway held a number of events within the movement with the immediate goal of developing a shadow report.¹⁰⁰³ Separately six DPOs came together in a coalition to prepare a shadow report. The DPO Coalition received funding from the IHREC to fund the production of a shadow report considering the challenges faced by the IDPM.¹⁰⁰⁴ It was originally intended that this initiative may provide a basis for the development of a new umbrella organisation. However, members of the coalition found it difficult to develop coherent ways of working.¹⁰⁰⁵ A member of the coalition interviewed for this research reported that the experience of the coalition indicated that there was a need for the movement to develop a greater appreciation of the need for a cross disability perspective that was inclusive of all impairment groups.

The movement therefore appears to be in a period of development with new organisations forming and a desire to develop coherence, leading to a number of networks being established.

6.4 Disability policy : UNCRPD Focal Point

Like in many states, responsibility for disability policy rests with a number of government departments in Ireland. National equality strategies are ‘the central policy framework adopted by Government to address inequality across Irish society’.¹⁰⁰⁶ Since 2005, a number of national disability strategies have been developed to coordinate disability policy. The National Disability Inclusion Strategy 2017-2021 (NDIS) is the current strategy. The strategy is described as a ‘whole of Government strategy’.¹⁰⁰⁷ The NDIS Steering Group is chaired by the Minister of State with responsibility for disability and includes representatives of other departments.¹⁰⁰⁸ As set out below the strategy has an accompanying participative structure.

Until 2020, the Department for Justice and Equality had lead responsibility for disability policy and also for the process of preparing for ratification. In October 2020, the disability function was passed from the Department for Justice and Equality to the new Department of Children, Equality, Disability, Integration and Youth (‘DCEDIY’). The DCEDIY is the UNCRPD focal point.¹⁰⁰⁹ The DCEDIY are responsible for developing a UNCRPD implementation plan and

¹⁰⁰³ Correspondence on file with the author

¹⁰⁰⁴ Interview with representative of IHREC 13 May 2022

¹⁰⁰⁵ Interview with representative of DPO 7 October 2021

¹⁰⁰⁶ Department of Children, Equality, Disability, Integration and Youth Equality Issues 2 December 2021

¹⁰⁰⁷ <[https://www.kildarestreet.com/wrans/?id=2021-12-02a.445&s="Irish+human+rights+and+equality+commission"#g447.r](https://www.kildarestreet.com/wrans/?id=2021-12-02a.445&s=)> (Accessed on 2 April 2022)

¹⁰⁰⁸ Department of Children, Equality, Disability, Integration and Youth, Initial State Report on Compliance with the UNCRPD, 2021, para 460

¹⁰⁰⁹ *ibid*

¹⁰⁰⁹ *ibid*

also have responsibility for the NDIS.¹⁰¹⁰ Interviewees for this research emphasised that there was a lack of clarity as to the relationship between the NDIS and the proposed UNCRPD implementation plan.¹⁰¹¹ Prior to ratification of the UNCRPD, the Department for Justice and Equality brought forward the Disability Miscellaneous Provisions Bill which included a number of legislative amendments considered necessary to provide for ratification. However, this Bill was never enacted. In November 2021, the Irish Government published the General Scheme of Assisted Decision Making (Capacity Amendment) Bill 2021 which incorporates a number of provisions of the Disability Miscellaneous Provisions Bill.¹⁰¹²

Responsibility for the commissioning of disability services has recently been transferred from the Department of Health to DCEIDY.¹⁰¹³ However, responsibility for the provision of disability services tends to be contracted out to third parties.¹⁰¹⁴ The provision of disability services in Ireland has been ‘forged by a history of disability charity driven by Catholic institutions’.¹⁰¹⁵ Historically, many services for disabled people were delivered through agencies controlled by the Catholic church.¹⁰¹⁶ The church conceptualised the provision of disability services as a form of charity. As a result, disability policy in Ireland has historically strongly reflected the medical and charitable models of disability.¹⁰¹⁷ Whilst the prominence of catholic agencies in the provision of disability services has diminished in recent years, the ‘culture of care’ which they developed continues to be promoted by service providers.¹⁰¹⁸ DPOs and disabled activists interviewed for this research consistently highlighted that the charitable model of disability often dominates discourse relating to disability policy in Ireland.

In addition to Government Departments, a number of non-departmental public bodies have responsibilities relating to disabled people, for instance the Mental Health Commission.¹⁰¹⁹ More significantly there is an independent state body with specific responsibility for disability policy, the National Disability Authority (NDA).

¹⁰¹⁰ Department of Children, Equality, Disability, Integration and Youth ‘National Disability Inclusion Strategy 2017 – 2021’ 2017

¹⁰¹¹ Interview with DPO representative 16 July 2021 (VI)

¹⁰¹² Department of Children, Equality, Disability, Integration and Youth ‘General Scheme and Heads of Bill: Assisted Decision Making (Capacity Amendment) Bill 2021’ (November 2021)

¹⁰¹³ Health (Miscellaneous Provisions) Act 2022 (12 April 2022)

¹⁰¹⁴ Quinn S, ‘Health services and disability’ in Suzanne Quin and Bairbre Redmond *Disability & Social Policy in Ireland* (University College Press Dublin) 200, p. 83

¹⁰¹⁵ Jurgen De Wispelaere and Judy Walsh, ‘Disability Rights in Ireland: Chronicle of a Missed Opportunity’ [2007] *Irish Political Studies* 517 p. 519

¹⁰¹⁶ Barrington R, *Health, medicine and politics in Ireland 1900–1970* (Institute of Public Administration 1987)

¹⁰¹⁷ McGettrick G, ‘Health services’ (n. 924) p. 82

¹⁰¹⁸ Donal Toolan, ‘An emerging rights perspective for disabled people in Ireland: an activist’s view’ in Suzanne Quin and Bairbre Redmond *Disability & Social Policy in Ireland* (University College Press Dublin) 2003, p. 173

¹⁰¹⁹ See Mental Health Commission website <https://www.mhcirl.ie>

The Commission on the Status of People with Disabilities recommended the establishment of a NDA to monitor implementation of its recommendations, to coordinate disability policy and to perform related functions including the creation of appropriate standards for disability services. The Commission recommended that 60% of the membership of the Board of the NDA should be disabled people and their families.¹⁰²⁰

The NDA was established by way of the NDA Act 1999 as a body corporate.¹⁰²¹ Members of the NDA are appointed by the Minister who must have regard to the objective ‘that a majority of the Authority would be persons with disabilities, their representatives, families or carers’ when making appointments’. The NDA website does not indicate which of its 14 members fall into this category. A press release issued by the Department at the time of the appointment of the current memberships does not indicate that any of the members are disabled people.¹⁰²² The NDA does not have formal arrangements for engaging with disabled people. The current strategic plan for the NDA suggests that it will hold thematic events with disabled people and their representative groups.¹⁰²³ DPO representatives interviewed for this research were generally critical of the approach adopted by the NDA and felt that in its composition and its workings it did not reflect the spirit of the Commission’s recommendation.¹⁰²⁴ One DPO leader stated; ‘what’s been really disappointing with the NDA has been it has sought to kind of co-opt the space as being kind of like the intermediary that manages the relationship between DPOs and the state’.¹⁰²⁵ Rather than providing a bridge between the state and civil society it appears that the NDA is providing a buffer. In 2022 amendments were made to the NDA 1999 to provide that the employees of the NDA shall be civil servants within the Civil Service of the Irish State.¹⁰²⁶ This development is likely to increase the perception of the NDA as an agent of government.

Independent of initiatives by the Government, in 2020 the Oireachtas established a Committee on Disability Matters to consider all disability matters, including monitoring Ireland’s implementation of the UNCRPD.¹⁰²⁷ The establishment of this Committee reflects the

¹⁰²⁰ Recommendation 20

¹⁰²¹ s. 6

¹⁰²² Department of Justice, Appointments to the Board of the National Disability Authority, August 2018 . Available at: <https://www.justice.ie/en/JELR/Pages/PR18000272>

¹⁰²³ NDA Strategic Plan 2022-2024, available at: <https://www.nda.ie/about-us/corporate-publications/strategic-plans/strategic%20plan%202022%20-2024/> (Accessed on 2 June 2022) p. 16

¹⁰²⁴ Interview with representative of DPO 7 October 2021 (KM)

¹⁰²⁵ An Interview with DPO representative 21 July 2021 (AI)

¹⁰²⁶ Assisted Decision-Making (Capacity) (Amendment) Act 2022 Section 93(1)(b)(ii)

¹⁰²⁷ See website of Committee on Disability Matters <https://www.oireachtas.ie/en/committees/33/disability-matters/> (accessed on 21 September 2021)

commitment of the Oireachtas to support the implementation of the UNCRPD. In 2020 the Committee issued a consultation on its terms of reference and work programme.¹⁰²⁸ The evidence sessions of the Committee have provided a forum in which DPOs and the IHREC can raise concerns relating to the rights of disabled people. In 2021 the Committee published a report on aligning disability funding with the UNCRPD.¹⁰²⁹

Whilst the Irish Government have emphasised that the NDIS constitutes a ‘whole of government’ approach to disability policy, this has not been demonstrated in practice. One DPO representative highlighted that the broad range of state bodies and committees with responsibility for disability can be confusing and in their view ‘dissipates efforts’.¹⁰³⁰

6.5 UNCRPD Article 33(2)

The Irish Government’s roadmap to ratification suggested that a IMF would be established comprised of both the IHREC and the NDA.¹⁰³¹

The IHREC has consistently encouraged reflection within Government and civil society on implementation of Article 33(2). In 2016, the IHREC published research conducted by the CDLP which considered options for establishing an IMF in Ireland. The report considered the guidance provided by the UNCRPD Committee on the composition of an IMF and on the designation of an IMM.¹⁰³² The CDLP recommended that the IHREC be designated as the IMM, alongside an advisory committee composed of a ‘diverse group of people with lived experience of disability’.¹⁰³³

The CDLP report noted that due to the absence of an umbrella DPO in Ireland, there were limited prospects for the establishment of an IMF framework including DPOs.¹⁰³⁴ As outlined above, since this research was produced a number of new DPOs have been established.

¹⁰²⁸ Joint Oireachtas Committee on Disability Matters, ‘Consultation on Terms of Reference and Work Programme’ 2020

¹⁰²⁹ Joint Committee on Disability Matters Aligning Disability Funding with the United Nations Convention on the Rights of Persons with Disabilities Budget 2022 Pre-Budget Submission July 2021 33/DM/02

¹⁰³⁰ Interview with DPO representative 21 July 2021 (AI)

¹⁰³¹ Department of Justice, Roadmap to Ratification of the United Nations Convention on the Rights of Persons with Disabilities

¹⁰³² NUIG CDLP, Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of Persons with Disabilities, 2016

¹⁰³³ *Ibid* p. 74

¹⁰³⁴ *Ibid*

As discussed below following on from this report the IHREC established a disability advisory committee, utilising its existing powers. The establishment and operation of the IHREC-DAC will be analysed below.

The Irish Government in 2021 indicated that the IHREC would be solely designated as the IMM.¹⁰³⁵ The designation of the IHREC as the IMM was originally to be provided for by way of the Disability Miscellaneous Provisions Bill. However this Bill did not progress. The designation will now be realised by way of the Assisted Decision-Making (Capacity) (Amendment) Bill 2022. The 2022 Bill will also include amendments to the 1999 Act to provide for the NDA to assist the IHREC in its monitoring role. The NDA has indicated that it will provide statistical information and advice to the IHREC.¹⁰³⁶ The Bill indicates that the NDA and the IHREC will agree a Memorandum of Understanding relating to the support to be provided by the NDA.

All DPOs interviewed for this research were content with the proposal to designate the IHREC solely as the IMM.¹⁰³⁷ I explored whether DPOs had reflected on the potential for DPOs to be designated as part of a Framework. A number of DPO representatives suggested that the potential inclusion of DPOs within a Framework should be revisited in a number of years as the IDPM develops. During pre-legislative scrutiny of the 2021 Bill a number of DPOs suggested that the IHREC should be placed under an obligation to engage directly with disabled people and their organisations when performing their role as an IMM.¹⁰³⁸ This suggestion was reflected in the report of the Oireachtas Committee on Children, Equality, Disability, Integration and Youth in their report on the General Scheme of the 2021 Bill.¹⁰³⁹ The IHREC has not raised an objection to this suggestion.

Joe McGrath of the National Platform of Self Advocates when providing evidence on the 2022 Bill questioned the necessity to provide a statutory basis for the involvement of the NDA.¹⁰⁴⁰ His view reflected a general lack of confidence within the IDPM in the NDA. The IHREC representatives interviewed for this research appreciated that the IDPM lacked confidence in

¹⁰³⁵ Ireland, Initial Report under the Convention on the Rights of Persons with Disabilities 2021 para 463

¹⁰³⁶ Department of Children, Equality, Disability, Integration and Youth 'General Scheme and Heads of Bill: Assisted Decision Making (Capacity Amendment) Bill 2021' (November 2021)

¹⁰³⁷ *ibid*

¹⁰³⁸ Committee on Children, Equality, Disability, Integration and Youth Report on Pre-legislative Scrutiny of the General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021 (CDEI 33 008) April 2022, p. 52

¹⁰³⁹ *ibid*

¹⁰⁴⁰ Joint Committee on Children, Equality, Disability, Integration and Youth, General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021: Discussion, 16 February 2022

the NDA and emphasised that the IHREC had sought to limit the involvement of the NDA within the IMM.¹⁰⁴¹

6.6 IHREC

6.6.1 Establishment of the IHREC

The IHREC was established by way of the Irish Human Rights and Equality Commission Act 2014. The IHREC is Ireland's NHRI and national equality authority.

The IHREC was formed following the merger of the IHRC with the Equality Authority. The Irish Government first proposed the merger of the two bodies in 2008 as part of a programme of public service rationalisation to address budgetary constraints brought on by the global financial crisis.¹⁰⁴² This proposal was not implemented due, in part, to concerns raised by civil society. However, both bodies were subject to significant reductions in their budgets which restricted their capacity to deliver their statutory responsibilities.¹⁰⁴³

Following on from this, in 2011 the then Minister for Justice, Equality and Defence announced that the Government intended to establish a 'new, integrated and independent' human rights and equality commission and to form a working group to advise on the mandate, structure, composition, functions, and performance of the new IHREC.¹⁰⁴⁴

To influence the work of the Committee, civil society in Ireland came together in a coalition group called the Irish Equality and Rights Alliance. OfDPs were included within the Alliance.¹⁰⁴⁵ The Alliance sought to influence the design of the IHREC. However, issues relating to the rights of disabled people were not substantively discussed. The report of the working group was broadly welcomed by the IHRC and by civil society.¹⁰⁴⁶

In referring to the obligation to establish an IMF in line with Article 33(2), the working group noted 'In other jurisdictions, the NHRI undertakes this role. In Ireland, the National Disability Authority could equally discharge this function'.¹⁰⁴⁷ It is notable that the working group did

¹⁰⁴¹ Interview with IHREC representative 13 May 2022

¹⁰⁴² Pegram T, *Bridging the Divide: The Merger of the Irish Equality Authority and Human Rights Commission* (TCD Press 2013)

¹⁰⁴³ *Ibid* p. 35

¹⁰⁴⁴ Department of Justice, 'Report of the Working Group on the new Human Rights and Equality Commission' 19 April 2012 para 121

¹⁰⁴⁵ Equality and Rights Alliance, *A Roadmap to a Strengthened Equality and Human Rights Infrastructure in Ireland* (Equality & Rights Alliance, 2011)

¹⁰⁴⁶ Pegram T, 'Bridging the Divide' (n. 955), p. 38

¹⁰⁴⁷ Report of Working Group on the proposed merger of the Irish Human Rights Commission and the Equality Authority into a Human Rights and Equality Commission November 2011, para 3.32

not consider the prospect of the NDA being submerged within a new Commission, nor did the working group consider the relationship between the new Commission and the NDA.¹⁰⁴⁸ Overall, there was a lack of discussion on how the IHREC should be designed in order to ensure that it was well placed to promote and protect the rights of disabled people.¹⁰⁴⁹

6.6.2 Structure of the IHREC

The IHREC is established as a body corporate.¹⁰⁵⁰ The IHREC is accountable to the Oireachtas. The IHREC is required to lay its annual reports before the Oireachtas, and the Director is accountable to the Public Accounts Committee of the Oireachtas.¹⁰⁵¹

The IHREC reflects the Commission model of NHRIs which is common throughout the Commonwealth. The IHREC consists of 15 Commissioners. Commissioners are appointed by the President of Ireland on the advice of Government, following a resolution of each House of the Oireachtas on the basis of an open recruitment process. There is no provision for the involvement of civil society in the appointment process. However, the Oireachtas must ensure that the composition broadly reflects the nature of Irish society.¹⁰⁵² Members are appointed in their individual capacity rather than as representatives of specific organisations.

The IHREC is required to develop a strategic plan, comprising of key objectives and priorities.¹⁰⁵³ The Commissioners meet on a monthly basis to take strategic decisions. The Commission has a number of sub-committees to ensure efficient decision making.¹⁰⁵⁴ It is supported by a secretariat of 62 staff, including a Director and four senior managers.¹⁰⁵⁵

6.6.3 Independence

The IHREC was re-accredited as an A status NHRI in June 2021.¹⁰⁵⁶ The GANHRI SCA did not raise any substantive concerns relating to compliance with the Paris Principles. However, the SCA did recommend that the IHREC ‘...advocate for the formalization and application of a uniform process that ensures the broad participation of civil society in the selection and

¹⁰⁴⁸ Interview with former senior staff member of IHREC 10 January 2022

¹⁰⁴⁹ Interview with representative of Human Rights NGO 14 January 2022

¹⁰⁵⁰ Irish Human Rights and Equality Act 2014 section 8(3)

¹⁰⁵¹ Ibid section 28

¹⁰⁵² Ibid section 13

¹⁰⁵³ Ibid section 25

¹⁰⁵⁴ Interview with IHREC staff member 19 May 2021 (I)

¹⁰⁵⁵ IHREC Annual Report 2020 p. 66

¹⁰⁵⁶ ICC Sub-Committee on Accreditation Report – June 2021

appointment process and the assessment of applicants on the basis of pre-determined and objective criteria'.¹⁰⁵⁷ Whilst the SCA considered the potential designation of the IHREC as a National Preventative Mechanism for the purposes of the UN Convention against Torture, it did not consider the proposed designation of the IHREC as Ireland's IMM.¹⁰⁵⁸ The IHREC publicised the accreditation process to civil society, however the SCA did not highlight any specific concerns raised by civil society in Ireland.¹⁰⁵⁹ DPOs interviewed for this research were generally unaware of the accreditation process.

The IHREC is funded through a vote of the Oireachtas. The 2021 budget for the IHREC was €7.014m.¹⁰⁶⁰ In an interview for this research, a representative of the IHREC indicated that the IHREC is well resourced and that requests for additional resources are likely to be granted.¹⁰⁶¹ One interviewee highlighted that whilst the IHREC has sufficient funding to meet the requirements of the Paris Principles, to effectively deliver their extensive statutory obligations, the IHREC would require significant additional resources.¹⁰⁶² In evidence given to the Oireachtas, the IHREC has emphasised that the allocation of additional responsibilities should be accompanied with the allocation of additional resources.¹⁰⁶³ The formal designation of the IHREC as the IMM may therefore be accompanied with increased funding.

As outlined in Chapter 2, the culture of an NHRI has the potential to impact significantly upon its independence. In general, the DPOs interviewed for this research felt that the Commission is independent and has a strong culture of independence. One DPO representative emphasised that '...whilst it does have to operate within the structures of being kind of like a state body ... it occupies a distinct voice within that space, and it's always sought to be independent and to highlight the issues that marginalised groups face and to also kind of advance human rights over highlighting the interests of the state'.¹⁰⁶⁴ Amongst interviewees, it was generally felt that the current composition of commissioners within the IHREC supported its independence.¹⁰⁶⁵ However, some DPOs questioned the willingness of the IHREC to openly criticise Government initiatives and the work of other public authorities, in particular the NDA. One interviewee

¹⁰⁵⁷ Ibid p. 17

¹⁰⁵⁸ Ibid

¹⁰⁵⁹ IHREC Press Release NGOs invited to make submissions to ICC on IHREC accreditation by 16 July 2015 07/07/2015 (Accessed on 21 September 2021)

¹⁰⁶⁰ IHREC, 'Annual Report 2021' (June 2022) p. 75

¹⁰⁶¹ Interview with IHREC senior staff member 19 May 2021 (I)

¹⁰⁶² Interview with DPO representative (DI) 17 January 2022

¹⁰⁶³ Joint Oireachtas Committee on Disability Matters, UN Convention on Rights of Persons with Disabilities and Ratification of Optional Protocol: Discussion, 17 June 2021

¹⁰⁶⁴ Interview with DPO representative 21 July 2021 (AI)

¹⁰⁶⁵ Interview with DPO representative 1 July 2021 (DA)

suggested that Commissioners are often conscious of the impact of their actions on their future employment opportunities.¹⁰⁶⁶ One interviewee suggested that the independence of the IHREC would be strengthened if it prioritised the appointment of staff who have experienced within the IDPM.¹⁰⁶⁷

6.6.4 Structures for engaging with disabled people

The structure of the IHREC does not expressly provide for the participation of civil society. The IHREC has a power to establish advisory committees ‘for the purpose of establishing and maintaining effective co-operation with representatives of relevant agencies and civil society’.¹⁰⁶⁸ Utilising this power the IHREC established the IHREC-DAC in 2019.¹⁰⁶⁹

The role of the IHREC-DAC is to assist and advise the Commission on ‘matters related to its function of keeping under review the adequacy and effectiveness of law and practice in the State relating to the protection of people with disabilities’ and on the fulfilment of its independent monitoring role under the UNCRPD.¹⁰⁷⁰ The Assisted Decision-Making (Capacity) (Amendment) Bill 2022 proposes amendments to the IHREC Act to provide a statutory basis for the appointment of an advisory committee to assist and advise IHREC on matters relating to its functions as an IMM.¹⁰⁷¹ The Bill will therefore provide a statutory basis for the IHREC-DAC.

The IHREC-DAC has fourteen members: three are Commissioners, including the Chair of the Commission and eleven were recruited through open competition, which included DPO representation.¹⁰⁷² When interviewed, three DPOs raised specific concerns relating to the IHREC’s approach to the recruitment of IHREC-DAC members. DPO representatives highlighted that the definition of disability which informed the recruitment of the IHREC-DAC members was based on the definition of disability included in the Disability Act 2005.¹⁰⁷³ One DPO representative specifically highlighted that this definition was not fully inclusive of persons with psychosocial disabilities.¹⁰⁷⁴ DPOs also felt that Irish disability activists should

¹⁰⁶⁶ Interview with DPO representative 16 July 2021 (VI)

¹⁰⁶⁷ Interview with DPO representative 13 August 2021 (DI)

¹⁰⁶⁸ Irish Human Rights and Equality Act 2014 section 18

¹⁰⁶⁹ IHREC Press Release New Departure on Rights of Persons with Disabilities as Formal Committee Begins Work in Monitoring Ireland’s Obligations 28/01/2019 (accessed 21 September 2021)

¹⁰⁷⁰ IHREC Press Release: New Departure on Rights of Persons with Disabilities as Formal Committee Begins Work in Monitoring Ireland’s Obligations 28 January 2019

¹⁰⁷¹ Section 18

¹⁰⁷² *ibid*

¹⁰⁷³ Interview with DPO representative 13 August 2021 (DW) and Interview with DPO representative 19 July 2021 (EE)

¹⁰⁷⁴ Interview with DPO representative 19 July 2021 (EE)

have been included in the recruitment process. It is noted that a recruitment exercise for five new members launched in June 2022 is based on the definition of disability included in Article 1 of the UNCRPD.¹⁰⁷⁵ However the Assisted Decision-Making (Capacity) (Amendment) Bill 2022 in referring to the composition of the IHREC-DAC refers to the definition of disability included in the 2005 Act rather than the definition provided in the UNCRPD.

The IHREC-DAC is an advisory body, it exists as a mechanism to inform the IHREC. It is considered by both IHREC representatives interviewed for this research and by DPOs to be influential. In the words of a senior staff member within IHREC ‘I would say the Disability Advisory Committee is probably the strongest expression of civil society being part of the structure of the commission’.¹⁰⁷⁶ The IHREC-DAC formally convened six times during 2020.¹⁰⁷⁷

Despite concerns raised in relation to the recruitment process, the establishment of the IHREC-DAC was in general welcomed by members of the IDPM interviewed for this research. The membership of the IHREC-DAC was considered to be broad based, with many members being drawn from established DPOs. One DPO representative highlighted that the absence of a member of the IHREC-DAC who identified as a person with a psychosocial disability undermines the potential for the IHREC-DAC to represent the views of such persons.¹⁰⁷⁸ The representative highlighted that they have raised the matter with senior staff in IHREC and have not received a clear response. However, the members of the IHREC-DAC interviewed for this research emphasised that they are conscious of this potential gap and have sought to address it through their broader activities.¹⁰⁷⁹

The establishment of the IHREC-DAC is considered to have bolstered the credibility of IHREC in the eyes of the IDPM. One interviewee stated that it was a way of ‘...saying to the DPOs and to the wider disability community that IHREC cares, that they want to do this monitoring job properly by having their own direct information’.¹⁰⁸⁰ It was noted positively that two

¹⁰⁷⁵ IHREC ‘Recruitment Pack’ Available at: https://osbornerecruit-my.sharepoint.com/:w/g/personal/dylan_gannon_osborne_ie/EQwD66-Fiv1MtdfoVLg78g8BBHXwqe6KkL4PjKgHNM_L4g?rttime=rCIJFWhp2kg (Accessed on 18 July 2022)

¹⁰⁷⁶ Interview with IHREC staff member 19 May 2021 (I)

¹⁰⁷⁷ IHREC ‘Annual Report 2020’ 13 July 2021

¹⁰⁷⁸ Interview with DPO representative 19 July 2021 (EE)

¹⁰⁷⁹ Interview with DPO representative 1 July 2021 (DA)

¹⁰⁸⁰ Interview with DPO representative 19 July 2021 (EE)

members of the IHREC-DAC have subsequently been appointed as commissioners of the IHREC.¹⁰⁸¹

Two members of the IHREC-DAC interviewed for this research emphasise that they were generally pleased with how the IHREC-DAC has operated and with the level of influence that they have over decisions and activities within the IHREC.¹⁰⁸² One member considered that they are valued as ‘a direct source of information of reality’.¹⁰⁸³ In support of this view, it is noted that the IHREC-DAC have been closely involved in the development of the IHREC Strategy Statement 2022-24.¹⁰⁸⁴ However, I do note that when a vacancy emerged in the membership of the IHREC-DAC this was not filled. In addition, the term of office of the first membership came to an end in January 2022. This is likely a result of the forthcoming legislation. However, the absence of public statements from the IHREC until the June 2022 recruitment initiative is a source of concern.

The members of the IHREC-DAC are appointed on an individual basis. Considering the emphasis which the UNCRPD Committee places on engaging with disabled people through their organisations, I explored if the IHREC had considered including representatives of DPOs within the IHREC-DAC. An IHREC senior staff member considered that appointing members on the basis of their expertise meant that members were more likely to provide a broad range of perspectives on matters under consideration. Individuals appointed due to their membership or relationship with an organisation may be less likely to share their own expertise and perspective and more likely to set out their organisation’s position.¹⁰⁸⁵ The senior staff member considered that there was a risk that having a mixture of members who were able to speak on behalf of organisations and individuals speaking based on their own expertise may undermine the capacity of the IHREC-DAC to provide robust advice.¹⁰⁸⁶ In addition, allocating membership on the IHREC-DAC to DPOs was considered contentious as it would involve the IHREC in determining the suitability of organisations to speak on behalf of disabled people.¹⁰⁸⁷

The Assisted Decision-Making (Capacity) (Amendment) Bill 2022 will provide a statutory basis for the advisory committee. The clause requires that half of the members shall have or

¹⁰⁸¹ Interview with DPO representative 1 July 2021 (DA)

¹⁰⁸² *ibid*

¹⁰⁸³ *ibid*

¹⁰⁸⁴ *ibid*

¹⁰⁸⁵ Interview with IHREC representative 13 May 2022

¹⁰⁸⁶ *ibid*

¹⁰⁸⁷ *ibid*

have had a disability.¹⁰⁸⁸ In June 2022 the IHREC committed to ensure that 75% of the external members of the IHREC will be disabled people, under the definition provided in the UNCRPD. The clause does not provide for individuals to be appointed to represent DPOs or other organisations. This issue was not raised in pre-legislative scrutiny. There is a risk that if the legislation were to require that representative organisations be included within the IHREC-DAC, OfDPs may effectively advocate for their own participation in the IHREC-DAC to be provided for in law.¹⁰⁸⁹ An IHREC senior staff member emphasised that it was important not to ‘underestimate the forces against DPOs’.¹⁰⁹⁰ It appears therefore that the clause will be enacted as drafted, responsibility for the appointment to the IHREC-DAC will continue to rest with the IHREC and that appointments will continue to be made on an individual basis. The merits of this approach will be discussed in my concluding chapter.

6.7 Collaboration between the IHREC and IDPM

In this section I will consider how the IHREC and IDPM have collaborated. I will begin by examining specific activities of the IHREC relating to DPOs and will then turn attention to their promotional activities and finally their protection activities. Across all activities I will assess how the IDPM is engaging with the IHREC to strengthen its voice and challenge the conditions which undermine its capacity.

6.7.1 Supporting the development of DPOs

The IHREC has an overarching statutory obligation to promote awareness of human rights and has interpreted this obligation broadly. Within its strategic plan and structure the IHREC places a strong emphasis on supporting civil society. The IHREC’s current strategic plan includes an objective to ‘strengthen relationships with civil society and foster an enabling environment for human rights development’.¹⁰⁹¹ The IHREC has specifically considered how its activities support the development of DPOs. A senior member of staff at the IHREC interviewed for this research emphasised that the IHREC has a multi-faceted role in supporting DPOs which includes: provision of financial support, educating and empowering DPOs and ‘steering the state’ to advocate for their inclusion.¹⁰⁹²

¹⁰⁸⁸ Section 8

¹⁰⁸⁹ Interview with DPO representative 16 July 2021

¹⁰⁹⁰ Interview with IHREC representative 13 May 2022

¹⁰⁹¹ IHREC Strategy Statement 2019-21 (IHREC 2019)

¹⁰⁹² Interview with IHREC staff member 19 May 2021 (I)

The IHREC administers a €350,000 grant programme, which provides small grants up to €6,000 and general grants up to €20,000 to CSOs involved in the promotion of human rights.¹⁰⁹³ Whilst one of the three strands of the 2021-22 grant scheme is progressing the rights of disabled people, it is notable that the grants programme does not seek to prioritise the provision of grants to DPOs.

There was broad awareness of the scheme amongst DPOs interviewed for this research.¹⁰⁹⁴ Unsurprisingly, a number of DPOs who had received funding under the scheme were generally quite complimentary.¹⁰⁹⁵ One DPO who applied through the scheme and was unsuccessful highlighted that the IHREC provided the organisations with clear reasons for the decision and constructive feedback.¹⁰⁹⁶

A number of DPOs highlighted that the programme was not accessible to them due to the requirement that organisations be registered either as a company or as a charity.¹⁰⁹⁷ Two DPOs highlighted that this requirement presents a potential obstacle to DPOs.¹⁰⁹⁸ It was noted that many DPOs originated and remain as grass roots organisations and do not have the capacity to register as companies or charitable organisations. Furthermore, one DPO highlighted that arrangements in place to register as a charitable organisation are out-dated and stigmatising for disabled people. One DPO leader stated that the requirement that DPOs be registered as a charity or company to access funding was ‘reinforcing systems that have historically contributed to disabled people’s exclusion’.¹⁰⁹⁹ A representative of the IHREC highlighted that these requirements were technical requirements considered necessary to ensure the proper use of public funds.¹¹⁰⁰

In addition to the grant programme, the IHREC operate a scholarship programme for civil society activists to fund their participation in a human rights diploma. A number of disability activists have benefited from this programme.¹¹⁰¹ However, one interviewee highlighted that the programme is only open to staff members of CSOs and that this requirement disadvantages

¹⁰⁹³ IHREC Human Rights & Equality Grants Scheme 2020-21 (IHREC 2020)

¹⁰⁹⁴ Interview with DPO representative 16 July 2021 (VI)

¹⁰⁹⁵ Interview with DPO representative 6 August 2021 (W)

¹⁰⁹⁶ Interview with DPO representative 21 July 2021 (AI)

¹⁰⁹⁷ IHREC Press Release Human Rights and Equality Grant Scheme 2021-22 Opens for Applications 12/03/2021 (Accessed 21 September 2021)

¹⁰⁹⁸ Interview with DPO representative 19 July 2021 (EE)

¹⁰⁹⁹ Interview with DPO representative 13 August 2021 (DW)

¹¹⁰⁰ Interview with former senior staff member of IHREC 10 January 2022

¹¹⁰¹ Interview with IHREC staff member 19 May 2021 (I)

grass roots DPOs which are composed principally of volunteers and are unlikely to have employed staff members.

Several interviewees considered that the IHREC should be more open to funding grass roots DPOs and to supporting them to become registered as organisations. Two interviewees felt the IDPM face unique challenges to establishing and sustaining advocacy organisation and suggested that the IHREC should be more proactive in seeking out and supporting DPOs.¹¹⁰² Overall, I found that the potential for the grant programme to support the growth of the IDPM was not being fully realised and the need for specific measures to ensure the programme was accessible to DPOs was not fully examined.

The IHREC is the only NHRI examined for this research which operated a grants programme. I investigated with interviewees whether there was a risk that DPOs and CSOs, more generally, would become unwilling to criticise the IHREC due to a concern that this may jeopardise a funding application. Overall interviewees considered that the programme had not had this effect.¹¹⁰³ In support of this view it was noted that the grants were relatively small and unlikely to substantively influence the core activities of a recipient.¹¹⁰⁴ A representative of the IHREC highlighted that applications were assessed by a rigorous process which was insulated from any potential undue influence from the IHREC staff members.¹¹⁰⁵ Overall, therefore I consider that the operation of the small grants programme has not had the effect of undermining the willingness of DPOs and civil society to critique the activities of the IHREC.

Empowering DPOs

As set out previously the UNCRPD Committee have emphasised that through the act of participating in policy discussions disabled people enhance their capacity to influence public policy.¹¹⁰⁶

The IHREC senior staff and members of the IHREC-DAC were conscious that by facilitating the participation of DPO leaders within their monitoring activities, the IHREC is supporting the development of the IDPM.¹¹⁰⁷ It is noted that whilst members of the IHREC-DAC are

¹¹⁰² Interview with DPO representative 16 July 2021 (VI)

¹¹⁰³ Interview with representative of Human Rights NGO 19 January 2022

¹¹⁰⁴ Interview with representative of Human Rights NGO 14 January 2022

¹¹⁰⁵ Interview with former senior staff member of IHREC 10 January 2022

¹¹⁰⁶ See chapter 3

¹¹⁰⁷ Interview with senior staff member of IHREC 19 May 2021

appointed in their individual capacity, a number of the members hold senior positions within DPOs. Members of the IHREC-DAC interviewed for this research believe that through their engagement within the IHREC-DAC they have developed their knowledge and skills, thereby enhanced their ability to support the growth and development of their own organisations.¹¹⁰⁸ A DPO representative interviewed for this research indicated that the initial conversations which led to the development of the DPO Coalition took place at the periphery of the IHREC-DAC meetings. They further highlighted that the IHREC facilitated the development of the DPO Coalition, in particular by providing meeting rooms and funding sign language interpretation to facilitate participation in their meetings.¹¹⁰⁹ This suggests that through the structures put in place to conduct their monitoring activities, the IHREC is supporting members of the movement to develop their policy expertise and facilitating coherence across the movement.

Through my evidence gathering I identified that DPOs have enhanced their understanding of human rights and their capacity to utilise human rights in their advocacy through their engagement with the IHREC.¹¹¹⁰ A representative of a DPO focused on the rights of people with autism which has engaged with the IHREC and whose members participate in the IHREC-DAC highlighted that ‘our dealings with [the] IHREC have really kind of shaped the way that we’ve seen autism and the way that we’ve seen disability as well, and it’s really kind of shaped our own view within that space and also our own advocacy in terms of advancing the human rights of autistic people as well’.¹¹¹¹

6.7.2 Steering the state : Priority to DPOs

DPOs interviewed for this research consistently emphasised that one of the key challenges to the establishment of a robust IDPM was the continued pre-eminence of OfDPs. These organisations continued to present themselves as the authentic voice of disabled people and to monopolise state funding.¹¹¹² Furthermore it was considered that OfDPs, who were often service providers continued to reinforce the influence of the charitable model on disability discourse in Ireland.¹¹¹³ Interviewees suggested that OfDPs put forward the view that disabled

¹¹⁰⁸ Interview with representative of Disability Advisory Committee 29 June 2021 (E)

¹¹⁰⁹ Interview with DPO representative 1 July 2021 (DA)

¹¹¹⁰ Interview with Commissioner of IHREC 16 August 2021

¹¹¹¹ Interview with DPO representative 21 July 2021 (AI)

¹¹¹² Interview with DPO representative 16 July 2021(VII)

¹¹¹³ Interview with DPO representative 17 January 2022 (DI)

people, in particular those with intellectual disabilities, needed the non-disabled to speak on their behalf.¹¹¹⁴

Representatives of the IHREC interviewed for this research considered that one of its key roles was ‘ensuring that the voice of people with disabilities are viewed as being legitimate...’.¹¹¹⁵ The IHREC in its policy submissions has consistently highlighted that the state is required to ‘...give priority to the views of DPOs on matters relating to persons with disabilities’.¹¹¹⁶ IHREC representatives also highlighted that they were conscious of the risk of service providers ‘human rights washing’ their activities and organisations. Indeed the IHREC have recommended that the Irish Government develop a framework for the recognition and support of DPOs.¹¹¹⁷

Despite these measures, DPOs consistently highlighted that IHREC needed to be more proactive in challenging OfDPs who seek to present themselves as the authentic voice of disabled people. Two DPOs specifically suggested that IHREC needed to provide advice on how the Irish Government could ensure the views of DPOs are prioritised in the Irish public policy process.¹¹¹⁸ It was considered that there was a need for IHREC to develop guidance on how GC 7 should be reflected in the Irish policy making process.¹¹¹⁹ As discussed below there is a need for IHREC to clearly set out the definition of DPOs included in GC 7.

GC 7 makes clear that states should provide funding to DPOs to allow them both to participate in the policy making and monitoring processes.¹¹²⁰ DPOs interviewed for this research consistently highlighted the lack of available funding to support their advocacy activities.¹¹²¹ The IHREC has highlighted the need for the state to provide funding for DPOs¹¹²² and influenced a report by the Oireachtas Committee which called for additional funding.¹¹²³ However, the IHREC has not put forward specific suggestions for the development of a funding programme and also has not offered critical comment when the state has established funding

¹¹¹⁴ Interview with DPO representative 17 January 2022

¹¹¹⁵ Interview with Commissioner of IHREC 16 August 2021

¹¹¹⁶ IHREC Submission to Consultation on Terms of Reference and Work Programme for the Joint Oireachtas Committee on Disability Matters (IHREC November 2020)

¹¹¹⁷ Joint Oireachtas Committee on Disability Matters UN Convention on Rights of Persons with Disabilities and Ratification of Optional Protocol: Discussion (17 June 2021) <https://www.kildarestreet.com/committees/?id=2021-06-17a.597&s=IHREC#g633>

¹¹¹⁸ Interview with DPO representative 1 July 2021 (ah)

¹¹¹⁹ Interview with DPO representative 16 July 2021 (VI)

¹¹²⁰ CRPD Committee (n. 62) para 11

¹¹²¹ Interview with DPO representative 6 August 2021

¹¹²² IHREC Observations on the General Scheme of the Equality / Disability (Miscellaneous Provisions) Bill (IHREC November 2016) p. 24

¹¹²³ Joint Committee on Disability Matters Aligning Disability Funding with the United Nations Convention on the Rights of Persons with Disabilities Budget 2022 Pre-Budget Submission July 2021 33/DM/02

programmes which fall short of the requirements of the GC 7. For instance, the IHREC did not highlight the failure of the Irish Government to ensure the Disability Participation and Awareness Fund 2021 prioritised DPOs.¹¹²⁴

6.7.3 Steering the State: Participative mechanisms

DPO representatives highlighted that the Irish Government had developed a range of participative structures that amounted only to ‘talking shops’.¹¹²⁵ It was considered by DPO representatives that there was a need for the IHREC to scrutinise participative structures established by the state to ensure they were providing DPOs with a genuine opportunity to influence the policy making process.

In my evidence gathering I critically assessed the role of the IHREC in scrutinising and advising on participative mechanisms. The Irish Government has established a Disability Stakeholder Group (‘DSG’) to monitor implementation of the NDIS. The DSG engage with the full range of Government Departments. Each Government Department is required to establish a ‘disability consultation committee (‘DCC’)’ to engage with the DSG and report on implementation of Departmental objectives relating to the NDIS. However the DSG has expressed concern that ‘DCCs are not running consistently across all Departments’.¹¹²⁶

During my evidence gathering the DCEDIY ran a recruitment process for the sixth DSG. For the first time representatives of organisations were invited to apply for membership of the DSG and the Minister specifically invited representatives of DPOs.¹¹²⁷ The current DSG includes representative of both DPOs and OfDP. It also includes both disabled people and people with ‘lived experience of disability’. In my evidence gathering I identified limited examples of the IHREC engaging with the DSG or engaging with Government in relation to the DSG. In contrast, the NDA has a specific role to support the DSG. As discussed below the lack of engagement by IHREC with the DSG seems in part to be a consequence of the IHREC not wishing to encroach upon the activities of the NDA.¹¹²⁸

¹¹²⁴ Department of Children, Equality, Disability, Integration and Youth Minister Rabbitte opens the first funding call for the Disability Participation and Awareness Fund 2021 22 October 2021

¹¹²⁵ Interview with DPO representative 6 August 2021 (DW)

¹¹²⁶ Disability Strategy Group, Draft Meeting Minutes Thursday 25th February 2021, Doc Ref: DSG5/75

¹¹²⁷ Department of Children, Equality, Disability, Integration and Youth, Written answers Tuesday, 12 October 2021

¹¹²⁸ Interview with former senior staff member of IHREC 10 January 2022

In 2019, the Government proposed the development of a consultation and participation model to ‘...support the emergence and ongoing operation of Disabled Persons Organisations in line with the Convention’.¹¹²⁹ In 2020, the Irish Government established a Disability Participation and Consultation Network (‘DPCN’) which is comprised of an organizing member, four grant funded members and 113 voluntary members, who are a mixture of individuals, DPOs and OfDPOs.¹¹³⁰ The stated goal of the DPCN is ‘to ensure disabled people and disability organisations are actively engaged and consulted on policies & legislation in line with UNCRPD’. One of the principal tasks of the DPCN since its establishment has been to develop a shadow report to the UNCRPD Committee. The DCEDIY has emphasised that the DPCN is intended to ‘build capacity within the disability community’.¹¹³¹ The Irish Government have not clarified how the DPCN will interact with the DSG. Whilst the DSG does not have a role in building the capacity of the disability community, the DSG does play a key role in monitoring and providing views on the NDIS, which is currently the principal policy vehicle for bringing about implementation of the UNCRPD. There is therefore an overlap between the roles of the DSG and the DPCN. Interviewees for this research consistently expressed confusion as to the relationship between the DSG and the DPCN. The DSG itself has raised concerns at the ‘fragmentation’ of oversight mechanisms.¹¹³² The IHREC is not an observer member of the DSG and does not currently have a formal relationship with the DPCN. Furthermore, the IHREC appear to have largely been absent from discussions relating to the development of the DPCN.¹¹³³

Interviewees expressed concern that the establishment of the DPCN was a largely tokenistic initiative. One DPO representative suggested that the DPCN had been developed to avoid criticism by the UNCRPD Committee.¹¹³⁴ Reflecting this view I note that the Irish Government’s initial state report on compliance with the UNCRPD indicates that the DPCN is ‘comprised primarily of Disabled Persons Organisations’.¹¹³⁵ However, from my review of the membership this is clearly not the case. A senior staff member in the IHREC highlighted that the Irish Government has adopted a more expansive interpretation of a DPO than that put forward by the UNCRPD Committee.¹¹³⁶ This interpretation has been challenged by the

¹¹²⁹ National Disability Authority Mid-term Review of Progress: The National Disability Inclusion Strategy and Indicators April 2020

¹¹³⁰ DCEDIY, Press Release Launch of Disability Participation and Consultation Network, 6 November 2020

¹¹³¹ Department of Children, Equality, Disability, Integration and Youth, Oral Questions: Disability Services 4 November 2021

¹¹³² Disability Stakeholders Group (n. 1028)

¹¹³³ Interview with senior staff member of IHREC 19 May 2021

¹¹³⁴ Interview with DPO representative 1 July 2021 (DA)

¹¹³⁵ Ireland, Initial Report under the Convention on the Rights of Persons with Disabilities 2020

¹¹³⁶ Interview with IHREC representative 13 May 2022

IHREC in meetings with officials. However the IHREC representative acknowledged that there was a need for the IHREC to issue a public statement clearly setting out the UNCRPD Committee’s definition of a DPO.¹¹³⁷

The involvement of OfDPs was considered to have stifled the potential for the DPCN to transform the relationship between DPOs and the Government. As expressed by one interviewee ‘OfDPs already have built and sort of developed those relationships with previous government departments. So, in effect they’re kind of carrying over those relationships over to the new department, and that kind of gives those organisations a leg up in terms of advocacy’.¹¹³⁸ Furthermore it was considered that the size of the membership created practical obstacles to the operation of the Network, for instance in developing collective statements.¹¹³⁹

It is notable that DPOs interviewed for this research had not raised their concerns relating to the operation of the DPCN with the IHREC. In addition, the IHREC has not offered a critique of the initiative. A representative of the IHREC stated that whilst they were aware of criticism of the DPCN the IHREC have not reviewed the issue in detail.¹¹⁴⁰ In the words of one DPO representative, ‘At every single step here, DPOs are excluded. If not excluded, they are marginalised. It’s just absolutely astonishing. How the hell can this be happening? And this is on IHREC’s watch?’.¹¹⁴¹

Given that the development of effective participative procedures is considered essential to the effective implementation of the UNCRPD, the absence of comments from the IHREC is disappointing.

6.7.4 Provision of advice on law reform proposals

The IHREC must keep under review the law of Ireland relating to human rights and equality and provide advice to the Oireachtas and Government on proposals for law reform and draft Bills prepared by Government and members of the Oireachtas.¹¹⁴² In addition, the IHREC may put forward proposals for reform based on its own analysis.

¹¹³⁷ *ibid*

¹¹³⁸ Interview with DPO representative 21 July 2021 (AI)

¹¹³⁹ Interview with DPO representative 16 July 2021 (VI)

¹¹⁴⁰ Interview with IHREC representative 13 May 2022

¹¹⁴¹ *Ibid*

¹¹⁴² Section 10(2)(b)-(d)

In my evidence gathering I sought to determine if DPOs and the IHREC were collaborating in responding to public consultations and proposals for reform. In my evidence gathering I found that DPOs were rarely contacting the IHREC to coordinate responses to law reform proposals.¹¹⁴³ The approach of the IHREC was mixed. The IHREC does not have a standardised approach to engaging with civil society when responding to a proposed reform.¹¹⁴⁴

In 2021, the Minister for DCEDIY announced a Review of the Equality Acts.¹¹⁴⁵ One of the stated objectives of the review is to respond to recommendations from the IHREC. In responding to this review, the IHREC has collaborated with the Federation of Legal Advice Clinics ('FLAC') in developing a guide to the review, to assist CSOs in responding.¹¹⁴⁶ A number of DPOs, including ILMI, attended discussions held by the IHREC on the review.¹¹⁴⁷ During the discussion, the IHREC shared key insights, including on the need for revision to the duty to make reasonable accommodations for disabled people in the provisions of goods and services. These initiatives therefore ensured coordinated approaches by the IHREC and IDPM, reinforcing their positions.

The IHREC therefore have demonstrated that when responding to law reform proposals, which have a significant impact on the rights of disabled people, that they will make an effort both to collaborate with the IDPM and to inform the IDPM to maximise impact. The decision as to whether the IHREC seeks the views of a DPO or other CSO seems to depend on a range of factors including; the significance of the proposal; the timeframe; and the potential for DPOs to contribute expertise and insights.¹¹⁴⁸ Senior staff in the IHREC informed me that there was no written procedure to determine whether the IHREC staff sought the views of DPOs or other CSOs when responding to a law reform proposal. However, senior staff did inform me that for certain policy areas the IHREC will routinely consult with CSOs who they consider to be experts in the field. For instance, in relation to prison conditions the IHREC staff will routinely consult with two leading CSOs recognised for expertise in this area.¹¹⁴⁹ In contrast, the IHREC had not developed a practice of consulting with a number of DPOs on disability policies. However, it was developing a practice of seeking the views of the IHREC-DAC.¹¹⁵⁰ I did not

¹¹⁴³ Interview with DPO representative 16 July 2021 (VI)

¹¹⁴⁴ Interview with former senior staff member of IHREC 10 January 2022

¹¹⁴⁵ Department of Children, Equality, Disability, Integration and Youth Consultation on the Review of the Equality Acts 6 July 2021

¹¹⁴⁶ IHREC & FLAC, Equality ACTION, 'Guide to the Review Process & Introduction to the Equality Acts', October 2021 . Available at: <https://www.ihrec.ie/app/uploads/2021/11/Equality-ACTION-Submission-Support-Note-Nov-2021.pdf> (Accessed 2 January 2022)

¹¹⁴⁷ ILMI Twitter Account 5 November 2021 Available at <https://twitter.com/17octcomIRL/status/1457624839146156034> (Accessed 21 January 2022)

¹¹⁴⁸ Interview with former senior staff member of IHREC 10 January 2022

¹¹⁴⁹ Interview with IHREC staff member 19 May 2021 (I)

¹¹⁵⁰ Interview with IHREC Commissioner 16 August 2021

identify evidence of IHREC routinely consulting OfDPs. However I note that senior staff within OfDPs have at times been appointed as IHREC Commissioners.¹¹⁵¹ As I will explore in my conclusions chapter, this suggests that the establishment of an advisory committee may actually be dissuading the IHREC from establishing formal relations with the DPM.

Interviewees in general were content with the advice provided by the IHREC. A number of interviewees noted that the IHRC had a reputation for providing robust advice and that this had been reflected in the work of the IHREC.¹¹⁵² I assessed advice provided by the IHREC relating to relevant laws and policies and found it to be well drafted and broadly reflective of the UNCRPD. In 2016, the Irish Government published the Disability (Miscellaneous Provisions) Bill 2016, the Bill identified a number of reforms necessary to facilitate ratification of the UNCRPD. In responding to the Bill, the IHREC set out in detail a number of reforms required to ensure Irish law was in compliance with the UNCRPD, including setting out the need for the legal definition of reasonable accommodation to be amended to reflect Article 5 of the UNCRPD.¹¹⁵³ The IHREC also provided advice concerning the Dying with Dignity Bill 2020, in which it made extensive reference to the UNCRPD, and provided practical advice on how the Bill could be designed to reflect the UNCRPD.¹¹⁵⁴ I note positively that in its submission to the review of the Equality Acts the IHREC both provided detailed comments on the substantive reforms and made comments relating to the need to ensure access to justice through the provision of legal aid.¹¹⁵⁵

In preparation for ratification the Irish Government brought forward the Assisted Decision Making (Capacity) Bill in 2013. The IHRC provided advice on the Bill raising concerns that the Bill failed to distinguish between legal capacity and mental capacity. The IHRC recommended that the Bill include a specific reference to the UNCRPD and made a number of recommendations to ensure the Bill reflected Article 12 of the UNCRPD.¹¹⁵⁶ To influence the passage of the Bill a coalition including the CDLP, Amnesty International's Mental Health Campaign and disabled people was established.¹¹⁵⁷ The coalition brought forward eight key proposals for reform of the Bill. During the passage of the Bill the IHRC was preparing for its

¹¹⁵¹ IHREC Press Release, Eight New Commission Members Proposed for the IHREC 12.06.2020

¹¹⁵² Interview with representative of Human Rights NGO 14 January 2022

¹¹⁵³ IHREC 'Observations on the General Scheme of the Equality / Disability (Miscellaneous Provisions) Bill' 02/12/2016

¹¹⁵⁴ IHREC 'Submission to the Committee on Justice on the Dying with Dignity Bill' 2020 03/02/2021

¹¹⁵⁵ IHREC, 'Submission on the Review of the Equality Acts' 10/01/2022

¹¹⁵⁶ IHRC Observations on the Assisted Decision-Making (Capacity) Bill 2013 March 2014

¹¹⁵⁷ Flynn E, *The Long Road to Ratification: Ireland and the CRPD* in Emily Julia Kakoullis and Kelley Johnson (eds) *Recognising Human Rights in Different Cultural Contexts: The United Nations Convention on the Rights of Persons with Disabilities* (Palgrave 2020), p. 140

amalgamation with the Equality Authority to form the IHREC. As a result there was limited engagement with the Oireachtas during the passage of the Bill.¹¹⁵⁸ Disability campaigners were disappointed that the Assisted Decision Making (Capacity) Act 2015 defines mental capacity based on a functional test.¹¹⁵⁹

DPOs have sought to ensure that the codes of practice required to give effect to the 2015 Act are reflective of the UNCRPD.¹¹⁶⁰ A number of DPO representatives were disappointed that the IHREC had not provided advice on the development of codes of practice relating to the Assisted Decision Making (Capacity) Act 2015.¹¹⁶¹ A representative of the IHREC indicated that due to resource constraints the IHREC lacked capacity to provide advice on the Codes.¹¹⁶² However, given the expertise within the IDPM in this area, in my view the IHREC could potentially have played a role in amplifying the voices of DPOs without having to invest significant time and expertise in developing its own analysis.

In November 2021, the Irish Cabinet published the General Scheme to the Assisted Decision-Making (Capacity) (Amendment) Bill. The Bill, *inter alia*, proposes amendments to the 2015 Act to provide additional safeguards.¹¹⁶³ The Bill was the subject of pre-legislative scrutiny by a Joint Oireachtas Committee in 2022. Along with other stakeholders the IHREC provided oral evidence to the Committee. Surprisingly, in giving advice the IHREC did not raise concerns relating to the continued centrality of functional assessment of capacity within the 2015 Act.¹¹⁶⁴ Whilst disability campaigners have raised these concerns, the IHREC has largely been silent on the compatibility of the 2015 Act with the UNCRPD Article 12. As a result Government officials have been able to claim that the 2015 Act will give ‘full effect to its obligations under Article 12 of the UNCRPD’.¹¹⁶⁵ The IHREC did not submit written advice on the Bill. Overall the IHREC did not provide analysis of the Bill on a clause by clause basis. Whilst the IHREC have shown themselves to be able to make significant and detailed contributions to the law

¹¹⁵⁸ Interview with DPO representative 13 August 2021

¹¹⁵⁹ Flynn, E., & Gooding, P. (2015). Warning over ‘assisted decision-making’ plans in new Bill. Irish Times [online]. Available at: <https://www.irishtimes.com/opinion/warning-over-assisted-decision-making-plans-in-new-bill-1.2254880>

¹¹⁶⁰ Decision Support Service, <https://decisionsupportservice.ie/news-events/dss-launch-phase-2-public-consultation-draft-codes-practice> 10 January 2022 Available at: <https://decisionsupportservice.ie/news-events/dss-launch-phase-2-public-consultation-draft-codes-practice> (Accessed on 2 June 2022)

¹¹⁶¹ Interview with representative of DPO 17 January 2022

¹¹⁶² Interview with IHREC representative 13 May 2022

¹¹⁶³ DCEDIY Press Release, Cabinet approves General Scheme on the Assisted Decision-Making (Capacity) (Amendment) Bill 22 November 2021

¹¹⁶⁴ IHREC, Opening statement by Adam Harris, Commission Member, Irish Human Rights and Equality Commission, To be delivered to the Joint Committee on Equality, Disability, Integration and Youth on the Pre-legislative scrutiny of the General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021 (16 February 2022)

¹¹⁶⁵ Statement of Aine Flynn to the Joint Committee on Disability Matters debate – (Thursday, 20 May 2021), Available at https://www.oireachtas.ie/en/debates/debate/joint_committee_on_disability_matters/2021-05-20/2/ (Accessed on 11 April 2022)

making process, they have failed to make contributions to important consultations relating to mental capacity law reform in Ireland.

The rights of disabled people in Ireland are often provided for within policy instruments rather than being set down in law.¹¹⁶⁶ In addition to advising on law reforms progressing through the Oireachtas, the IHREC can make a significant contribution towards the rights of disabled people through advising Departments and public officials on the development of policies.

In my analysis I sought to determine the extent to which the IHREC were engaging with public officials in the development of disability policy. A senior staff member in the IHREC informed me that in the past public officials have rarely sought the advice of the IHREC when developing policy instruments: ‘I mean you’ve probably heard this from others as well – nobody came knocking on the door of the NHRI during the Covid pandemic. Nobody came to us’.¹¹⁶⁷ However, the staff member noted that the perception of the IHREC within the Irish civil service was slowly changing. With respect to the Covid pandemic, it was noted that the publication of a Guidance Notice for public authorities on compliance with the public sector human rights and equality duty (‘PSHRED’) has been welcomed by public authorities.¹¹⁶⁸ The senior staff member considered that through their engagement with Departments in the development of PSHRED plans, the IHREC was slowly establishing itself as a centre of expertise on the requirements of PSHRED and on compliance with human rights and equality obligations more generally.¹¹⁶⁹

DPO representatives highlighted that in discussions relating to the development and implementation of national disability strategies the IHREC has largely been absent.¹¹⁷⁰ A DPO representative suggested that part of the reasons for this was an unwillingness to counter the views of the NDA.¹¹⁷¹ An IHREC senior staff member highlighted that the IHREC was conscious of criticism of the NDA from the IDPM and emphasised that the IHREC sought to maintain a distinct voice from that of the NDA.¹¹⁷² However, DPO representatives consistently highlighted that there was a need for the IHREC to be more proactive in disability policy

¹¹⁶⁶ Interview with former senior staff member of IHREC 10 January 2022

¹¹⁶⁷ Interview with IHREC staff member 19 May 2021 (I)

¹¹⁶⁸ IHREC, Guidance Note on Covid 19 and the PSEHRD Feb 2021 <https://www.ihrec.ie/app/uploads/2020/08/Guidance-Note-on-COVID-19-and-the-Public-Sector-Equality-and-Human-Right-Duty-002.pdf>

¹¹⁶⁹ Interview with Senior staff member 19 May 2021

¹¹⁷⁰ Interview with DPO representative 16 July 2021 (VI)

¹¹⁷¹ Ibid

¹¹⁷² Interview with IHREC representative 13 May 2022

discourse, in particular to counter restrictive interpretations of the UNCRPD put forward by the NDA.¹¹⁷³

The absence of the IHREC from discussions relating to the NDIS has meant that DPOs have not been able to collaborate with the IHREC when engaging with officials on the implementation of the UNCRPD through the NDIS. DPO representatives highlighted that in discussions relating to the NDIS their voices are often eclipsed by the voices of service providers.¹¹⁷⁴ Whilst DPOs would benefit from the support of the IHREC to strengthen their voice in policy discussions relating to the NDIS, the IHREC has not yet fully entered these discussions.

The Irish Government has committed to develop a UNCRPD implementation plan.¹¹⁷⁵ In developing this plan public officials are likely to seek out the advice and support of the IHREC in designing policy measures to domesticate the articles of the UNCRPD. A senior staff member highlighted that there was a need for the IHREC to develop its own expertise on a range of policy issues to ensure that the IHREC can offer meaningful advice on policy issues. In the words of the senior staff member, they ‘don't want some abstract notion, you need to tell the State this is the change, and this is the activity’.¹¹⁷⁶ The IHREC intend to develop its capacity to produce detailed and substantive policy advice on the implementation of the UNCRPD.

6.7.5 Awareness Raising

DPO representatives interviewed for this research consistently highlighted that public discourse relating to disabled people in Ireland continued to be heavily influenced by the medical and charity model of disability. Writing in 2003, Donal Toolan highlighted that the dominant ‘culture of care’ presented disabled people as passive individuals, in need of support from the able bodied.¹¹⁷⁷ IDPM representatives highlighted that this culture continued to pervade discussions relating to disability policy and a key objective of the IDPM was moving

¹¹⁷³ Interview with former senior staff member of IHREC 10 January 2022

¹¹⁷⁴ Interview with DPO representative 16 July 2021 (VI)

¹¹⁷⁵ CRPD Initial State Report – December 2020, para 12

¹¹⁷⁶ Interview with representative of IHREC 13 May 2022

¹¹⁷⁷ Donal Toolan, ‘An emerging rights perspective’ (n. 937), p. 172

‘the conversation away from viewing disabled people as objects of pity or charity, to being rights holders in their own right’.¹¹⁷⁸

The IHREC engages in awareness raising to influence attitudes within society and to promote understanding. Throughout 2019, the IHREC held an awareness raising campaign entitled ‘Because we’re all human. Means we’re all equal’.¹¹⁷⁹ The campaign - which involved TV, radio and cinema advertisements - promoted positive attitudes towards disabled people. Interviewees were generally complimentary of this awareness raising campaign which placed disabled people at the centre of the campaign. One DPO leader commented: ‘...that kind of awareness campaign has really started to move the dial in terms of the conversation around people with disabilities’.¹¹⁸⁰ DPOs in general felt that the IHREC were key allies in bringing about cultural changes in Irish society. However, there was an appreciation that a broader public awareness campaign coordinated by Government was required to address ingrained paternalistic attitudes towards disabled people.¹¹⁸¹

The IHREC has an extensive media engagement strategy and regularly appears on a range of media. DPO representatives were generally content with the IHREC’s media engagement activities. However, some felt that the IHREC could be more responsive when public figures make statements which reflect the medical or charitable model of disability. One interviewee highlighted that a senior psychiatrist has regularly made public statements suggesting that electro convulsive therapy is permissible under the UNCRPD.¹¹⁸² The interviewee expressed disappointment that the IHREC has not sought to counter such statements.

6.7.6 Research

The IHREC may undertake, sponsor or commission research.¹¹⁸³ Through its research activities, the IHREC has developed new insights into the lived experience of disabled people. For instance, its 2018 report ‘Disability and Discrimination in Ireland’ set out the range of ways in which disabled people experience disability in Ireland.¹¹⁸⁴ DPO representatives interviewed for this enquiry in general felt that the IHREC’s research reports provided a valuable evidence

¹¹⁷⁸ Interview with DPO representative 21 July 2021 (AI)

¹¹⁷⁹ IHREC, Annual Report 2019 (2019)

¹¹⁸⁰ Interview with DPO representative 21 July 2021 (AI)

¹¹⁸¹ Interview with representative of DPO 17 January 2022

¹¹⁸² Prof Brendan Kelly ‘Don’t deny them this treatment’ Irish Independent 13 January 2016

¹¹⁸³ IHREC Act 2014 Section 10(2)(p)

¹¹⁸⁴ Joanne Banks, Raffaele Grotti, Eamonn Fahey and Dorothy Watson, Disability and Discrimination in Ireland (IHREC 2018)

base which DPOs could draw on in their engagement with the state.¹¹⁸⁵ The IHREC utilise the evidence gathered through their advice line to assist in their broader advocacy activities. For example, in 2019 the IHREC highlighted that it had received persistently high number of requests for assistance in relation to disability discrimination in the work place.¹¹⁸⁶ The provision of a helpline therefore provides the IHREC with an evidence base to advance policy reforms and provides a source of first hand insights into the lived experience of disabled people.

The IHREC has funded a research project entitled 'What works? Sharing best practice in how CSOs use the internet in organising and building for socio-economic rights'.¹¹⁸⁷ This research has been utilised by DPOs to provide training to disability activists on the value of online activism.¹¹⁸⁸ The IHREC has also funded the CDLP to hold several events to stimulate dialogue and engagement on rights and to encourage knowledge exchange between academia, civil society and DPOs.¹¹⁸⁹ A number of interviewees commended the researchers involved in these events.¹¹⁹⁰ However, they were not always aware that these activities were funded by the IHREC.

In chapter 4 I set out the need for NHRI(IMM) to take on a key role in advising on Article 31 and in critiquing evidence gathering processes and encourage more participative approaches to evidence gathering. In my evidence gathering I found that whilst the IHREC have at times highlighted the need to collect disaggregated data, it has not yet put forward specific proposals for the development of new data collection systems modelled on Article 31 or for the utilisation of indicators in monitoring processes.¹¹⁹¹

6.7.7 Engagement with the International Human Rights System

During the negotiation of the UNCRPD, the IDPM and the IHRC engaged closely. At that point Gerard Quinn was an IHRC Commissioner. Quinn attended the Ad Hoc Committee as a representative of Rehabilitation International and also provided statements on behalf of the International Coordinating Committee of NHRIs.¹¹⁹² The IHRC held an event during the

¹¹⁸⁵ Interview with DPO representative 21 July 2021 (AI)

¹¹⁸⁶ IHREC Annual Report 2019 (2019) p. 10

¹¹⁸⁷ Aileen O'Carroll and David Landy, 'Sharing Best Practices in how Civil Society Organisations use the Internet in Organising and Building for Socio-Economic Rights and Trust' (IHREC 2020)

¹¹⁸⁸ ILMI Building Online Social Movements: Interactive Workshop for Disabled Activists 4 November 2020, Available at: <https://www.wheel.ie/notices/building-online-social-movements-interactive-workshop-disabled-activists-4-nov> (Accessed on 2 April 2022)

¹¹⁸⁹ CDLP 'Disability/Visibility Conference' 3 September 2019, Available at: <https://www.nuigalway.ie/centre-disability-law-policy/research/projects/completed/disabilityvisibility/> (Accessed on 2 April 2022)

¹¹⁹⁰ Interview with DPO Representative 16 July 2021 VII

¹¹⁹¹ IHREC Submission to the Special Committee on COVID-19 Response The Impact of COVID-19 on People with Disabilities June 2020, para 12

¹¹⁹² IHREC, Minutes of the 62nd Ordinary Meeting of the Human Rights Commission -Thursday, 7th December 2006, 10.30 a.m.

negotiation of the UNCRPD looking specifically at treaty monitoring options.¹¹⁹³ At this event, representatives of the Forum of People with Disabilities provided their perspective on the monitoring arrangements for Ireland. The IHREC has continued to encourage reflection within the IDPM on the implementation of the UNCRPD. Since ratification the IHREC has continued to advocate for Ireland to ratify the Optional Protocol to the UNCRPD.¹¹⁹⁴

Ireland has not yet been examined by the UNCRPD Committee. To inform my assessment of how DPOs have collaborated with the IHREC in engaging with the international human rights system I have reviewed documentation relating to six treaty body examination processes and relating to the examination of Ireland during the third cycle of the Universal Periodic Review Process.¹¹⁹⁵

In my analysis of submissions from Irish CSOs to Treaty bodies I found that DPOs have rarely made submissions. In 2005, the DPO ‘Mind Freedom’ made a submission to the ‘International Convention on Economic Social and Cultural Rights (‘ICESCR’) Committee.¹¹⁹⁶ The DPO ‘Recovery Experts by Experience’ made submissions to the UN Human Rights Committee examination in 2014 and to the UN Committee against Torture examination in 2017.¹¹⁹⁷ A number of DPOs had contributed to civil society coalitions who produced sector wide shadow reports including reports produced by FLAC to the ICESCR Committee,¹¹⁹⁸ by the National Women’s Council to the CEDAW Committee¹¹⁹⁹ and by the Child Rights Alliance to the CRC Committee.¹²⁰⁰ Only one DPO representative interviewed for this research had attended a Treaty body examination. One DPO representative had attended the negotiations leading up to the UNCRPD.

Since its establishment, the IHREC has developed participative approaches to the development of its reports to Treaty bodies. In developing its 2019 report to the CERD Committee the IHREC invited the views of civil society through an engagement event and online

¹¹⁹³ IHREC, ‘Seminar on Treaty Monitoring Options for proposed UN Human Rights Disability Treaty’ 16 April 2005

¹¹⁹⁴ Oireachtas Joint Committee on Disability Matters debate - Thursday, 17 Jun 2021

¹¹⁹⁵ ICCPR 2014, ICESCR 2015, UNCAT 2017, CEDAW 2017, CRC 2016, CERD 2020

¹¹⁹⁶ Mind Freedom, ‘Submission to CESCRC Committee examination of Ireland’ 2015, INT_CESCRC_ICO_IRL_18836_E

¹¹⁹⁷ Recovery Experts by Experience, ‘Submission to UN CAT Committee examination of Ireland’ 2017

¹¹⁹⁸ FLAC ‘Our Voice, Our Rights: An Update To the Civil Society Parallel Report in response to Ireland’s Third Report under the International Covenant on Economic, Social and Cultural Rights submitted’ May 2015

¹¹⁹⁹ National Women’s Council of Ireland, ‘Shadow Report in advance of the examination of Ireland’s combined sixth and seventh periodic reports under the CEDAW Committee’ January 2017

¹²⁰⁰ Child Rights Alliance, ‘Parallel Report to Ireland’s Third and Fourth Combined Report under the UN Convention on the Rights of the Child’ September 2015

questionnaire.¹²⁰¹ The IHREC also provided training to support the development of a collective civil society shadow report.

In their submissions to each of the Treaty Bodies the IHREC gave some attention to disability rights issues. In its 2017 submission to the Committee Against Torture, the IHREC highlighted the need to reform the Mental Health Act 2001 in order to ensure compliance with Article 12 of the UNCRPD.¹²⁰² The IHREC highlighted similar issues in its 2020 submission to the UN Human Rights Committee. In its 2021 submission to the third Universal Periodic Review, the IHREC highlighted the need for a number of legislative and policy reforms to ensure compliance with the UNCRPD.¹²⁰³ A DPO leader who had attended the UN Committee against Torture examination reported that during the state dialogue that IHREC staff had been open to coordinating their engagements with the Committee.¹²⁰⁴

Building on these efforts the IHREC has sought to support DPOs to engage with the UNCRPD Committee. Representatives of the IHREC interviewed for this research considered that there was a significant need for the IHREC to support the IDPM to ensure DPOs were well placed to engage in the UNCRPD examinations process.¹²⁰⁵ Reflecting this commitment, in preparation for the forthcoming examination process the IHREC has developed an explainer document providing guidance to DPOs and others on the UNCRPD examination process.¹²⁰⁶ The IHREC has also developed an accessible online video explaining the examination process.¹²⁰⁷ As set out above through the grants programme the IHREC funded the development of a shadow report by the DPO Coalition. The IHREC also provided funding to Inclusion Ireland to produce a shadow report.¹²⁰⁸

The IHREC appear to be conscious that due to the coronavirus pandemic, Ireland is not likely to be examined by the UNCRPD Committee for some time. Reflecting this, the IHREC has encouraged the Minister for Equality and the Minister of State for Disability to commit to making an annual statement on UNCRPD compliance to the Dail.¹²⁰⁹ This is a positive example

¹²⁰¹ IHREC Submission to the UNCERD Committee July 2019

¹²⁰² IHREC Submission to the UNCAT on Ireland's second periodic report July 2017, p. 42

¹²⁰³ IHREC Submission to the Third Universal Periodic Review Cycle for Ireland 24 March 2021

¹²⁰⁴ Interview with DPO representative 19 July 2021

¹²⁰⁵ Interview with Commissioner of IHREC 16 August 2021

¹²⁰⁶ IHREC A brief guide to the United Nations Convention on the Rights of Persons with Disabilities 2020

¹²⁰⁷ IHREC UN Convention on the Rights of Persons of Disabilities and Ireland 2020 Available at <https://vimeo.com/292291408> (accessed 5 August 2021)

¹²⁰⁸ Inclusion Ireland, What people with an intellectual disability have to say about how their rights under the UNCRPD are respected in Ireland, November 2021

¹²⁰⁹ IHREC Press Release Commission Calls on Government to Establish Annual Dáil Statement on Progress on Ireland's Disability Rights Obligations, 17 June 2021

of the IHREC suggesting an innovative domestic process to address deficiencies in the international system. However, given the centrality of civil society and DPOs to the examination process, it is disappointing that the IHREC have not proposed a more participative process. For instance, in light of delays in the examination process the New Zealand Human Rights Commission are investigating with DPOs whether a mock examination process could take place.¹²¹⁰ Such a process would afford greater opportunities for the participation of DPOs and disabled people.

6.7.8 Provision of advice and legal assistance to the public

The IHREC operates a helpline entitled ‘Your Rights’ - a service which provides information to the public on the rights, remedies and obligations provided for under human rights law and equality law in Ireland. In 2019, the IHREC helpline dealt with 2,165 queries. The overwhelming majority of these concerned domestic equality protections (1,146), over a third of which related to disability grounds.¹²¹¹

The IHREC may offer legal assistance to individuals in relation to both human rights and equality proceedings. In its 2019 annual report, the IHREC records that it has supported 128 individual clients. Views on the value of the helpline to disabled people were mixed. The majority of DPO representatives felt that the helpline operated quite effectively. During my evidence gathering, the IHREC launched a new resource providing a guide to relevant sources of advice.¹²¹² This initiative will potentially assist disabled people to navigate the various sources of legal advice in Ireland.

Three DPO representatives raised concerns that the processes for applying for legal assistance were inaccessible. One representative suggested that relevant documentation is not available in braille.¹²¹³ A further DPO representative suggested that applicants with psychosocial disabilities have been asked to provide significant detail on their experiences in writing before being offered a face-to-face meeting with IHREC representatives.¹²¹⁴ This approach was

¹²¹⁰ See chapter 5

¹²¹¹ IHREC Annual Report 2019 (2019)

¹²¹² IHREC ‘Guides and Tools’, available at: <<https://www.ihrec.ie/guides-and-tools/>> (Accessed on 2 April 2022)

¹²¹³ Interview with DPO representative 16 July 2021 (VI)

¹²¹⁴ Interview with DPO representative 19 July 2021 (R2)

considered to place the onus on the individuals without providing sufficient support, which has the potential to be traumatizing for applicants.¹²¹⁵

A number of interviewees suggested that the IHREC should be supporting more cases and should be more proactive in identifying issues where strategic litigation could bring about change.¹²¹⁶ In addition to offering legal assistance, the Commission may institute proceedings in any court of competent jurisdiction for the purpose of obtaining relief of a declaratory or other nature in respect of any matter concerning the human rights of any person or class of persons. It has not brought such proceedings to date.¹²¹⁷

Under Section 10 of the IHREC Act 2014 the IHREC may apply to appear before the High Court or the Supreme Court, as the case may be, as *amicus curiae* in proceedings before that Court which involve or are concerned with human rights or equality rights. In general, DPOs interviewed for this research were complimentary of the IHREC's approach to intervening in cases. In its 2019 annual report, the IHREC recorded nine interventions during the reporting year. Through its interventions the IHREC has highlighted the need to bring about compliance with the UNCRPD and has influenced the establishment of judicial precedents. In 2020, the IHREC intervened in a case concerning the right to marry of a man with an intellectual disability.¹²¹⁸ The case involved a challenge to the Marriage of Lunatics Act 1811 and provided the IHREC with an opportunity to highlight the need to repeal the 1811 Act, in order to ensure compliance with the UNCRPD.¹²¹⁹

The IHREC intervened in the important case of Nagle which related to the obligation on an employer to reconfigure a role to accommodate the return of an employee with an acquired disability. In their intervention, the IHREC highlighted the need to interpret the duty to make reasonable accommodation in line with UNCRPD.¹²²⁰ The IHREC specifically recommended that 'consultation and dialogue with persons with disabilities is a key element that guides the implementation of the duty to provide reasonable accommodation'.¹²²¹ Through its intervention, the IHREC appears to have influenced the decision of the Supreme Court. Mr.

¹²¹⁵ Ibid

¹²¹⁶ Interview with representative of Human Rights NGO 14 January 2022

¹²¹⁷ IHREC Act 2014

¹²¹⁸ *V. v Minister for Health and Ors (TBD)*

¹²¹⁹ IHREC Press Release, Human Rights and Equality Commission Granted Leave to Appear as *Amicus Curiae* in Disability Rights Case, 14 October 2021

¹²²⁰ IHREC Legal Submissions in the case of Marie Daly v Nano Nagle School Available at <https://www.ihrec.ie/documents/marie-daly-v-nano-nagle-school/> (visited 3 August 2021)

¹²²¹ Ibid

Justice Peter Charleton stated that it is not: ‘...particularly useful to see disability as medical in nature. A person with a disability remains a person, an individual with human dignity who is required to be treated as such’.¹²²² The judgement clarified the parameters of an employer’s duty to provide reasonable accommodation. To promote this clarification and raise awareness of the judgement, the IHREC held a conference for the legal profession and other stakeholders.¹²²³ Furthermore, the IHREC announced its intention to develop a Code of Practice under section 31 of the 2014 Act. Therefore, in addition to utilising their powers to intervene the IHREC is following up through exercising its related powers.

A number of DPO representatives felt that the IHREC could be more proactive in putting forward progressive interpretations of the UNCRPD in its interventions.¹²²⁴ However, there was an acknowledgement that the Irish court system may not be receptive to such interpretations.¹²²⁵ Indeed, as discussed in my case study on the EHRC, commentators have warned that strategic litigation which seeks to bring about significant expansions in legal protections can often lead to unintended consequences when cases are heard by judges who operate with disability biases.¹²²⁶

The contribution of the IHREC’s interventions to the development of important precedents has been acknowledged by legal commentators.¹²²⁷ However, it is through supporting disabled people to bring cases that the IHREC has the greatest potential to add value to the advocacy efforts of the IDPM and, overall, the IHREC has supported only a small number of disabled people to bring proceedings.

6.7.9 Equality Regulator

The IHREC Act 2004 places a specific duty on public bodies to have due regard to the need to eliminate discrimination, promote equality of opportunity and protect human rights – the Public Sector Equality and Human Rights Duty (‘PSEHRD’).¹²²⁸ The IHREC has a specific role to monitor the PSEHRD. The IHREC have the power to review how a public body has complied

¹²²² Nagle School v. Marie Daly [2019] IESC 63

¹²²³ IHREC, ‘Achieving Equality at Work: Reasonable Accommodation in Practice’ 7 October 2019

¹²²⁴ Interview with DPO representative 16 July 2021 (VI)

¹²²⁵ Interview with DPO representative 13 August 2021 (DW)

¹²²⁶ János Fiala-Butora, Matthew S. Smith, & Michael Ashley Stein (n. 882) p. 25

¹²²⁷ Desmond Ryan and Mark Bell ‘Disability, Reasonable Accommodation and the Employer’s Obligations: Nano Nagle School v Daly’ [2020] The Modern Law 1059

¹²²⁸ IHREC Act Section 43

with this duty and may make recommendations for improvements to practices within the public body.¹²²⁹

The IHREC has made clear that the PSEHRD offers ‘a pathway’ to the human rights model of disability and to compliance with the UNCRPD.¹²³⁰ The IHREC utilises the UNCRPD when advising on measures required to ensure compliance with the PSEHRD.¹²³¹ A DPO representative considered that the duty was isolated from the broader equality framework and could not address the inadequacies within the framework.¹²³²

The IHREC has worked with Government Departments in developing their PSEHRD Action Plans.¹²³³ In its guide, the IHREC highlight that the duty complements the NDIS and reference is made to the UNCRPD. In addition, the IHREC has published a separate guide on the development of a consultative approach.¹²³⁴ This guide emphasises the importance of accessibility. Both guides appear broadly conclusive. However both guides make reference to an NDA guide on consultation with persons with disabilities produced in 2002.¹²³⁵ Guidance produced by the NDA was criticised by numerous DPOs interviewed for this research for being outdated and promoting a restrictive view of the State’s obligations.¹²³⁶ The continued reference to guidance produced by the NDA underscores a concern raised by DPOs that the overlapping roles of the IHREC and the NDA is restricting the ability of the IHREC to guide public authorities in developing innovative approaches to including disabled people and DPOs.¹²³⁷

Interviewees were in general complimentary of the IHREC’s approach to promoting the PSEHRD. DPOs considered that the IHREC had adopted a ‘participative approach’ to its enforcement.¹²³⁸ In 2021 the IHREC held an engagement event with ILMI setting out how DPOs could utilise the duty in their advocacy activities.¹²³⁹ However there was a view that the

¹²²⁹ *ibid*

¹²³⁰ IHREC, The Impact of COVID-19 on People with Disabilities Submission by the Irish Human Rights and Equality Commission to the Oireachtas Special Committee on COVID-19 Response, June 2020, at paras.46-48.

¹²³¹ *ibid*

¹²³² Interview with DPO representative 13 August 2021 (DW)

¹²³³ Department of Transport, Tourism and Sport Written answers ‘Departmental Policies’ Tuesday, 29 June 2021

¹²³⁴ IHREC, Assisting the Effective Implementation of the Public Sector Equality and Human Rights Duty: Tool for a Consultative Approach (IHREC 2020) Available at: <https://www.ihrec.ie/app/uploads/2020/09/IHREC-Tool-for-a-Consultative-Approach.pdf>, (Accessed on 2 April 2022)

¹²³⁵ NDA Guidelines for effective consultation with people with disabilities (NDA 2002) Available at: <http://nda.ie/nda-files/-ask-me-guidelines-for-effective-consultation-with-people-with-disabilities1.pdf> (Accessed on 2 April 2022)

¹²³⁶ Interview with DPO representative 16 July 2021 (VI)

¹²³⁷ *ibid*

¹²³⁸ Interview with representative of Human Rights NGO 14 January 2022

¹²³⁹ ILMI, The Public Sector & Human Rights Duty, 15 July 2021

IHREC could be doing more to empower DPOs to utilise the duty.¹²⁴⁰ Furthermore much of the activities of the IHREC had focused on implementing the duty in local authorities.¹²⁴¹ As set out above during the coronavirus pandemic the PSEHRD has provided a basis for engagement with Government Departments. It appears that there is significant potential for collaboration between the IHREC and the IDPM in imbedding the PSEHRD within the policy making process in Ireland. To do so would go some way to ensuring that the voices of disabled people and their representative groups were sought when disability policies were developed. However, the continued reference to guidance issued by the NDA undermines the potential for IDPM and the IHREC to advocate for innovative measures to ensure the inclusion of disabled people and their representative groups.

During my evidence gathering the IHREC were engaging with public servants responsible for training and personnel development within the Irish civil service to ensure that the PSEHRD is fully reflected in their training programmes.¹²⁴² This resulted in the publication of a new learning module for Irish civil servants on the PSEHRD.¹²⁴³ This initiative is likely to reinforce the centrality of the PSEHRD to the policy making process.

6.7.10 Inquiry

The IHREC may conduct an inquiry when it considers that a serious violation of human rights or equality of treatment obligations in respect of a person or a class of persons, or a systemic failure to comply with human rights or equality of treatment obligations has occurred.¹²⁴⁴ On the conclusion of an inquiry the IHREC must report to the Minister making such recommendations as it thinks fit.¹²⁴⁵

The IHREC's powers to conduct an inquiry are quite substantial. Whilst the IHRC conducted an inquiry into the John Paul Centre in Galway in 2010, the IHREC has not yet initiated an inquiry.¹²⁴⁶ In my evidence gathering I identified limited evidence of CSOs or DPOs in Ireland making requests for the IHREC to initiate an inquiry. In 2016, a number of disabled activists, with the support of the OfDP Inclusion Ireland, called on the IHREC to conduct an inquiry into

¹²⁴⁰ Interview with representative of DPO 17 January 2022

¹²⁴¹ Interview with representative of Human Rights NGO 19 January 2022

¹²⁴² Interview with IHREC staff member 19 May 2021 (I)

¹²⁴³ IHREC Press Release, Minister O'Gorman Launches New Equality and Human Rights Module for Public Service 25/04/2022, Available at <https://www.ihrec.ie/minister-ogorman-launches-new-equality-and-human-rights-module-for-public-service/> (Accessed on 18 May 2022)

¹²⁴⁴ IHREC Act 2014 Section 35

¹²⁴⁵ Schedule 2 Paragraph 15

¹²⁴⁶ IHRC, Report on John Paul Centre, Galway 2010

the use of congregated settings.¹²⁴⁷ The IHREC did not launch an inquiry in response to this request. The then Chief Commissioner of the IHREC indicated that the IHREC would publicly respond to the request.¹²⁴⁸ However, the IHREC did not issue a public statement explaining how the request was considered and addressed. Unlike the EHRC, the IHREC has not published guidance for civil society on how requests to undertake an inquiry are considered.

In the absence of guidance there appears to be a lack of awareness amongst DPOs of the IHREC's powers to conduct an inquiry.¹²⁴⁹ Representatives of the IHREC interviewed for this research considered that conducting an inquiry 'is a very significant step to take and it has its own huge potential upsides, but also hugely significant and involved considerations before we actually embark on something like that..'.¹²⁵⁰ As set out in chapter 4 through their inquiry powers NHRI(IMM)s have raised awareness of the abuses of disabled people that have previously gone unrecorded. The potential for an inquiry to provide a mechanism for disabled people and DPOs to voice their concerns and raise awareness of their experiences seems not to be fully appreciated either within the IHREC or within the IDPM.

In addition to its formal inquiry powers the IHREC has the power to invite private or public organisations to carry out a review of equality of opportunity generally, or a particular aspect of discrimination under Ireland's anti-discrimination laws.¹²⁵¹ The IHREC is yet to exercise this power relating to the rights of disabled people.

6.8 Conclusions.

In my concluding chapter I will set out my overall conclusions. In this section I will make four conclusions relating to the IHREC.

The IHREC operate in a political environment in which the rights of disabled people are on the political agenda. The ratification of the UNCRPD has created a window of opportunity in which the Government is reassessing its relationship with the IDPM.¹²⁵² The IHREC has highlighted the state's obligations under Article 4(3) but could be more specific in advising on activities the state could undertake to fund and support the growth of DPOs. There is also a

¹²⁴⁷ Elaine Edwards, Call for inquiry into use of outdated institutions, Irish Times, 26 January 2016

¹²⁴⁸ Ibid

¹²⁴⁹ Interview with DPO representative 21 July 2021 (AI)

¹²⁵⁰ Interview with Commissioner of IHREC 16 August 2021

¹²⁵¹ IHREC Act section 37

¹²⁵² Jon Kingdon 'Agendas, alternatives and public policies' (2nd ed. Harper Collins 1995)

need for the IHREC to scrutinise the effectiveness of participative structures put in place by the state, to determine if they are truly emancipatory. There is a need to rationalise participative structures and arrangements for the oversight of disability policy in Ireland. The IHREC could be more pro-active in critically assessing these arrangements.

The relationship between the IHREC and the NDA requires clarification. The fact that the NDA are providing advice and guidance which does not fully reflect the UNCRPD was a source of concern amongst DPOs. However, this issue has not been raised by the IHREC. Unless this is addressed the potential for the IHREC to promote culture changes necessary to bring about the implementation of the UNCRPD will not be realised. Furthermore, in the long term the IDPM is likely to lose confidence in the IHREC if it does not challenge the restrictive interpretations put forward by the NDA.

The IHREC have given detailed and considered reflection to their role as the IMM for the purposes of Article 33(2). The IHREC Commissioners and senior staff appreciate the importance of ensuring that disabled people and their representative groups are included in the monitoring activities of the IHREC. They have reflected this through establishing the IHREC-DAC. Reflecting the general practice of NHRIs, the IHREC has appointed members to the IHREC-DAC in their individual capacity rather than as organisational representatives. Whilst the establishment of the IHREC-DAC was welcomed by the IDPM, I identified that its establishment has potentially superseded efforts by the IHREC to develop closer working relations with DPOs.

In my interviews with DPO leaders I was surprised at the high levels of satisfaction with the work of the IHREC amongst the majority of interviewees. Notably DPOs interviewed for this research had higher levels of satisfaction with the work of the IHREC than representatives of human rights NGOs interviewed for this research. Upon exploration I identified that one of the key factors behind the high level of satisfaction was a history of disabled people being poorly served by statutory bodies, in particular the NDA. Expectations amongst DPOs are therefore relatively low and the IHREC has met these and significantly outperformed other statutory bodies. However, a number of DPO representatives highlighted that the IDPM need to develop its understandings of the powers and functions of the IHREC, to ensure they are able to effectively hold the IHREC to account. There is clearly a desire within the IHREC to manage the expectations of the IDPM and civil society more generally, it is important that this desire

does not undermine constructive discussions between the IDPM and the IHREC on advancing the rights of disabled people.

7. Discussion, Conclusions and Recommendations

7.1 Introduction

In this enquiry I have explored the ways in which NHRIs and DPOs are collaborating to strengthen the voice of disabled people and the capacity of the DPM to influence change. In doing so I have reviewed the legal context and the social context in which NHRIs and DPOs operate.

In my legal analysis I explored the requirements placed on state parties to develop their capacity to implement the UNCRPD through the designation of a focal point and the development of a reform programme, including reforms to the state's data collection systems. I set out how the requirement to establish an IMM is central to the delivery of these obligations. In conjunction with these obligations, the state is required to recognise and support the development of DPOs.

The theoretical underpinnings which informed the development of the UNCRPD were also considered in the legal analysis. I discussed how two complimentary objectives coalesced in the development of obligations on the state to reform its policy making system. Human rights theorists who had witnessed the inability of the international treaty system to effect change at the domestic level sought to put in place structures to facilitate local oversight.¹²⁵³ Disability activists had the objective of seeking to correct the historic exclusion of disabled people from domestic policy making processes.¹²⁵⁴ This resulted in a sophisticated approach to domestic implementation and oversight, which brings together domestic and international oversights creating opportunities for collaboration.

In Chapter 3 I examined the challenges which the DPM face in trying to influence the policy making process. I observed how the DPM face unique challenges in engaging with existing systems for the design and delivery of disability policies. I explored more generally how social movement organisations influence change, and in doing so I noted that DPOs have faced the challenge of making their voice heard above other organisations seeking to speak for disabled people. This chapter identified the needs which could potentially be met by an NHRI designated as an IMM.

¹²⁵³ Gatjens 'Analysis of article 33' (n. 24)

¹²⁵⁴ Gerard Quinn, 'The United Nations Convention' (n. 114)

In Chapter 4, I began by considering the theories which underpinned the development of NHRIs more generally and then proceeded to specifically consider why NHRIs have become the presumptive nominee as a state's IMM. In doing so I examined how the suitability of NHRIs to perform the role of a IMM is informed by a number of presumptions relating to the functions, expertise and influence of an NHRI. In this chapter I demonstrated that there is a disconnect between the roles which the UNCRPD Committee have recommended that a NHRI(IMM) should perform and the roles which they are performing in practice. I noted that the functions performed by NHRIs are diverse. NHRIs must balance their responsibilities to monitor how the state meets its obligations with the duty to advise the state on how it goes about doing so. I considered that the ability of a NHRI to effect change is dependent on their capacity to influence and convince the decision makers in government. Drawing on the writings of political scientists, I highlight that the assessment of whether a NHRI is being an effective influencer is complex.¹²⁵⁵

Through my case studies in Chapters 5 and 6 I explore the specific examples of the EHRC and the IHREC, and I set out the perspectives of the DPM and examine how through their activities NHRIs (IMMs) are supporting DPOs.

In this concluding chapter, I will begin with a discussion on the approach of states to designating their IMMs. I will then analyse the ways in which NHRIs are interacting with DPOs. This analysis is informed principally by my two case studies. As set out, I have also considered the activities of seven NHRIs which I identified as adopting innovative approaches in their role as IMMs. My analysis of the activities of these institutions have provided a reference point when developing these conclusions.

In this chapter I will demonstrate how in a range of direct and indirect ways NHRI(IMM)s are strengthening the capacity of DPOs. However, as I will discuss, NHRI(IMM)s have not yet purposefully considered how they can be a resource to DPOs, and this means that the range of ways in which they can support DPOs is not being fully realised. Overall, there is a need for NHRIs to reflect on how they can be an effective ally to the DPM.

In my legal analysis I highlighted how the 2001 seminal report by Quinn and Degener informed the development of the UNCRPD. Within the report Quinn and Degener suggest four ways in

¹²⁵⁵ Michael Mintrom, 'The Policy Analysis Movement' (n. 362)

which NHRIs can support DPOs to influence change at the domestic level. Namely by: ‘building the human rights capacities’ of the DPM; advocating for their inclusion in the ‘policy-making apparatus’; ‘validating’ their claims; and addressing ‘alleged violations’ of their rights.¹²⁵⁶ I will structure my conclusions in line with these suggestions. I will then make an overall conclusion.

Literature relating to NHRIs emphasises that there is a need to develop a clear understanding of the powers of a NHRI when critiquing their activities.¹²⁵⁷ To a large degree the effectiveness of a NHRI(IMM) is dependent upon the statutory powers and funding provided to them. In both my case studies I have acknowledged the statutory and funding framework in which both institutions operate. As independent bodies NHRI(IMM)s have a high degree of operational discretion and the way in which they exercise their powers can have a significant impact on their effectiveness. In this enquiry I have sought to focus on the operational discretion of a NHRI.

7.2 State obligations

UNCRPD scholars suggest that the ratification of the UNCRPD should provide a ‘regulatory moment’ within state bodies, encouraging critical reflection on the ability of domestic institutions, including NHRIs, to realise regulatory goals and to the development of reforms to address any deficiencies.¹²⁵⁸ My analysis suggests that many states have designated their NHRIs as an IMM without critically assessing the suitability of the NHRI.¹²⁵⁹ In considering my case studies, the designation of the EHRC as an IMM took place without a robust assessment of its suitability. By contrast, in Ireland the suitability of the IHREC to perform the role of an IMM has received greater attention, with amendments proposed to its founding statute to ensure the participation of disabled people.¹²⁶⁰ The IHREC has influenced these discussions, highlighting the need to ensure that it is appropriately empowered and structured to perform their role as a IMM effectively. There is also an increasing appreciation amongst DPOs of the role which a NHRI(IMM) should perform.¹²⁶¹ Nevertheless discussions relating to the role of the IHREC as the IMM have broadly taken place in isolation from discussions

¹²⁵⁶ Quinn, Gerard, and Theresia Degener, ‘Human rights and disability’ (n. 38)

¹²⁵⁷ De Beco, G and Murray, R ‘A commentary on the paris principles’ on national human rights institutions’ Cambridge University Press 2014, p. 64

¹²⁵⁸ Michael Howlett and Joshua Newman (2013) ‘After “the Regulatory Moment” in Comparative Regulatory Studies: Modeling the Early Stages of Regulatory Life Cycles’ [2013] *Journal of Comparative Policy Analysis: Research and Practice* 107

¹²⁵⁹ See Introduction

¹²⁶⁰ See chapter 6 (6.6.4)

¹²⁶¹ See chapter 4 (4.9)

relating to the strengthening of the IDPM or to the designation of a focal point.¹²⁶² Overall there is a need for greater reflection at the state level as to how the procedural innovations contained in the UNCRPD are realised in practice. NHRI(IMM)s, including the IHREC, must look beyond their own roles and consider how the window of opportunity that emerges following ratification of a treaty can be maximised to effect change.

7.3 Collaboration between NHRIs and DPOs

7.3.1 Advocating for the inclusion of DPOs in the ‘policy-making apparatus’

One of the key roles of a NHRI(IMM) is advising on state measures required to bring about compliance with the UNCRPD. The UNCRPD is unique in containing provisions designed to correct the historic exclusion of disabled people from the policy making process and a NHRI(IMM) should play a key role in convincing the state to adopt these corrective measures.

As set out in my legal analysis, a UNCRPD focal point is intended both to ensure that disabled people remain on the political agenda and to provide an access point for disabled people to the policy making process. A NHRI(IMM) can play a key role in advising the state on the importance of establishing a robust focal point with a clear mandate, sufficient resources, and powers to coordinate implementation. During the period of my evidence gathering in Ireland, the Government was in the process of designating its UNCRPD focal point. I found that during these discussions, the IHREC had not highlighted the role of the focal point or the need for the focal point to provide a conduit for DPOs to engage with Government.¹²⁶³ DPOs and the IHREC have not collaborated to encourage the state to establish a robust focal point. In my evidence gathering I explored the reasons behind this. It was apparent that DPOs in Ireland did not appreciate the centrality of the role of a UNCRPD focal point. The IHREC representatives similarly had not fully reflected on the role of a UNCRPD focal point.¹²⁶⁴ Given the responsibility of the IHREC to promote awareness of the UNCRPD, the absence of discourse relating to focal points is, at least in part, a consequence of the IHREC not clearly explaining the central role of the focal point in monitoring and implementing the UNCRPD both to Government and to the DPM. Similarly in the UK, when the UNCRPD focal point has been subject to reform the EHRC has not provided substantive comment. During my interviews with

¹²⁶² See chapter 6 (6.7.3)

¹²⁶³ *ibid*

¹²⁶⁴ Interview with IHREC representatives May 2022

representatives of both the IHREC and the EHRC, I found that there was a lack of full appreciation for the important role which a UNCRPD focal point should perform, including the role which a focal point could play in facilitating engagement between government and the DPM. The potential for a UNCRPD focal point to act as an ally of DPOs within government is not being realised in either of my case studies and in my view each NHRI shoulders some responsibility for the lack of understanding of the role of a focal point.

In some states a national disability action plan (NDAP) has provided an important policy vehicle to facilitate the participation of disabled people in the policy making process.¹²⁶⁵ Existing literature emphasises the role of NHRI(IMM)s in guiding and monitoring the implementation of a NDAP.¹²⁶⁶ In the UK, whilst DPOs have significant concerns relating to both the process leading to the development of the disability strategy and its content, they did not collaborate with the EHRC in challenging the strategy.¹²⁶⁷ In Ireland the IHREC has been notably absent from policy discussions relating to the National Disability Inclusion Strategy (NDIS), which has meant that DPOs have been unable to rely on the IHREC for support and assistance when engaging with the state. Therefore, both these case studies indicate that neither the EHRC nor the IHREC are advocating for states to develop innovative NDAPs which provide a policy vehicle for the inclusion of disabled people and DPOs in the policy making process.

My evidence gathering with DPOs in both the UK and Ireland corroborates pre-existing research which identifies that existing state data collection systems are inaccessible to disabled people and do not value the lived experience of disabled people.¹²⁶⁸ My research broadly corresponds with the view that expanding evidence gathering processes has the potential to shift debates regarding the experiences of disabled people outside of political preferences and into the bureaucratic routines of the civil service.¹²⁶⁹ In my broader evidence gathering, I identified several positive examples of NHRIs seeking to influence data collection systems to ensure that they fully record the experiences of disabled people, including through the use of indicators.¹²⁷⁰ For example, the EHRC has successfully collaborated with the UK National

¹²⁶⁵ New Zealand Human Rights Commission, 'Independent Monitoring Mechanism on the Disability Convention' Available at: <https://www.hrc.co.nz> (Accessed 3 March 2022)

¹²⁶⁶ Quinn, Gerard and Neil Crowther 'Human rights and disability: A Manual for NHRIs' (Asia Pacific Forum 2017) para 10.2

¹²⁶⁷ Chapter 5 (5.7.10)

¹²⁶⁸ OHCHR Statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities 28 December 2021 A/HRC/49/60

¹²⁶⁹ Sally Engle Merry, Kevin Davis and Benedict Kingsbury (eds), *The Quiet Power of Indicators. Measuring Development, Corruption, and the Rule of Law* (Cambridge University Press 2015) 2.

¹²⁷⁰ Chapter 4 (4.9.5)

Statistics Office to adjust data collection processes. Furthermore, in the UK several DPOs have collaborated with the EHRC in developing a new methodology to measure the cumulative impact of social security reforms.¹²⁷¹ Whilst the EHRC were unsuccessful in convincing the UK Government to adopt this methodology, the analysis they developed provided DPOs with new evidence to inform their advocacy efforts and make the case for further reforms.

The experience of the EHRC reflects the varying degrees of success which NHRI(IMM)s have had when attempting to influence data collection systems. There are emerging examples of good practice, for instance a number of NHRIs with the support of the OHCHR have now entered into formal agreements with national statistics offices and are shaping data collection systems.¹²⁷² In 2021 the OHCHR published an information note on Article 31 which is likely to lead to further reflection within NHRI(IMM)s concerning reforms to the data collection systems to ensure that they fully capture the lived experiences of disabled people.¹²⁷³ This information note will provide a basis for NHRIs to engage with government, in advocating for more sophisticated approaches to data collection.

The UNCRPD Article 4(3) makes clear that priority should be given to the views of disabled people and DPOs over other non-representative organisations.¹²⁷⁴ However, in both of my case studies DPOs suggested that the state often prioritises engagement with service providers and OfDPs over them.¹²⁷⁵ Both the IHREC and EHRC have a role in regulating the policy making process. In performing this role, a NHRI(IMM) have the potential to convince policy makers of the value of prioritising engagement with DPOs over engagement with OfDPs.¹²⁷⁶ Whilst both NHRI(IMM)s have published guidance encouraging policy makers to engage with civil society in the policy making process, neither NHRI(IMM) have issued specific guidance relating to DPOs.¹²⁷⁷ Furthermore neither NHRI(IMM) has provided advice on how to prioritise the views of DPOs over the views of other CSOs. EHRC representatives were somewhat uncomfortable with the prospect of the EHRC taking on a role in critiquing the legitimacy of organisations who speak on behalf of disabled people.¹²⁷⁸ In their advice to the Irish Government, the IHREC were more forthright in arguing for the need to prioritise

¹²⁷¹ Chapter 5 (5.7.13)

¹²⁷² Chapter 4 (4.9.4)

¹²⁷³ OHCHR Statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities 28 December 2021 A/HRC/49/60

¹²⁷⁴ CRPD Committee (n. 162)

¹²⁷⁵ Chapter 3 (3.2.2)

¹²⁷⁶ David Barrett, The regulatory space of equality and human rights in Britain: the role of the EHRC [2019] 247, 250

¹²⁷⁷ Chapter 5 (5.7.12)

¹²⁷⁸ Chapter 5 (5.7.3)

engagement with DPOs. However, the IHREC have not provided specific advice on how this would be realised in practice. The position of both NHRI(IMM)s was disappointing as DPOs in both of my case studies highlighted that OfDPs continue to present a significant obstacle to their effective engagement with government. In both the IHREC and the EHRC there is a need for further reflection on the implementation of Article 4(3) of the UNCRPD and on the development of mechanisms for the assessment of organisations against the guidance provided in GC7. In more general terms, there is a need for an exploration of measures which a state should take to ensure disabled people and their organisations are able to effectively engage in the policy making process.

In my analysis I outlined how the UNCRPD seeks to bring about its own implementation through requiring reforms to the domestic policy making system in order to ensure that the rights of disabled people receive appropriate attention. Broadly speaking the UNCRPD requires states to strengthen the voice of national DPMs; to provide new opportunities for them to influence the policy making process; to provide new allies within a UNCRPD focal point; and to ensure that data collection processes fully capture the lived reality of disabled people. Overall, I found that NHRI(IMM)s needed to do more to highlight the structural reforms required to bring about implementation of the UNCRPD. Both the EHRC and the IHREC must develop more sophisticated approaches in advising on the designation of focal points and the development of NDAPs and data collection processes in order to ensure that these building blocks of effective implementation are inclusive of disabled people and their organisations. NHRIs also must develop the expertise of their personnel to ensure that they are well placed to provide credible advice on reforms to domestic policy making systems which facilitate the implementation of the UNCRPD. The UNCRPD goes beyond earlier human rights treaties in attempting to adapt the policy making system to ensure the inclusion of disabled people and DPOs. Both institutions, in my view, should move beyond simply highlighting the need for reforms to suggesting reforms that could be made.

7.3.2 Building the human rights capacities of the DPM

Throughout this enquiry I have considered what it means for an organisation to have ‘human rights capacities’.¹²⁷⁹ Disability scholars have highlighted the need for DPOs to develop ‘new

¹²⁷⁹ Degener and Quinn, (n. 72) p. 269

political entrepreneurial skills’ to ensure that DPOs are able both to engage in the international human rights system and to influence the domestic political agenda.¹²⁸⁰

In this enquiry I have explored how an organisation develops its ability to influence change. In recent years political commentators have developed their understanding of the skills and knowledge required for organisations and professionals to influence the policy making process.¹²⁸¹ DPOs which lack sustainable funding often struggle to attract and retain qualified professionals to support their policy influencing strategies.¹²⁸² Furthermore, the fact that disabled people themselves have to overcome the impact of their impairments means that they are more susceptible to burn out impacting on their professional growth.¹²⁸³ There is therefore a need for accessible training and capacity building programmes to support the development of DPO staff and officers.

The UNCRPD Committee have suggested that NHRI(IMM)s should provide training to DPOs.¹²⁸⁴ In my evidence gathering I found limited evidence of NHRIs developing and delivering training programmes for DPOs on human rights advocacy. Those NHRIs which had provided training events tended to focus on providing training on the international human rights system and on engagement with the UNCRPD Committee. Given that an active domestic DPM is considered key to the effective implementation of the UNCRPD, I explored with the EHRC, the IHREC and with NHRIs in my broader evidence gathering whether they felt that they could take on a role in providing training to DPOs.¹²⁸⁵ Whilst acknowledging that there was a need for DPOs to have access to training on human rights advocacy, the overwhelming majority felt that they could not provide this. NHRI representatives tended to take the view that whilst they could play a role in explaining the international human rights system, they could not take on a role in training DPOs on engaging in human rights advocacy at the international and domestic levels.¹²⁸⁶ Their views are in certain respects disappointing, as without training and capacity building DPOs may be excluded from human rights discourse. A number of NHRIs suggested that other organisations existed within civil society which could provide such training to DPOs. However, neither the IHREC nor the EHRC had critically assessed the availability of training

¹²⁸⁰ Quinn ‘The temptation of elegance’ (n. 4) p. 256

¹²⁸¹ Edward Page ‘Bureaucrats and Expertise’ (n. 367)

¹²⁸² Chapter 5 and Chapter 6

¹²⁸³ Chapter 3 (3.2.1)

¹²⁸⁴ CRPD Committee (n. 5)

¹²⁸⁵ Interview with representative of GIHR 28 January 2021

¹²⁸⁶ Interview with representative of DIHR 4 January 2021

or funding programmes to assist DPOs in developing their capacity to engage in the policy making process. In both my case studies, DPOs asserted that such training programmes did not exist. Given that it is considered essential for the effective implementation for the UNCRPD that disabled people and their organisations are equipped with political entrepreneurial skills, this finding is a source of concern.

As set out in Chapter 4, through their activities NHRIs can provide informal policy-oriented learning opportunities to DPOs.¹²⁸⁷ I discovered several examples of this through my evidence gathering. Most significantly, I found that individuals included in the disability advisory committees of both the EHRC and the IHREC were presented with opportunities for policy-oriented learning. Members of the IHREC-DAC, in particular, noted that through participation in the IHREC-DAC they had gained insights into the policy making process and significantly strengthened their capacity to engage in human rights discourse.¹²⁸⁸ This could indirectly benefit DPOs as a number of members of the IHREC-DAC also hold senior positions within such organisations. However, this is not the case for all members and there is no guarantee that individuals appointed to either institution's disability advisory committees who are staff members in DPOs will share their expertise with their employers or organisations.

The experience of the EHRC-DAC and the IHREC-DAC suggest that through developing participative structures a NHRI can develop policy-oriented learning networks.¹²⁸⁹ The fact that members of the both disability advisory committees are appointed as individuals rather than as representatives of DPOs creates a risk that the DPM will not benefit from the learning opportunities which they present. Ensuring that members of a disability advisory committee are appointed by DPOs would provide a greater degree of certainty that the skills and insights which they garner from participation in formal mechanisms will be shared with their organisations and with the broader movement.

Whilst NHRIs may not consider it their role to provide training and capacity building to DPOs, the UNCRPD Committee make clear that the state has an obligation to ensure DPOs have access to training programmes and funding.¹²⁹⁰ As monitors of the UNCRPD a NHRI(IMM)

¹²⁸⁷ True, Jacqui, and Michael Mintrom, 'Transnational networks and policy diffusion: The case of gender mainstreaming.' [2001] *International Studies Quarterly* 27

¹²⁸⁸ Chapter 6 (6.6.4)

¹²⁸⁹ Diane Stone *Learning Lessons, Policy Transfer and the International Diffusion of Policy Ideas* (University of Warwick 2001)

¹²⁹⁰ CRPD Committee (n. 5)

has a responsibility to assess whether the state is meeting this obligation. As discussed above, I discovered limited evidence of either the IHREC or the EHRC monitoring the availability of funding and training to support the development of DPOs. Whilst both the IHREC and EHRC have highlighted the need for the state to provide funding and support to DPOs, neither institution has provided specific advice on the establishment of programmes to develop the capacity of DPOs.¹²⁹¹ Overall, there appears to be a need for NHRI(IMM)s to develop their monitoring activities to incorporate an assessment of the state's efforts to respect, protect and fulfil their obligations towards DPOs.

7.3.3 Validating the claims of the DPM

Reporting on the lived experiences of disabled people

In my case studies I found that DPOs were bringing accounts of the lived experiences of disabled people to the EHRC and the IHREC in the hope that this would lead to action.

In Ireland, DPOs and disabled people often brought accounts of their lived experience through the IHREC's advice line. Operating the advice line performed a dual function of providing an advice service to disabled people and providing the IHREC with important insights into the lived experiences of disabled people. Collecting data related to the advice line enabled the IHREC to produce important statistics on the challenges experienced by disabled people.¹²⁹² Utilising data gathered through their advice line has meant that the IHREC have been able to publish credible reports on the lived experiences of disabled people that can be utilised by DPOs to inform their policy influencing activities.

As set out when first established the EHRC had responsibility for operating a legal advice helpline. The UK Government removed responsibility for operating the helpline from the Commission early in its operation. This decision removed an important link between the EHRC and rights holders. In my evidence gathering I discovered that disabled people and DPOs often found it difficult to access the EHRC. DPOs have on a number of occasions brought issues of concern to the EHRC in the hope that it will initiate a statutory inquiry.

¹²⁹¹ *ibid*

¹²⁹² Chapter 6 (6.7.6)

DPOs considered that through conducting an inquiry the EHRC have raised awareness of the lived experience of disabled people and broadened public discourse and understanding.¹²⁹³ DPOs were complimentary of the EHRC's approach to conducting inquiries. During my evidence gathering the EHRC was conducting an inquiry into the use of restraint in schools and a number of DPOs reported positive engagement with the EHRC investigation team. It appears that through conducting inquiries a NHRI can play a key role in exploring and documenting the lived experiences of disabled people. In my broader evidence gathering I noted that a number of NHRIs conduct oral hearings as part of their inquiry process.¹²⁹⁴ Such hearings can provide disabled people with a platform for sharing their experiences. Furthermore, a number of NHRIs have included DPOs in advisory committees which are established to guide the process of an inquiry.¹²⁹⁵ The EHRC has not incorporated an oral hearing element into their inquiry processes and has not included DPOs within an inquiry advisory committee. Whilst DPOs were generally pleased with the EHRC's approach to conducting an inquiry, there appears to be significant scope for these processes to be more collaborative. The IHREC has not yet initiated an inquiry. In both of my case studies I found that there was a need for further consideration between DPOs and the NHRI on the contribution which an inquiry can make to domestic policy discourse. In addition to providing a vehicle for disabled people and DPOs to share their experiences, inquiries can provide a basis for DPOs to engage directly with decision makers and can play a key role in holding decision makers to account. DPOs in the UK consider that inquiries have significant potential to effect change. In contrast, DPOs in Ireland do not yet have a full appreciation of the value which an inquiry can bring. I will discuss below how the EHRC's decision making concerning the exercise of its inquiry powers has impacted on its relationship with the DPM.

In my analysis of both institutions, I sought to determine the extent to which they were reflecting lived experience in their domestic monitoring reports. The IHREC has funded several research reports highlighting the lived experiences of disabled people.¹²⁹⁶ In contrast, the EHRC's research reports tended to focus on the analysis of pre-existing statistics rather than augmenting data sets with accounts of the lived experience of disabled people.¹²⁹⁷ As set out in Chapter 5, the EHRC have expressed caution at utilising 'lived experience' as a source

¹²⁹³ Chapter 5 (5.7.9)

¹²⁹⁴ Chapter 4 (4.9.10)

¹²⁹⁵ Interview with representative of the Australian Human Rights Commission 3 December 2020

¹²⁹⁶ Joanne Banks, et al, 'Disability and Discrimination in Ireland: (EHRC 2018)

¹²⁹⁷ EHRC, 'Is Britain Fairer?', (2018) Available at: <https://www.equalityhumanrights.com/en/publication-download/britain-fairer-2018>

of evidence. Overall, I found that both institutions have not fully considered how they should utilise the lived experience of disabled people in their domestic monitoring activities. Both institutions need to develop their understanding on how experiential knowledge can complement official statistics to inform conclusive analysis of the requirements of the UNCRPD.¹²⁹⁸

In Chapter 4 I considered how through access to their international networks NHRIs could draw comparative analysis of a state's performance in supporting disabled people benchmarked against global comparators. I found limited examples of either the EHRC or the IHREC conducting comparative analysis in my case studies. The potential for networks of NHRIs to act as epistemic communities in which human rights professionals share experiences and identify emerging examples of good practice is often discussed.¹²⁹⁹ However I identified limited evidence of either the IHREC or the EHRC utilising their membership of regional or international networks of NHRIs to inform domestic discussions.

UNCRPD Committee Examination and Follow Up

As a result of their broad mandate, NHRIs tend to be active across the international human rights system. These organisations have developed expertise and knowledge in engaging in the system and have, in general, sought to share this expertise with civil society. I found that NHRIs have shared their expertise on international reporting with DPOs and sought to include DPOs in the process of developing their reports to the UNCRPD Committee.

In my evidence gathering I found that NHRIs and DPOs are increasingly collaborating in the production of shadow reports for submission to the UNCRPD Committee. NHRIs in both of my case studies had provided funding to DPOs to facilitate the production of shadow reports. Social movement scholars highlight that human rights have provided a unifying concept for social movements.¹³⁰⁰ DPOs in the UK indicated that the development of an EHRC funded shadow report was a unifying activity which provided a basis for DPOs with different perspectives to come together and agree positions.¹³⁰¹ Similarly in Ireland the IHREC provided

¹²⁹⁸ Laufey Love, Rannveig Traustadottir, Gerard Quinn and James Rice 'The Inclusion of the Lived Experience of Disability in Policymaking' [2017] *Laws* 33

¹²⁹⁹ European Network of NHRIs 'Annual Report 2020' 2020, Available at: https://ennhri.org/wp-content/uploads/2021/08/ENNHRI_Annual_Report_August2020.pdf (Accessed on 4 April 2022)

¹³⁰⁰ Neil Stammer, 'Social Movements' (n. 256)

¹³⁰¹ Chapter 5 (5.7.8)

funding to a coalition of DPOs to produce a shadow report during the preparation of the Irish state report. This funding provided an impetus for DPOs to come together in a new coalition.¹³⁰² However, as set out in Chapter 6, this coalition proved unsustainable. This finding suggests NHRI(IMM)s can and have played a role in ensuring that the UNCRPD examination process is a unifying activity, in which DPOs of different perspectives come together to discuss the rights of disabled people. However, there is a need for further consideration into how to sustain alliances beyond the examination process.

I also discovered that NHRIs have played a role in supporting DPOs to engage in other international human rights system examination processes. However, both the IHREC and EHRC could do more to support DPOs to engage in other treaty body examination processes and in the Universal Periodic Review process. Through facilitating their participation in other treaty processes, a NHRI can both mitigate the risk of disabled people's rights being siloed within the UNCRPD process and can facilitate deliberative learning both within the DPM and within the broader human rights movement.

In Chapter 3 I set out that as domestic actors who partner with the international human rights system NHRIs are uniquely placed to create linkages between the international reporting requirements and the domestic policy process. Human rights compliance theorists highlight the potential for reporting and follow up obligations to act as an impetus for the development of domestic reporting processes.¹³⁰³ In my evidence gathering in the UK I found that whilst both the EHRC and DPOs had submitted follow up reports to the UNCRPD Committee, they have not collaborated in these endeavours. It appears that the EHRC and DPOs have not utilized the opportunity presented by reporting obligations on the state to form an impetus for the development of domestic procedural obligations. In my broader evidence gathering I did identify examples of NHRIs, most notably the New Zealand Human Rights Commission, utilising the development of a disability strategy as an opportunity to link domestic and international reporting obligations.¹³⁰⁴ However, in its advice on the UK disability strategy the EHRC did not refer to the state's UNCRPD reporting obligations.¹³⁰⁵ The IHREC has been largely silent on the linkages between the National Disability Inclusion Strategy and Ireland's

¹³⁰² Chapter 6 (6.7.1)

¹³⁰³ Cosette D. Creamer and Beth A. Simmons, 'The Dynamic Impact of Periodic Review on Women's Rights' 81 *Law and Contemporary Problems* (2018)

¹³⁰⁴ Interview with representatives of the New Zealand Human Rights Commission

¹³⁰⁵ Chapter 5 (5.7.3)

UNCRPD reporting obligations. The OHCHR are currently considering new approaches to ensuring reporting and follow up to the treaty body system.¹³⁰⁶ Whilst the EHRC and the IHREC have both been active in engaging in the treaty body process and in supporting DPOs to engage with the treaty body process, both institutions could be more innovative in collaborating with DPOs and other CSOs in following up to examinations.

NHRIs have followed up treaty body examinations through their own reports. In my literature review I set out the view that a NHRI(IMM) can act as an internal regulator of the UNCRPD, exercising authority delegated from the UNCRPD Committee to assess and make pronouncements on compliance.¹³⁰⁷ Reflecting this, the EHRC has developed a system for tracking the UK Government's compliance with recommendations emerging from treaty body examinations. The EHRC routinely publish progress assessments concerning the implementation of treaty body recommendations including those from the UNCRPD Committee. In these assessments, the EHRC add depth to the UNCRPD Committee recommendations and identify broad indicators of progression and regression. This is an innovative initiative which in my view reflects the role of the EHRC as a key partner of the international human rights system. Whilst DPOs welcomed this initiative, it is not a collaborative initiative. The views of disabled people and DPOs are not sought before assessments of progress are made. This approach reflects a general trend for NHRI(IMM)s to develop their analysis without the input from DPOs or civil society. Considering the significant delays in the UNCRPD Committee's examination process, such tracker systems are likely to assume greater prominence.¹³⁰⁸ Noting these delays in the treaty body process, the IHREC has suggested that the Irish Government commit on an annual basis to report to the Oireachtas on its efforts to bring about implementation of the UNCRPD.¹³⁰⁹ Disappointingly, the IHREC also failed to suggest the development of a process for assessment which included DPOs.

Overall, my assessment of the ways in which the EHRC and the IHREC are collaborating with DPOs to maximise the opportunities presented by the examination process is mixed. Whilst NHRIs have adopted collaborative approaches to engaging with the UNCRPD Committee examination processes, these approaches have not been reflected in following up on an examination. Furthermore, whilst NHRIs are being imaginative in developing and advocating

¹³⁰⁶ Caughey C, Government human rights focal points (n. 129)

¹³⁰⁷ Sarah Arduin, 'Taking meta-regulation to the United Nations human rights regime: the case of the CRPD' (2019) Law & Policy 41

¹³⁰⁸ Interview with representative of the New Zealand Human Rights Commission

¹³⁰⁹ Chapter 6 (6.7.7)

for domestic compliance systems, they have not yet sought to develop these in a participative way. Therefore, I posit that there does appear to be potential for greater collaboration between DPOs and NHRIs.

Provision of Advice on reform proposals

As outlined in my literature review, one of the central roles of a NHRI is the provision of advice to government and the legislature on measures required to bring about compliance with international human rights law.

Through the provision of their advice a NHRI can validate and corroborate the views of DPOs. In general, I found that DPOs were pleased with the content of advice provided by the IHREC and EHRC on legislation. However, DPOs were critical of both the EHRC and the IHREC for being absent from a number of key policy discussions.¹³¹⁰ In Ireland I found it surprising that the IHREC has not provided advice on the content and implementation of the National Disability Implementation Strategy.¹³¹¹ NHRIs clearly have to prioritise the policy issues which they chose to engage with. However, both the EHRC and the IHREC should provide further detail on how they go about prioritising policy issues.

Policy advice produced by the IHREC and EHRC examined for this research reflected the UNCRPD. However, in my view the advice produced by both institutions lacks sufficient detail on how the provisions of the UNCRPD could be domesticated. For example, both institutions could provide greater detail on how to give effect to Article 4(3). Furthermore, in advising on legal capacity reforms both institutions simply set out the relevant guidance from the UNCRPD Committee and do not make suggestions for how the guidance can be given effect to in domestic law.¹³¹² I was somewhat surprised that DPOs in neither of my case studies have raised opposition concerning the positions taken by either the EHRC or the IHREC in their advice documents. Upon reflection this lack of opposition appears to reflect a tendency for both institutions to set out their advice in broad terms without suggesting a definitive course of action. The inclusion of abstract references to bringing about compliance with the articles of

¹³¹⁰ Chapter 6 (6.7.4)

¹³¹¹ The Housing Agency, *The National Housing Strategy for Persons with Disabilities 2022-2027: Have Your Say* (Irish Government 2021)

¹³¹² EHRC 'Advice on Mental Capacity' 2012 and IHRC Advice on ADM Bill 2013

the UNCRPD may generate limited opposition. However, they do little to move domestic debates on UNCRPD compliance onto the methods of implementation.

DPOs indicated that they would welcome an opportunity to inform and shape the advice of the NHRI. Neither the EHRC nor the IHREC have adopted formal arrangements for consulting civil society during the preparation of their advice. A number of NHRI representatives expressed concern that if they were to seek input from civil society, this may expose them to the risk that the government will perceive the NHRI as simply reflecting the views of civil society rather than providing its own independent assessment.¹³¹³

Whilst neither the IHREC nor the EHRC have developed formal arrangements for consulting CSOs, staff in both institutions indicated that they will often informally contact representatives of CSOs whom they consider experts on the subject of a consultation.¹³¹⁴ Human rights NGOs similarly reported that they often discuss proposed reforms with both the IHREC and the EHRC. Both institutions therefore appear to have an informal collection of CSOs whose expertise they seek when formulating their submissions on policy issues. These collections may be classed as what Peter Haas refers to as an ‘epistemic community’, composed of organisations considered to have valuable evidence and views which a NHRI can draw on when developing their submissions.¹³¹⁵ Neither the EHRC nor the IHREC staff indicated that DPOs were included within their informal epistemic communities. This suggests that the expertise of DPOs is not sufficiently valued by either NHRI.

The failure to include DPOs within informal networks appears in part to be a consequence of each institution having established a disability advisory committee. I would posit that the establishment of a disability advisory committee composed of individuals provides a valuable resource to NHRI(IMM)s but dissuades NHRI(IMM)s from developing relationships with DPOs to coordinate engagement in the policy making process. Whilst disabled people on a disability advisory committee may make important contributions in the formation of the NHRI(IMM)s advice, the DPM will lose out on the opportunity to develop more constructive and longer lasting relationships with the NHRI(IMM). A potential consequence of the establishment of a disability advisory committee may therefore be that a NHRI de-prioritises engagement with DPOs as it has its own in-house source of expertise. Such a consequence

¹³¹³ Chapter 5 (5.6.6)

¹³¹⁴ Chapter 6 (6.7.4)

¹³¹⁵ Peter Haas, *Introduction: epistemic communities and international policy coordination* (Cambridge University Press, 2009)

undermines engagement with the broader movement and is not in my view in the spirit of the UNCRPD which specifically acknowledges the importance of engaging with disabled people through their ‘representative groups’. There is a need for reflection within NHRI(IMM)s on the potential benefits which the inclusion of representatives of DPOs on advisory committees can contribute.

Bridge to Government

Literature relating to NHRIs tends to emphasise their role in creating linkages between civil society and the government.¹³¹⁶ A number of DPOs in the UK made clear that they have decided to engage in outsider tactics and not to formally engage with the Government. They took the view that the fundamental changes required by disabled people would not be realised through applying the domestic equality or rights framework.¹³¹⁷ In an engagement event with DPOs and academics in the UK a participant highlighted the academic Audre Lorde’s warning that ‘the master's tools will never dismantle the master's house’.¹³¹⁸ This quote reflected a scepticism amongst DPOs in the UK on the potential for engagement in the policy making process to effect change. Notably DPOs who had chosen to disengage from the UK Government had maintained their links with the EHRC. This is interesting as it suggests that NHRIs can provide an important link to policy influencing processes for social movement organisations (SMO) who have prioritised outsider tactics. The establishment of a NHRI presents a new route for DPOs to engage in the policy making process, through an independent statutory body. This finding complements a small body of literature which has considered the relationship between government sponsored gender units and the women’s movement.¹³¹⁹ An assessment of whether through engagement with a NHRI a SMO can harness the benefits of interaction with the state, whilst mitigating the risk of institutionalisation, will require further longitudinal analysis. However, this research has identified a possibility that a NHRI can provide an alternative form of policy influencing to SMOs who have prioritised outsider tactics.

¹³¹⁶ Uggla (n. 523)

¹³¹⁷ Chapter 5 (5.7.5)

¹³¹⁸ Audre Lorde, *The Master's Tools Will Never Dismantle the Master's House*, Series: Penguin Modern 22/02/2018

¹³¹⁹ See chapter 3

7.3.4 Addressing ‘alleged violations’ of the rights of disabled people

Strategic Litigation

Both the EHRC and the IHREC are empowered to provide individuals with legal help and assistance. However, the EHRC has limited resources to fund cases. DPOs in both of my case studies reported high levels of legal need amongst disabled people and expressed a desire for the NHRI(IMM) to increase the number of disabled people supported to bring litigation. DPOs levelled criticisms about the approach to offering legal assistance and the processes for obtaining assistance. In my view both NHRI(IMM)s have failed to explain to DPOs how their role in providing legal advice and assistance complements the existing forms of publicly funded legal services available in the states. It is important that NHRI(IMM)s do not overstate their ability to meet legal need. Through developing a more participative approach to setting legal priorities, a NHRI(IMM) could inform both itself and its stakeholders of circumstances in which it could add value through the exercise of its strategic litigation powers.

Neither NHRI has brought proceedings in their own name. However, the EHRC has referred to this power when advocating for change. The EHRC has also funded litigation which has created precedents expanding existing protections for disabled people.¹³²⁰ Assessing the effectiveness of any institution which embarks on strategic litigation is a complex exercise.¹³²¹ For the purposes of this research, it is notable that both NHRIs tend to see the principal role of a DPO as assisting the NHRI in identifying cases which they may wish to support or intervene in. There is limited reflection within either NHRI(IMM) as to how they can potentially collaborate with a DPO in embarking on litigation or co-ordinate their strategic litigation activities with civil society. The fact that neither institution has exercised their powers to bring proceedings in their own name appears to be a consequence of a concern that such litigation may damage the NHRI’s relationship with Government.

Noting the unique attributes of a NHRI they are well placed to perform the role of an intervener assisting the court and putting forward new and innovative interpretations of domestic

¹³²⁰ Chapter 5 (5.7.11)

¹³²¹ Catherine Corey Barber ‘Tackling the evaluation challenge in human rights: assessing the impact of strategic litigation organisations’ [2012] *The International Journal of Human Rights* 411

provisions. I identified positive examples of both the IHREC and the EHRC influencing important precedents which have supported the rights of disabled people.

A NHRI can play an important role in supporting the development of precedents which advance the rights of disabled people. The potential for a NHRI to collaborate with DPOs to generate strategic litigation and influence the development of new precedents requires further exploration. The potential for a NHRI to protect the rights of disabled people through bringing litigation in its own name, requires further exploration.

A NHRI can potentially play a key role in facilitating discussions across civil society on opportunities for strategic litigation and for follow up to litigation. As more DPOs become involved in strategic litigation, a NHRI(IMM) has the potential to play a role in co-ordinating civil society to stimulate change following successful litigation.¹³²²

Investigation and Regulatory

Both NHRIs in my case studies are also the national equality body. DPOs in both my case studies were of the view that their NHRI could exercise their regulatory powers more effectively. A number of DPOs in the UK considered that the transformative effect of equality laws is not being realised, in part, because of organisational failures within the EHRC to exercise their regulatory powers efficiently.¹³²³ In citing the failure of the EHRC to respond to their concerns DPOs suggested that they had lost trust in the EHRC as a regulator. To a degree the focus on the inadequacies of the EHRC as a regulator has obscured the failure of the UK Government to ensure that the regulatory framework is sufficiently robust and to ensure that the EHRC is appropriately resourced to perform its functions effectively.

The role of the IHREC as a regulator is more limited and DPOs were more complimentary of the IHREC's approach to their regulatory powers. However, there was a view that the IHREC are not being sufficiently ambitious in the way in which they are exercising their regulatory powers.¹³²⁴ The IHREC have placed a notable emphasis on managing the expectations of civil society in relation to its role as an equality regulator. This approach may go some way to

¹³²² Jacqui Kinghan and Lisa Vanhala, 'Supporting systems changers through the use of collaborative legal approaches' (PLP 2020) p. 6

¹³²³ *ibid*

¹³²⁴ Chapter 6 (6.7.9)

mitigating the risk of DPOs and other CSOs losing confidence in its role as a regulator. However, this approach may also lead to a lack of ambition, undermining the potential for the IHREC to collaborate with DPOs in harnessing the potentially transformative power of the public sector human rights and equality duty.

The experience of the EHRC underscores the need for a NHRI(IMM) to explain its role as a regulator and highlights the risk that a NHRI(IMM) which performs the role of an equality regulator may become associated with failings in the equality framework which are outside of its control.¹³²⁵ The EHRC has unsuccessfully attempted, through engaging in strategic litigation, to extend the public sector equality duty to require policy makers to have to consider the UNCRPD when developing disability policy.¹³²⁶ The question of how a NHRI(IMM) addresses the challenge of promoting the UNCRPD whilst regulating an equality framework which does not fully reflect the UNCRPD, requires further exploration.

7.3.5 Principle of nothing about us without us

NHRIs are required to be pluralistic. Much of the literature relating to the designation of NHRIs as IMMs has presumed that as pluralistic bodies NHRIs will have developed participative ways of working with civil society. It was hoped that these ways of working would provide a foundation for the development of bespoke arrangements to facilitate the participation of disabled people and DPOs in the monitoring of the UNCRPD.¹³²⁷ However, in my evidence gathering I found that there has been a lack of exploration of the relationship between NHRIs and civil society. NHRIs do not necessarily have effective mechanisms for engaging with civil society.

Pre-existing literature focuses on how the requirement that a NHRI be pluralistic can provide a bulwark against the independence of the NHRI being encroached upon by the state. The pluralistic character of a NHRI has rarely been examined as a feature which supports both its effectiveness and the effectiveness of civil society. The Paris principles do not offer guidance to how individuals who have been appointed as members of a NHRI should manage their

¹³²⁵ UK Government Equalities Office, Tailored Review of the Equality and Human Rights Commission (UK Gov 2018)

¹³²⁶ Stuart Bracking & Ors v Secretary of State for Work and Pensions [2013] EWCA Civ 1345 (06 November 2013)

¹³²⁷ Meredith Raley (2016) The drafting of Article 33 of the Convention on the Rights of Persons with Disabilities: the creation of a novel mechanism, *The International Journal of Human Rights*, 20:1, 138-152 p. 140

relationship with sectors of society or with any CSO.¹³²⁸ As set out, the GANHRI SCA has made clear that office holders should act in their individual capacity. NHRI representatives broadly support this position.¹³²⁹ However this position stands in stark contrast to the emphasis which the text of the UNCRPD and UNCRPD Committee place on disabled people being represented through their representative groups.¹³³⁰

NHRIs are responding to emerging jurisprudence from the UNCRPD Committee by establishing advisory committees. A model which was reflected in both of my case studies during my evidence gathering. Notably in both NHRIs individuals have been appointed to advisory committees in their individual capacity rather than as representatives of their organisation. I observed that the appointment of members on an individual basis undermines the potential for these advisory committees to support the development of the DPM and the potential for advisory committees to act as a mechanism for engagement with DPOs.

My overarching conclusion is that there is a need for further reflection on what it means to operationalise the principle of ‘nothing about us without us’ amongst those NHRIs which have been designated as IMMs. NHRIs have a concern that to include DPOs in all their monitoring activities may create governance issues and may dilute the unique status of a NHRI as a trusted adviser of government. This concern is not completely unfounded. NHRI representatives highlighted that their staff and officers have often developed constructive working relationships with civil servants who tend to grant them greater access due to their status as public servants. These relations could potentially be undermined if NHRI staff sought to include DPOs.¹³³¹ However there are many circumstances in which the inclusion of a DPO could potentially enrich discussions. There is a need for reflection on when it is appropriate for a NHRI to realise the principle of ‘nothing about us without us’ through including a DPO representative in a meeting and when it is possible to realise the principle through other measures. Overall, NHRIs need to develop their confidence in engaging in participative working practices.

¹³²⁸ De Beco G and Murray R, A commentary on the Paris principles on national human rights institutions (Cambridge University Press 2014) p. 67

¹³²⁹ Quinn, Gerard and Crowther, Neil ‘Human rights and disability: A Manual for NHRIs’ (Asia Pacific Forum 2017), p. 111, see further Chapter 4

¹³³⁰ Article 4(3)

¹³³¹ Pegram, Tom ‘The New Architecture in Global Human Rights Governance’ Millennium vol 43(2), p 618-639, 2015

The relationship between NHRIs and DPOs in both of my case studies would benefit from an open discussion on where it is and is not possible to include disabled people and their representative groups. An open discussion on the ways in which a NHRI can influence change is also necessary. DPOs in both of my case studies tended to have a high expectation that a NHRI can effect change through the exercise of their powers. NHRI representatives interviewed for this research tended to be more circumspect and less confident of their ability to effect change. It is important that NHRIs engage in open and honest conversations with DPOs about the level of influence they exert. NHRI(IMM) need to reflect on their staffing structures. DPOs interviewed for this research continually emphasised the value of a NHRI(IMM) having staff members with responsibility for engagement with disabled people. NHRI(IMM) need to consider appointed staff members with specific responsibility for engaging with DPOs and need to consider whether they have appropriately trained staff members who can engage with DPOs and account to DPOs for the decisions taken by the NHRI(IMM).

NHRIs also need to reflect on how they make and explain their decisions. As institutions with broad mandates NHRIs inevitably must make strategic decisions on issues which are prioritised and those that are not. As my case study on the UK indicates, if a NHRI does not seek to explain their decision-making process to DPOs, there is potential for a perception to develop that a NHRI is unresponsive to civil society requests. This can lead to a breakdown of trust in the institution which can have long-term damaging effect.

In light of these findings and conclusions I have made a number of recommendations which I consider will address some of the issues I have identified in my research.

7.4 Recommendations

Whilst this PhD is focused on the exploration of existing practices, I have throughout asked myself how the situation could be improved. I propose a number of recommendations for reform.

DPOs have only been included within a IMF in two jurisdictions.¹³³² This is partly a consequence of a lack of umbrella DPOs with sufficient capacity to take on a role in monitoring the UNCRPD at the time of ratification. However, if a state meets its obligations towards disabled people and DPOs, this should result in the establishment of DPOs and coalitions of DPOs are likely to emerge. Going forward, the UNCRPD Committee should encourage states to reflect on the composition of its monitoring framework with a view to ensuring the participation of DPOs. The Committee should also routinely ask NHRI(IMM)s in states under examination whether a DPO could potentially be included in an IMF. Rather than the designation of a IMM being seen as a one-off event, it should be considered during the periodic examination process.

The GANHRI are both the regulators and representative body for NHRIs. A number of academics have in my view correctly raised concerns relating to the robustness of the accreditation process.¹³³³ The unique feature of a NHRI is that it has been accredited as being in compliance with the Paris Principles. The Paris Principles focus on the independence of an institution from government. They do not in my view elaborate fully on the relationship between NHRIs and CSOs. Human rights theorists strongly emphasise the necessity of a vibrant civil society for the realisation of human rights compliance.¹³³⁴ Throughout my research I detected a tendency for NHRIs to take civil society and the existence of CSOs for granted. There has been a lack of reflection on the role of a NHRI in supporting CSOs to form and sustain themselves. A number of NHRIs, in particular the EHRC, operate on the assumption that the effective execution of their statutory duties creates ancillary benefits for CSOs. However, they do not consider that they have a role in supporting civil society. This has in my view contributed to a breakdown in relations between the EHRC and significant sections of civil society in GB. There is a need for GANHRI to reflect on the role of a NHRI in supporting civil society generally. Whilst the GANHRI has adopted a general observation relating to the role of NHRIs designated as IMMs, this is rather vague and is not routinely applied by the SCA during accreditation hearings. I recommend that the GANHRI develop a more specific observation on NHRIs designated as IMMs which should include a section on the inclusion of disabled people and their organisations in the full range of activities of a NHRI(IMM).

¹³³² Namely Spain and New Zealand

¹³³³ Rosenblum (n. 22)

¹³³⁴ Beth Simmons, *Mobilizing for Human Rights* (Cambridge University Press 2009)

DPOs are currently entitled to make submissions during the accreditation process. However, this is not well known amongst DPOs.¹³³⁵ The GANHRI should conduct a review of the ways in which CSOs are engaging in the accreditation and re-accreditation processes. The GANHRI should place a specific obligation on NHRIs to promote awareness of the accreditation and re-accreditation process amongst civil society and DPOs. DPOs should be supported by the GANHRI to provide views on the activities of a NHRI(IMM) in advance of the accreditation hearing. The GANHRI staff should also engage with DPOs during the UNCRPD examination process to record their views on the activities of a NHRI(IMM). These should then be tabled at the NHRI(IMM)'s next re-accreditation hearing. The International Disability Alliance as the transnational DPO could also play a key role in supporting DPOs to make submissions in advance of an accreditation hearing.

Noting the recent survey of NHRI(IMM) activities by GANHRI I consider that there is a need for the GANHRI Working Group on the UNCRPD to consider how NHRIs can engage with disabled people through their organisations.¹³³⁶ There is a need for GANHRI to raise awareness amongst NHRIs as to the value of engaging with disabled people through their organisations and to provide them with guidance on collaborative working with DPOs and disabled people. NHRIs need to be supported to mainstream disability and engagement with DPOs across all its functions. GANHRI should consider the development and delivery of a training programme to educate NHRI officers and staff on participative ways of working.

I make these recommendations firstly because I consider that they will encourage reflection amongst NHRI(IMM)s as to how they are including disabled people and their representative groups within their monitoring activities. Secondly, I consider that they will potentially provide NHRIs with a basis upon which to argue for new powers or resources to support their role as an IMM. In addition, they will provide DPOs with a stronger basis upon which to engage in the accreditation process and to raise any concerns they may have.

Finally, I recommend that the OHCHR reflect on how they are promoting new techniques for bringing about implementation of the UNCRPD at the domestic level. The OHCHR and other international organisations have prioritised the transmission of technical knowledge to NHRIs

¹³³⁵ Chapter 5 (5.6.3)

¹³³⁶ GANNHRI Working Group on UNCRPD 2019 survey, available at: <https://ganhri.org/2019-survey-report/>

over other actors.¹³³⁷ NHRIs have shared knowledge on engagement with the international system with DPOs and civil society more generally. However, they have not always shared technical knowledge relating to the domestic implementation of rights. I suggest that the OHCHR and other international organisations which provide funding and training to NHRI(IM)s place a requirement on the NHRI(IM) to ensure the diffusion of knowledge on UNCRPD implementation throughout DPOs. This recommendation will encourage reflection amongst NHRI(IM) on how they can share their expertise with DPOs and other CSOs.

7.5 Warrants on Research

As I have interviewed a relatively small number of NHRI(IM) I consider that it is important that I do not make exaggerated claims relating to the general application of my findings and conclusions. My findings are principally of relevance to NHRI(IM)s which reflect the Commonwealth Commission model. I have assessed the activities of the two NHRIs in my case studies against evidence gathered through interviews with seven NHRI(IM)s who have been particularly active in their role as an IMM. I therefore consider that my findings may be taken to be illustrative of the challenges and opportunities emerging from collaboration between a DPO and NHRI(IM). However, they should not be considered to be a conclusive assessment of activities by all NHRI(IM)s.

7.6 Further research

In my evidence gathering I noted that there was a lack of published research on the approaches of NHRIs and DPOs to examination processes by treaty bodies. I have explored whether there are any emerging practices in how NHRIs and DPOs have engaged with the UNCRPD Committee. Due partly to coronavirus restrictions, I was unable to explore fully the ways in which NHRIs and DPOs have engaged with the UNCRPD Committee. This is a topic that would merit further exploration.

In addition, I consider that there is a need for the further research into the potential for public sector equality duties to be used as a domestic policy vehicle for bringing about implementation of the UNCRPD and other international human rights treaties.

¹³³⁷ See for instance OHCHR 'Tripartite Partnership to Support NHRIs' 2019

Finally, I consider that the role of a NHRI in supporting the advocacy activities of SMOs who have chosen to prioritise outsider tactics requires further reflection.

Bibliography

Books

Aichele V, Article 33 National Implementation and Monitoring in Ilias Bantekas, et al (eds) in *The UN Convention on the Rights of Persons with Disabilities : A Commentary* (Oxford University Press 2018).

Anthony G, *Judicial Review in Northern Ireland*, Hart Publishing 2014

Arnardóttir O M, ‘A Future of Multidimensional Disadvantage Equality’ in Arnardóttir OM and Quinn G (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)

Anna Arstein-Kerslake A, *Legal Capacity & Gender: Realising the Human Right to Legal Personhood and Agency of Women, Disabled Women, and Gender Minorities* (Springer, 2020)

Bantekas, I, Article 40: Conference of States Parties in Ilias Bantekas, et al (eds) in *The UN Convention on the Rights of Persons with Disabilities : A Commentary* (Oxford University Press 2018).

Bagentos S, *Law and the Contradictions of the Disability Rights Movement* (Yale University Press 2009)

De Beco G and Murray R, *A commentary on the Paris principles on national human rights institutions* (Cambridge University Press 2014)

Brandsen T and Johnston K, *Collaborative Governance and the Third Sector: Something Old, Something New*’ in Edoardo O and Thiel S (eds), *The Palgrave Handbook of Public Administration and Management in Europe* (Palgrave Macmillan UK 2017)

Buyse A, *The Court’s Ears and Arms: National Human Rights Institutions and the European Court of Human Rights* in Meuwissen, K. and Wouters, J (eds.) *National Human Rights Institutions in Europe: Comparative, European and International Perspectives* (Intersentia, 2013)

Bacchi C, *Analysing Policy: What’s the Problem Represented to Be?*(Frenchs Forest 2009)

Bantekas, I, Article 40: Conference of States Parties in Ilias Bantekas, et al (eds) in *The UN Convention on the Rights of Persons with Disabilities : A Commentary* (Oxford University Press 2018)

Barnes C, Geof Mercer G, and Shakespeare T, *Exploring Disability: A Sociological Introduction*, (Cambridge 1999)

Barrington R, *Health, medicine and politics in Ireland 1900–1970* (Institute of Public Administration 1987)

- Campbell, J. and Oliver, M. *Disability Politics: Understanding Our Past, Changing Our Future*. (Routledge 1996)
- Cardenas S, National Human Rights Institutions and State Compliance in Goodman , R and Pogram, T *Human Rights, State Compliance, and Social Change* (Cambridge University Press 2011)
- Boucher N and Fiset D, 'Monitoring Individual Experiences' in Rioux, M.H., Pinto, P.C., & Parekh, G (eds.) *Disability, Rights Monitoring, and Social Change: Building Power out of Evidence*. (Canadian Scholars Press 2015)
- Carver R, *Assessing the Effectiveness of National Human Rights Institutions International* (Council on Human Rights Policy 2005)
- Charlesworth H, 'A regulatory perspective on the international human rights system' in Peter Drahos (ed.) *Regulatory Theory: Foundations and Applications* (ANU Press 2017),
- Clifford E, *The War on Disabled People* (Zed Books 2020)
- Combrinik H, 'Article 36 Consideration of Reports' in Ilias Bantekas, et al (eds) *The UN Convention on the Rights of Persons with Disabilities : A Commentary*, (Oxford University Press 2018)
- Conroy P, *A Bit Different: Disability in Ireland*, (Orpen Press 2018)
- Charmaz K, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis* (2nd ed. Thousand Oaks: Sage 2014)
- Crowther N and Sayce L, 'Was Ratification of the CRPD the High Watermark for United Kingdom Disability Rights? Ten Years of Monitoring Implementation of the CRPD' in Kakoullis, E and Johnson, K (eds) *Recognising Human Rights in Different Cultural Contexts*. (Palgrave Macmillan 2020)
- Dai X, 'The 'Compliance Gap' and the Efficacy of International Human Rights Institutions in Risse T, Ropp S and Sikkink K (eds.), *The Persistent Power of Human Rights: From Commitment to Compliance* (Cambridge University Press 2013).
- Darnovsky M, Barbara Epstein B, and Flack R, 'Cultural Politics and Social Movements' (1995 Temple University Press) vii
- De Beco, G 'Compliance with the Paris Principles and the ICC Sub.Committee on Accreditation' in Meuwissen, K. and Wouters, J (eds.) *National Human Rights Institutions in Europe: Comparative, European and International Perspectives* (Intersentia 2013)
- De Búrca, G 'The activation of the Convention on the Rights of Persons with Disabilities in Argentina' in de Búrca, G(ed) *Reframing Human Rights in a Turbulent Era* (Oxford 2021)
- Dickson B, 'The Protection Role of the Northern Ireland Human Rights Commission in Ramcharan B (ed.) *The Protection Role of National Human Rights Institutions* ([Nijhoff Law Specials](#) 2005)

Goodman R and Pegram T, 'Introduction: National Human Rights Institutions, State Conformity, and Social Change' in Ryan Goodman and Thomas Pegram (eds) *Human Rights, State Compliance and Social Change*

Hiebert J, *Legislative Rights Review: Addressing the Gap between Ideals and Constraints in* Murray Hunt, Hayley Hooper and Paul Yowell (eds) *Parliaments and Human Rights Redressing the Democratic Deficit* (Bloomsbury 2015)

Hunt J, 'No Limits: The Disabled People's Movement, (Creative Commons 2019)

Lipsky M, *Street Level Bureaucracy: Dilemmas of the Individual in Public Services* (1980 Russell Sage Foundation)

Corsi J, Article 5 Equality And Non-Discrimination in Ilias Bantekas, et al (eds) in *The UN Convention on the Rights of Persons with Disabilities : A Commentary* (Oxford University Press 2018)

Darnovsky M, Barbara Epstein B, and Flack R, 'Cultural Politics and Social Movements' (1995 Temple University Press)

Davis, K. and Mullender, A., *Ten Turbulent Years: a review of the work of the Derbyshire Coalition of Disabled People.* (University of Nottingham 1993)

Degener T and Begg A, *From Invisible Citizens to Agents of Change: A Short History of the Struggle for the Recognition of the Rights of Persons with Disabilities at the UN in* Fina, V, et al (ed.) *The United Nations Convention on the Rights of Persons with Disabilities : A Commentary,* (Springer 2017)

Cera R, *Participation in Political and Public Life in* Fina, V, et al (ed.) *The United Nations Convention on the Rights of Persons with Disabilities : A Commentary,* (Springer 2017)

Driedge D, *The Last Civil Rights Movement* (Disabled People's International 1989)

Dye T, *Understanding Public Policy* (Prentice-Hall 1972)

Edwards M, *Introduction: Civil Society and the Geometry of Human Relations in* Edwards, M (ed) *The Oxford Handbook of Civil Society* (Oxford University Press 2011)

Egan S, *Reform of the UN Human Rights Treaty Body System,* Frédéric Mégret, and Philip Alston (eds) *The United Nations and Human Rights : A Critical Appraisal* (2nd edn, Oxford University Press 2020)

Elizondo G and Aguilar I, *The Ombudsman Institution in Latin America: Minimum Standards for its Existence in* Lindsnaes B, Lindholt L and Yigen K, (eds,) *National Human Rights Institutions, Articles and working papers,* (The Danish Centre for Human Rights 2012)

Epstein L and Martin A, *An Introduction to Empirical Legal Research* (Oxford University Press 2014)

Flynn E, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2011)

Flynn E, *Participatory Justice, Deliberation and Representation in Public and Political Life*, in Eillionoir Flynn (ed) *Participatory Justice, Deliberation and Representation in Public and Political Life* (2016.)

Foucault, M, *Truth and Power* in Colin Gordon (ed) *Power/Knowledge: Selected Interviews and Other Writings, 1972-1977* (Pantheon Books 1980)

Fricker M, *Epistemic Injustice: Power and the Ethics of Knowing* (OUP, 2007)

Giddens, A, *Sociology* (2nd edition, Cambridge University Press 1993)

Gliszczyńska-Grabias A and Sękowska -Kozłowska K, *NHRI in Poland: As good as it gets?* in Meuwissen, K. and Wouters, J (eds.) *National Human Rights Institutions in Europe: Comparative, European and International Perspectives* (Intersentia, 2013)

Griggs S and Howarth D, *Post-structuralism, social movements and citizen politics.*' in Heln Heijden (ed.) *Handbook of Political Citizenship and Social Movements.* (2016 Elgar Publishing)

Guernsey K, 'Committee on the UNCRPD' in Ilias Bantekas, et al (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press 2018)

Hallsworth M, Parker S and Rutter j, *Policy Making in the Real World: Evidence and Analysis* (Institute for Governance 2011)

Halvorsen R, Waldschmidt, A Hvinden B and Bøhler K, *Diversity and dynamics of disability policy Europe An analytical framework* in Rune Halvorsen R et. Al (eds) *The Changing Disability Policy System Active Citizenship and Disability in Europe* (Routledge 2017)

Hans-Otto S, and Martin T, *Inside the Organization. Methods of researching human rights and organizational dynamics* in Andreassen B et. Al. (eds.) *Research Methods in Human Rights: A Handbook* (Edward Elgar Publishing 2016)

Halvorsen R, Waldschmidt, A Hvinden B and Bøhler K, *Diversity and dynamics of disability policy Europe An analytical framework* in Rune Halvorsen R et. Al (eds) *The Changing Disability Policy System Active Citizenship and Disability in Europe* (Routledge 2017)

Halvorsen R et. al, *The contours of the emerging disability policy in Europe* in *The Changing Disability Policy System Active Citizenship and Disability* in Halvorsen R et al. (eds) *The Changing Disability Policy System Active Citizenship and Disability in Europe* (Routledge 2017)

Howlett M, et. al, *Policy formulation, policy advice and policy appraisal: the distribution of analytical tools* in A and Turnpenny J, *The tools of Policy Formulation* (Elgar Press 2015)

Hunt J, *'No Limits: The Disabled People's Movement*, (Creative Commons 2019)

- Jacobsson B, Standardization and Expert Knowledge in Nils Brunsson et al. (eds), *A World of Standards* (Oxford University Press, 2000)
- Jensen L, *Lessons from Research on National Human Rights Institutions* (Danish Institute for Human Rights 2018)
- Kabue, S *Disability Rights, Development and the Roles of the Disability Movement in Rioux M et. al, Disability, Rights Monitoring, and Social Change* (Canadian Scholars' Press, 2015)
- Lawson, A *The Human Rights Act 1998 and Disabled People: A Right to be Human?* Human Rights in the Community : Rights As Agents for Change, edited by Colin Harvey, Bloomsbury Publishing Plc, 2005
- Lelajo R, Postpositivism and and the policy process in Araral E, et al., *Routledge Handbook of Public Policy* (Taylor & Francis Group 2012)
- Lindeman M, Opinion quality and policy preferences in deliberative research in Delli Carpini *MX et al., (ed) Research in Micropolitics: Political Decisionmaking, Deliberation and Participation*, (JAI Press 2002)
- Jacobs L Lomax Cook F and Delli Carpini M, *Talking together: Public deliberation and political participation in America* (University of Chicago Press 2009)
- Kohn M, *Language, Power, and Persuasion: Toward a Critique of Deliberative Democracy* (2000),
- Lawson A, *Duties to Make Adjustments and Human Rights'* in Lawson A (ed.), *Disability and Equality Law in Britain: The Role of Reasonable Adjustment* (Hart Publishing, Oxford, 2008)
- Markku L, (2015) *Indicators: tools for informing, monitoring or controlling?* in Jordan, A and Turnpenny J (eds.) *The Tools of Policy Formulation: Actors, Capacities, Venues and Effects. New Horizons in Public Policy* . (Edward Elgar 2015)
- Longmore P, *A Note on Language and the Social Identify of Disabled People*
- Manca L, *Article 33 [National Implementation and Monitoring]'* in Fina, V, et al (ed.) *The United Nations Convention on the Rights of Persons with Disabilities : A Commentary*, (Springer 2017)
- McInerney-Lankford S, *Legal methodologies and human rights research: challenges and opportunities."* in Andreassen H, Sano H and McInerney-Lankford S, *Research Methods in Human Rights: A Handbook* (Edward Elgar Publishing 2018)
- McKeown M and Spandler H, *Solidarity across difference: organising for democratic alliances* in Helen Spandler, Jill Anderson, and Bob Sapey (eds) *Madness, distress and the politics of disablement* (Policy Press 2015)
- McGettrick G, *Health services and disability* in Suzanne Quin and Bairdre Redmond (eds) *'Disability & Social Policy in Ireland'* (UCD Press 2003)

Melish, T J, An Eye Toward Effective Enforcement: A Technical-Comparative Approach to the Drafting Negotiations.” in Maya Sabatello and Marianne Schulze (eds), *Human rights and disability advocacy* (University of Pennsylvania Press 2014)

Melucci, A. *Challenging Codes. Collective Action in the Information Age* (Cambridge University Press 1996)

Mertus J, *Human rights matters: Local politics and national human rights institutions* (Stanford University Press 2009)

Meyer D, *Social movements and Public Policy: Eggs, Chicken and Theory* in Meyer D and Ingram H, *Routing the Opposition: Social Movements, Public Policy, and Democracy*, (University of Minnesota Press 2005)

Meyer D, *National Human Rights Institutions, Opportunities, and Activism* in Goodman R, and Pegram T (eds) *Human rights, state compliance and social change: assessing national human rights institutions* (Cambridge University Press 2012)

Meyer D and Tarrow S, *The Social Movement Society* (Rowman & Littlefield Publishers 1997)

Mintrom M, ‘The Policy Analysis Movement’, in Dobuzinskis L et al., (eds) *Policy Analysis in Canada: The State of the Art* (University of Toronto Press 2005)

Moeckli D, ‘Equality and Non-Discrimination’ in Daniel Moeckli D et al., (eds) *International Human Rights Law* (2nd edn, OUP 2013)

Morris J, *Pride against Prejudice* (New Society Publishers 1991)

Murray, R and Johnson K, ‘Implementation of Article 33 CRPD in the United Kingdom: The Need to Consolidate Civil Society Engagement’ in Gaultheir De Beco (ed) *Article 33 of the UN Convention on the Rights of Persons with Disabilities National Structures for the Implementation and Monitoring of the Convention* (Brill 2013)

Nelken D, ‘Conclusion: Contesting Global Indicators’ in Merry S et al. (eds) *The quiet power of indicators: Measuring development, corruption, and the rule of law* (Cambridge University Press 2015)

Oliver M, ‘Defining Impairment and Disability: Issues at Stake’ in Barnes C and Mercer G (eds.), *Exploring the Divide: Illness and Disability* (The Disability Press 1996).

Porta D et al., ‘How many approaches in the social sciences?’ in Porta D and Keating M *Approaches and Methodologies in the Social Sciences* (Cambridge University Press 2013)

Pegram T, ‘National human rights institutions in Latin America: politics and institutionalization’ in Goodman R and Pegram T (eds) *Human rights, state compliance and social change: assessing national human rights institutions* (Cambridge University Press 2012)

- Pegram T, *Bridging the Divide: The Merger of the Irish Equality Authority and Human Rights Commission* (TCD Press 2013)
- Piven F and Cloward R, *Poor People's Movements: Why They Succeed, How They Fail* (Pantheon Books 1977)
- Posner E, *The Twilight of Human Rights Law* (Oxford University Press 2014)
- Priestly M, *Disability Politics and Community Care* (Kingsley Publishers 1999)
- Putnam, R.D, *Bowling Alone: The Collapse and Revival of American Community* (Simon & Schuster 2000)
- Quinn G, 'Resisting the 'temptation of elegance': can the Convention on the Rights of Persons with Disabilities socialize States to right behaviour?' in Oddyn Arnardóttir and Gerard Quinn (eds) *The United Nations Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff Publishers, 2009)
- Quinn G, 'The International Covenant on Civil And Political Rights and Disability: A Conceptual Framework', in Theresa Degener T and Yolán Koster-Dreese, (eds,) *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments*, (Martinus Nijhoff, 1995)
- Quinn S, 'Health services and disability' in Suzanne Quin and Bairbre Redmond *Disability & Social Policy in Ireland* (University College Press Dublin) 2003
- Reif L, 'The shifting boundaries of NHRI definition in the international system' in Ryan Goodman and Thomas Pegram (eds) *Human rights, state compliance and social change: assessing national human rights institutions* (Cambridge University Press 2012)
- Roberts S, Stafford B and Hill K, 'Diluting Substantive Equality: Why the UK Government doesn't Know if its Welfare Reforms Promote Equality' in David Fée and Anémone Kober-Smith (eds) *Inequalities in the UK New Discourses, Evolutions and Actions* (Emerald Publishing 2017)
- Rosenblum P, 'Tainted Origins and Uncertain Outcomes: Evaluating NHRIs' in Ryan Goodman and Thomas Pegram (eds) *Human rights, state compliance and social change: assessing national human rights institutions* (Cambridge University Press 2012)
- Sabatello M, *The New Diplomacy in Disability Advocacy* (2013 University of Pennsylvania Press)
- Sansome J, 'The Links Between Models and Theories to Social Changes as Seen and Understood' in Maria Berghs, et al (eds) *The Routledge Handbook of Disability Activism* (Routledge 2019)
- Series L and Nilsson A, 'Article 12 CRPD: Equal recognition before the law' in

Scott J, 'Mechanisms of influence: interest groups, lobbyists and policy formulation' in Michael Howlett and Ishani Mukherjee (eds) *Handbooks of Research on Public Policy* series (Elgar Publishing 2017)

Simmons B, 'International Law' in Carlsnaes Walter, Thomas Risse and Beth Simmons, (eds) *Handbook of International Relations* (Sage Publications 2012).

Smith, D. *The Conceptual Practices of Power: A Feminist Sociology of Knowledge*. (1990 Northeastern University Press).

Soldatic, K., & Meekosha, H. 'Disability and neoliberal state formations' in Nick Watson, Alan Roulstone, and Carol Thomas (Eds.), *Routledge Handbook of Disability Studies* (Routledge 2012)

Soorenian, A. 'Media Disability and Human Rights' in Michael Gill and Cathy J. Schlund-Vials (eds) *Disability, Human Rights and the Limits of Humanitarianism* (Routledge 2014)

Spencer S and I. Bynoe I. *A Human Rights Commission: The Options for Britain and Northern Ireland* (Institute for Public Policy Research 1998)

Spencer S, 'Partner rediscovered: Human rights and equality in the UK' in Colin Harvey (Ed) *Human Rights in the Community* (Oxford 2004)

Stammer N, *Human Rights and Social Movements* (2009 Pluto Press)

Start D and Hovland I, *Tools for Policy Impact: A Handbook for Researchers* (Overseas Development Institute 2004)

Stein M and Lord J, 'Future prospects for the UNCRPD' in Arnardóttir OM and Quinn G (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)

Steiner H, 'Individual Claims in a World of Massive Violations: What Role for the Human Rights Committee' in Phil Alston and James Crawford (eds.), *The Future of UN Human Rights Treaty Monitoring XXXV* (Cambridge University Press, 2000)

Stone, D. *Learning Lessons, Policy Transfer and the International Diffusion of Policy Ideas* (University of Warwick 2001)

Tarrow S. *Power in Movement: Social Movement and Contentious Politics* (Cambridge University Press 2012)

Tarrow S. *Power in Movement. Social Movements, Collective Action and Politics* (Cambridge University Press 1994)

Tilly C. *The Contentious French* (Harvard University Press 1986).

Toolan, D, 'An emerging rights perspective for disabled people in Ireland: an activist's view' in Suzanne Quin and Bairbre Redmond (eds.), *Disability & Social Policy in Ireland* (University College Press Dublin 2003)

Traustadottir R, 'Disability Studies, the Social Model and Legal Developments', in Oddny Mjoll Arnardottir and Gerard Quinn (eds.), *The UN Convention on the Rights of Persons with Disabilities*, 3 (Martinus Nijhoff, 2009)

Tsui J. *The effectiveness of measuring influence* (University of Birmingham 2013)

Verhoeven I and Bröer C, 'Contentious Governance' in Duyvendak J and Jasper J (eds) *Breaking Down the State* (Amsterdam University Press 2015)

Waldschmidt, A. Sturm, A. Karačić and T. Dins, *Implementing the UN CRPD in European countries* in Halvorsen R et al. (eds) *The Changing Disability Policy System Active Citizenship and Disability in Europe* (Routledge 2017)

Wu, X et al, *The public policy primer: Managing public policy* (Routledge 2010)

Yin, R. K, *Case study research: Design and methods* (Sage 1994)

Zald M Morrill C and Rao H, 'The impact of social movement organisations: environment and responses' in G. Davis, et al., (Eds.), *Social Movements and Organization Theory* (Cambridge University Press 2005)

Articles

Nicholas Acheson & Arthur Williamson, 'The Ambiguous Role of Welfare Structures in Relation to the Emergence of Activism Among Disabled People: Research evidence from Northern Ireland' [2001] *Disability & Society* 87

George Anderson, 'The new focus on the policy capacity of the federal government' [1996] *Canadian Public Administration* 469

Colin Barnes, 'Re-thinking Disability, Work and Welfare' [2012] *Sociology Compass* 6/6: 472

Angharad E. Beckett, 'Understanding Social Movements: theorising the disability movement in conditions of late modernity' [2006] *Sociological Review* 54(4), 734

Robert D. Benford and David A. Snow 'Framing Processes and Social Movements: An Overview and Assessment' [2000] *Annual Review of Sociology* 611

Anthony M. Bertelli, 'Governing the Quango: An Auditing and Cheating Model of Quasi-Governmental Authorities' [2006] *Journal of Public Administration Research and Theory* 239

Jerome Bickenbach, 'Monitoring the United Nation's Convention on the Rights of Persons with Disabilities: data and the International Classification of Functioning, Disability and Health, [2011] *BMC Public Health* 1

Stuart Braye, "You Shall Not Murder": Atos at the Paralympic Games', [2017] *Journal of Disability & Religion* 215

Meg Brodie, 'Uncomfortable Truths: Protecting the Independence of National Human Rights Institutions to Inquire' [2015] UNSW Law Journal 1215

Paul Burstein and Sarah Sausner, 'The Incidence and Impact of Policy-Oriented Collective Action: Competing Views' [2005] Sociological Forum 403

Anne-Marie Callus, 'From 'for' to 'of': a typology of Maltese disability organisations' [2014] Disability & Society 1

Peter Cairney, 'Standing on the Shoulders of Giants: How Do We Combine the Insights of Multiple Theories in Public Policy Studies?' [2013] The Policy Studies Journal 1

Campbell, T and Beckett, A (2015) The social model of disability as oppositional device. *Disability and Society*, 30 (2). 270

Sonia Cardenas, 'Emerging Global Actors: The United Nations and National Human Rights Institutions' [2003] *Global Governance* 23

Hilary Charlesworth, 'International Law: A Discipline of Crisis' [2002] *The Modern Law Review* 377

Cosette D. Creamer and Beth A. Simmons, 'Ratification, Reporting, and Rights: Quality of Participation in the Convention against Torture' [2015] *Human Rights Quarterly* 579

Cosette D. Creamer and Beth A. Simmons, 'The Dynamic Impact of Periodic Review on Women's Rights' 81 [2018] *Law and Contemporary Problems* 81

John R. Crook 'The International Court of Justice and Human Rights' [2004] *Northwestern Journal of International Human Rights* 8

Nick Crossley, 'From Reproduction to Transformation Social Movement Fields and the Radical Habitus' [2017] *Studies in Arts and Humanities* 6

Antje Daniel & Dieter Neubert, 'Civil society and social movements: conceptual insights and challenges in African contexts' [2019] *Critical African Studies* 176

K Davis, Brian Kingsbury, & Sally Engle Merry, 'Indicators as a Technology of Global Governance. [2012] *Law & Society Review* 71

Gauthier de Beco, 'Human Rights Indicators: From Theoretical Debate to Practical Application' [2013] *Journal of Human Rights Practice* 380

Jurgen De Wispelaere and Judy Walsh, 'Disability Rights in Ireland: Chronicle of a Missed Opportunity' [2007] *Irish Political Studies* 517

Theresia Degener, *Disability in a Human Rights Context* [2016] *Laws*, 5(3), 35

Robert F. Drake, 'Disabled people, voluntary organisations and participation in policy making' [2002] *Policy & Politics* 373

Shaheed Fatima, 'Using International Law in Domestic Courts – Part II: Undomesticated Treaties' [2003] *Judicial Review* 138

John Fenwick, Karen Miller Johnston and Duncan McTavish, 'Co-governance or meta-bureaucracy? Perspectives of local governance 'partnerships' in England and Scotland' [2012] *Policy & Politics* 405

Janos Fiala-Butora, Michael Stein and Janet Lord, 'The Democratic Life of the Union: Toward Equal Voting Participation for Europeans with Disabilities' [2014] *Harv. Int'l LJ* 55

Martha Finnemore and Kathryn Sikkink. 'International norm dynamics and political change' [1998] *International Organization* 887

Mathew Flinders 'Governance in Whitehall' [2002] *Public Administration* 51

Eilionoir Flynn, 'Mental (in)Capacity or Legal Capacity: A Human Rights Analysis of the Proposed Fusion of Mental Health and Mental Capacity Law in Northern Ireland' [2013] *N. IR. Legal Quarterly* 485

Kayleigh Garthwaite 'The language of shirkers and scroungers?' Talking about illness, disability and coalition welfare reform, [2011] *Disability & Society* 369

Alex Geisinger and Michael A. Stein, 'A Theory of Expressive International Law' [2019] *Vanderbilt Law Review* 75

Faye Ginsburg, Rayna Rapp, 'Crippling the new normal: Making disability count' [2017] *European Journal of Disability Research* 179

Lucas Glusac, 'National Human Rights Institutions and Oversight of the Security Services' [2018] *Journal of Human Rights Practice* 58

Maria Green, 'What We Talk About When We Talk About Indicators: Current Approaches to Human Rights Measurement' [2001] *Human Rights Quarterly* 1062

Harlan Hahn, 'Introduction: Disability policy and the problem of discrimination' [1985] *American Behavioural Scientist* 293

Oona Hathaway, 'Do Human Rights Treaties Make a Difference?' [2002] *Yale L.J* 1935

Michael Howlett, 'The supply and demand for policy analysis in government' [2015] *Policy and Society* 173

Paula Hyde and Huw T.O. Davies, 'Service design, culture and performance: Collusion and co-production in health care' [2004] *Human Relations* 1407

Arlene Kanter 'The Law: What's Disability Studies Got to Do with It or An Introduction to Disability Legal Studies' April 2011 *Columbia Human Rights Law Review* 42(2)

Rob Kitchin and Robert Wilton, 'Disability activism and the politics of scale' [2003] *Canadian Geographer* 97

Harry Koh, 'Internalization Through Socialization', [2005] *Duke LJ* 975

Corina Lacatus, 'Explaining Institutional Strength: The case of national human rights institutions in Europe and its Neighbourhood' [2018] *Journal of European Public Policy* 1657

Stéphanie Lagoutte, 'The Role of State Actors Within the National Human Rights System' [2019] *Nordic Journal of Human Rights* 177

Per Læg Reid, Tiina Randma-Liiv, Lise H. Rykkja and Ku'lli Sarapuu, 'Emerging coordination practices of European central governments' [2015] *International Review of Administrative Sciences* 346

Anna Lawson & Angharad E. Beckett, 'The social and human rights models of disability: towards a complementarity thesis', [2021] *The International Journal of Human Rights*, 25:2, 348

Anna Lawson and Mark Priestley, 'Potential, Principle and Pragmatism in Concurrent Multinational Monitoring: Disability Rights in the European Union' [2013] *The International Journal of Human Rights* 739

Jackie Leach Scully, 'From "She Would Say That, Wouldn't She?" to "Does She Take Sugar?" Epistemic Injustice and Disability' [2018] *International Journal of Feminist Approaches to Bioethics* 106

Rasmussen M, Lewis O 'Introductory Note to the United Nations Convention on the rights of persons with disabilities' [2007] *International Legal Materials* 441

Katerina Linos and Tom Pegram, 'Architects of Their own Making: National Human Rights Institutions and the United Nations' [2016] *Human Rights Quarterly* 1109

Janet E. Lord & Michael Ashely Stein, 'The Domestic Incorporation of Human Rights Law and the United Nations Convention on the Rights of Persons with Disabilities' [2008] *Wash. L. Rev.* 449

Sébastien Lorion, 'A Model for National Human Rights Systems? New Governance and the Convention on the Rights of Persons with Disabilities' [2019] *Nordic Journal of Human Rights* 234

Laufey Love, Rannveig Traustadottir, Gerard Quinn and James Rice, 'The Inclusion of the Lived Experience of Disability in Policymaking' [2017] *Laws* 33

Laufey Love, Rannveig Traustadottie & James Rice, 'Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People's Organizations in Securing a Seat at the Table' [2019] *Laws* 1

Inger Marie Lid, 'Vulnerability and disability: a citizenship perspective [2015] *Disability & Society* 1554

- Faraaz Mahomed, Janet E. Lord & Michael Ashely Stein, 'Transposing the Convention on the Rights of Persons with Disabilities in Africa: The Role of Disabled Peoples' Organisations' [2019] *African Journal of International and Comparative Law* 335
- Frédéric Mégret, 'The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?' [2008] *Human Rights Quarterly* 494
- Sally Engle Merry, 'Measuring the World: Indicators, Human Rights, and Global Governance' [2011] *Current Anthropology* 583
- Katrien Meuwissen, 'NHRIs and the State: New and Independent Actors in the Multi-layered Human Rights System?' [2015] *Human Rights Law Review* 441
- Lana Moriarity and Kevin Dew, 'The United Nations Convention on the Rights of PWDs and Participation in Aotearoa New Zealand' [2011] *Disability & Society* 685
- Janet Newman, Marian Barnes, Helen Sullivan, and Andrew Knops 'Public participation and collaborative governance' [2004] *Journal of Social Policy* 203
- Obiora Chinedu Okafor and Shedrack C. Agbakwa, 'On Legalism, Popular Agency and Voices of Suffering: The Nigerian National Human Rights Commission in Context' [2002] *Human Rights Quarterly*, 662
- Mike Oliver 'Rewriting history: the case of the Disability Discrimination Act 1995' [2016] *Disability & Society* 966
- Mike Oliver and Gerry Zarb, 'The Politics of Disability: A New Approach Disability' [1989] *Handicap & Society* 221
- Charlotte Pearson and Filippo Trevisan, 'Disability Activism in the New Media Ecology: Campaigning Strategies in the Digital Era,' [2015] *Disability & Society* 924
- Perri, 'Joined-Up Government in the Western World in Comparative Perspective: A Preliminary Literature Review and Exploration' [2004] *Journal of Public Administration Research and Theory* 103
- Gabor Petri, Julie Beadle-Brown and Jill Bradshaw, "'More Honoured in the Breach than in the Observance"—Self-Advocacy and Human Rights' [2017] *Laws* 26
- Tom Pegram 'The New Architecture in Global Human Rights Governance' [2015] *Millennium* 618
- Paula Pinto, 'At the crossroads: Human rights and the politics of disability and gender in Portugal (2011)' *European Journal of Disability Research* 116
- Gaile Pohlhaus, 'Relational Knowing and Epistemic Injustice: Toward a Theory of Wilful Hermeneutical Ignorance' [2012] *Hypatia* 715
- Gerard Quinn, 'The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability' [2009] *Tex. J. on C.L. & C.R.* 33

Harriet Radermacher Christopher Sonn, Christopher Keys and Paul Duckett 'Disability and Participation: It's About Us but Still Without Us!' [2010] *Community and Applied Social Psychology* 333

Catherine Renshaw, 'National Human Rights Institutions and Civil Society Organizations: New Dynamics of Engagement at Domestic, Regional, and International Levels' *Global Governance* [2012] 299

Catherine Renshaw, Andrew Byrnes and Andrea Durbach, 'Testing the Mettle of National Human Rights Institutions: A Case Study of the Human Rights Commission of Malaysia' [2011] *Asian Journal of International Law* 165

Desmond Ryan and Mark Bell 'Disability, Reasonable Accommodation and the Employer's Obligations: Nano Nagle School v Daly' [2020] *The Modern Law* 1059

Richard K. Scotch, 'Politics and Policy in the History of the Disability Rights Movement' [1989] *The Milbank Quarterly* 380

Richard K. Scotch 'Disability as the Basis for a Social Movement: Advocacy and the Politics of Definition' [1988] *Journal of Social Issues*. 159

Arno Simons & Jan-Peter Voß, 'The concept of instrument constituencies: accounting for dynamics and practices of knowing governance' [2018] *Policy and Society* 14

Anne Smith, 'The Unique Position of National Human Rights Institutions: A Mixed Blessing?' [2006] *Human Rights Quarterly* 937

Merry Smith, 'Vernacularization on the Ground: Local Uses of Global Women's Rights in Peru, China, India and the United States' [2009] *Global Networks* 441

Sarah Spencer and Colin Harvey, 'Context, Institution or Accountability? Exploring the Factors that Shape the Performance of National Human Rights and Equality Bodies' [2014] *Policy and Politics* 89

Neil Stammer. 'Social Movements and the Social Construction of Human Rights' [1999] *Human Rights Quarterly* 980

Michael Stein and Janet Lord, 'Monitoring the Convention on the Rights of Persons with Disabilities: Innovations, Lost Opportunities, and Future Potential' [2010] *Human Rights Quarterly* 689

Jacqui True and Michael Mintrom, 'Transnational networks and policy diffusion: The case of gender mainstreaming.' [2001] *International Studies Quarterly* 27

Lisa Vanhala, 'Fighting discrimination through litigation in the UK: the social model of disability and the EU anti-discrimination directive' [2006] *Disability and Society* 551

Juho Vesa, Anu Kantola and Anne Skorkjær Binderkrantz, 'A Stronghold of Routine Corporatism? The Involvement of Interest Groups in Policy Making in Finland Scandinavian' [2018] *Political Studies* 239

Oscar Vilhena Vieira and A. Scott Dupree, 'Reflections on Civil Society and Human Rights' [2004] *Int'l J. on Hum Rts.* 47

Mitzi Waltz & Alice Schippers, Politically disabled: barriers and facilitating factors affecting people with disabilities in political life within the European Union, [2021] *Disability & Society*, 36:4, 517

Rebekah Young, Mathew Reeve, Nathan Grills, 'The Functions of Disabled People's Organisations (DPOs) in Low and Middle-income Countries: a Literature Review' [2016] *Disability CBR & Inclusive Development* 45

Domenico Zipoli 'NHRI Engagement with UN Human Rights Treaty Bodies: A Goal-based Approach' [2019] *Nordic Journal of Human Rights* 259

Reports

Commission on the Status of People with Disabilities 2006, *A Strategy for Equality*, Dublin: Stationery Office. 1996

Department of Justice Roadmap to Ratification of the United Nations Convention on the Rights of Persons with Disabilities 2014

NUI Galway / The Centre for Disability Law and Policy, *Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of Persons with Disabilities* (Irish Human Rights and Equality Commission 2016) 22

Disability Legislation Consultation Group (DLCG) (2003) *Equal Citizens: Proposals for Core Elements of Disability Legislation* (Dublin: DLCG).

Ireland, *Initial Report under the Convention on the Rights of Persons with Disabilities* 2020

Law Reform Commission, *Discussion Paper: Domestic Implementation of International Obligations* 2020

HM Government *Building a Fairer Britain: Reform of the Equality and Human Rights Commission* (HM Government, 2011).

Quinn, Gerard, and Theresia Degener. 2002. *Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability*. United Nations Publications.

Quinn, Gerard and Crowther, Neil 'Human rights and disability: A Manual for NHRIs' (Asia Pacific Forum 2017)

OHCHR 'Working with the United Nations Human Rights Programme: A Handbook for Civil Society' UN (New York 2006)

OHCHR Statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities 28 December 2021 A/HRC/49/60

OHCHR A Manual for National Human Rights Institutions on Monitoring Economic, Social and Cultural Rights (UN 2011)

OHCHR National Human Rights Institutions: History, Principles, Roles and Responsibilities Professional Training Series (UN 2010)

Special Rapporteur, Report to the Seventy-first session of the UN GA (2016) UN Doc A/71/314

United Nations General Assembly, 'Declaration of Madrid: Making It Work: Civil Society Participation in the Implementation of the Convention on the Rights of Persons with Disabilities', UNGA Resolution A/62/654

UPIAS Fundamental Principles of Disability (UPIAS 1976)

Vienna Declaration and Programme of Action, adopted by the World Conference on Human Rights in Vienna on 25 June 1993

UK Social Security Advisory Committee 'How DWP involves disabled people when developing or evaluating programmes that affect them' (HM Gov 2020)

Women's Equality Committee, 'Enforcing the Equality Act: the law and the role of the Equality and Human Rights Commission (HM Parliament 2019)

Unpublished works

Sébastien Lorion 'The institutional turn of international human rights law and its reception by state administrations in developing countries' PhD Thesis University of Copenhagen 2019

Newspaper articles

Paul Butler 'How the Spartacus Welfare Cuts Campaign Went Viral' The Guardian (London 17 January 2012).

Elaine Edwards, 'Call for inquiry into use of outdated institutions', Irish Times, (Dublin 26 January 2016)

Deaglan De Breadun, 'Protesters' disability becomes their greatest strength' Irish Times (Dublin 8 September 2012)

Rónán Duffy, 'Disability advocate says 'it's time to put up or shut up' as she joins board of Irish Rail' *The Journal* (Dublin 3 August 2018)

Editor Minister intervenes in row at group for disabled Irish Independent (Dublin February 27 1998)

Editor 'Uncomfortable reading for some civil servants' Irish Times, (Dublin 9 October 1999)

Mark Hilliard, 'Noted disability campaigner Martin Naughton dies at 62' (Dublin 13 October 2016)

Prof Brendan Kelly 'Don't deny them this treatment' Irish Independent (Dublin 13 January 2016)

Colm Keena 'Acting head of council for the disabled dismissed after 2 months' Irish Times (Dublin 9 October 1998)

Rosaleen McDonagh, 'Travellers and people with disabilities must use their vote for change' Irish Times (Dublin 24 April 2019)

Aine McMahon, Protest at cuts to disability payments, Irish Times (Dublin 22 November 2021)

Andy McSmith 'Wheelchair warriors target Blair', The Guardian (London 16 May 1999)

Carl O'Brien 'Major changes to disability legislation urged' *Irish Times*, (Dublin 9 February 2005)

John Pring Equality watchdog to scrap vital disability committee (Disability News Service 19 July 2013)

John Pring, Network neglect leaves government 'closer to coercion than co-production' (Disability News Service 12 April 2018)

John Pring Outrage over 'rehashed' strategy that is 'not fit for purpose' (30 July 2021 Disability News Service)

John Pring DPOs take control after Tomlinson 'shuts down his own forum' Disability News Service (3 June 2021 Online)

John Pring, Deaf campaigner takes court action over BSL jury ban' Disability News Service (23 August 2018 Online)

John Pring, 'Disability strategy delayed again as government consultation faces high court challenge' (22 July 2021 Online)

John Pring 'Government must rewrite its National Disability Strategy, court is told' Disability News Service (4 November 2021 Online)

John Pring, Anger after watchdog appears to back away from inquiry into DWP deaths Disability News Service (29 April 2021 Online)

John Pring 'Watchdog's 'invaluable' inquiry set to expose 'fragility' of social care system' Disability News Service (29 April 2021 Online)

Speeches

Gerard Quinn, *The CRPD as an Engine of Domestic Law Reform*, UN Headquarters, New York City, October 31, 2008

Cases

AM-V v Finland. ECHR 273, 2017

Bracking & Ors v Secretary of State for Work and Pensions [2013] EWCA Civ 1345 (06 November 2013)

R v Brent London Borough Council, ex parte Gunning, (1985) 84 LGR 168

Burnip v Birmingham City Council & Anor [2012] EWCA Civ 629 (15 May 2012)

In re E (a child) (AP) (Appellant) (Northern Ireland) [2008] UKHL 66

In the matter of an application by the Northern Ireland Human Rights Commission for Judicial Review (Northern Ireland) [2018] UKSC 27

Hainsworth v MOD [2014] EWCA Civ 763

R (on the application of SC, CB and 8 children) (Appellants) v Secretary of State for Work and Pensions and others (Respondents) [2021] UKSC 26

JH Rayner (Mincing Lane) Ltd v Department of Trade and Industry [1990] 2 AC 418