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Percy Carter

Universal Legal Capacity for Persons with Disabilities:

Will, Preferences and Communication

EMA, The European Master's Programme
in Human Rights and Democratisation

PERCY CARTER

UNIVERSAL LEGAL CAPACITY FOR PERSONS
WITH DISABILITIES:
WILL, PREFERENCES AND COMMUNICATION

FOREWORD

The European Master's Degree in Human Rights and Democratisation (EMA) is a one-year intensive programme launched in 1997 as a joint initiative of 8 universities which now has participating universities in all EU Member States with support from the European Commission. Based on an action- and policy-oriented approach to learning, it combines legal, political, historical, anthropological and philosophical perspectives on the study of human rights and democracy with targeted skills-building activities. The aim from the outset was to prepare young professionals to respond to the requirements and challenges of work in international organisations, field operations, governmental and non-governmental bodies, and academia. As a measure of its success, EMA has served as a model of inspiration for the establishment of seven other EU-sponsored regional master's programmes in the area of human rights and democratisation in different parts of the world. Today these programmes cooperate closely in the framework of the Global Campus of Human Rights, with its headquarters in Venice, Italy.

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Each year the EMA Council selects five theses, which stand out for their formal academic qualities and the originality of the research topics, their relevance to the promotion and implementation of human rights and democratic values, the innovation of their argument, methodology, and theoretical approach, their Exceptional knowledge of the academic literature and the excellent capacity for critical analysis demonstrated by the authors

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- Carter, Percy Elena Virginia, *Universal Legal Capacity for Persons with Disabilities: Will, Preferences and Communication*. Supervisor: Andrea Broderick, Maastricht University.
- Gscheidlen, Anne Sophie, *At Risk of Falling through the Cracks? The Protection of Children in State Care in Conflict Situations in International Law and Practice*. Supervisor: Katre Luhamaa, University of Tartu.
- Keogh, Bríana Maria, *Preimplantation Genetic Testing: the Conflict between Reproductive Autonomy and Disability Rights. With the UK, Ireland, and Portugal as Case Studies*. Supervisor: Helena Pereira de Melo, New University of Lisbon.
- Sheppard, Phoebe Eleanor, *Imperialist Queerphobia. The Curtailment of LGBTQ+ Rights in Uganda and South Africa as a Product of Colonialism, Religion, and Patriarchy*. Supervisor: Ekaterina Yahyaoui, University of Galway.
- Vodopija, Helena, *When the 'Terrorists' Speak the Language of Humanity. Counter-Memory of 15th July Coup d'État*. Supervisor: Josip Glaurdić, Université du Luxembourg.

The selected theses demonstrate the breadth, depth and reach of the EMA programme and the passion and talent of its students. We are proud of the range of topics as well as the curiosity and research skills demonstrated by this year's students. On behalf of the Governing Bodies of EMA and of all participating universities, we applaud and congratulate them.

Prof. Manfred NOWAK
Global Campus Secretary General

Prof. Thérèse MURPHY
EMA Chairperson

Dr Orla Ní CHEALLACHÁIN
EMA Programme Director

This publication includes the thesis *Universal Legal Capacity for Persons with Disabilities: Will, Preferences and Communication* written by Percy Elena Virginia Carter and supervised by Andrea Broderick, Maastricht University.

BIOGRAPHY

Percy is an activist for women's rights and persons with disabilities, with a special focus on persons with autism. She graduated from the University of Edinburgh in 2016 with an LLB honours degree in law and politics, and has completed work for the ICRC, NATO and the Supreme Court of New York. In 2022, she completed her EMA thesis at Maastricht University, focusing on the rights of persons with disabilities.

ABSTRACT

The right to legal capacity is a fundamental right that allows individuals to be a person before the law and exercise control over their own lives. For persons with disabilities, the right to legal capacity has often been restricted through 'substitute decision-making' where another individual exercises legal capacity on their behalf. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities seeks to undo the norm of substitute decision-making by asserting that all persons with disabilities have the right to exercise their own legal capacity, and should never be stripped of this right. Per article 12, where persons with disabilities face challenges in exercising their legal capacity, states parties should rather implement frameworks of supported decision-making which adhere to the will and preferences of the individual. This thesis is concerned with the expression of will and preferences under frameworks of supported decision-making, specifically, the expression of will and preferences by persons with disabilities who have communication support needs and use varying forms of both verbal and non-verbal communication. This thesis will explore the interpretation of article 12 regarding supported decision-making, will and preferences, and communication, and use these considerations to analyse frameworks of supported decision-making under the Irish Assisted Decision-Making (Capacity) Act (ADMCA). The purpose of analysing both article 12 and the ADMCA is to propose a framework for persons tasked with providing support to persons with disabilities under the Act derived from the capability approach, a normative framework that re-conceives classic welfarist notions that the possession of goods and resources were adequate indicators of justice. Using the capability approach, this thesis will put forth a framework that may be used by support persons under the ADMCA to determine the most appropriate method of communication to ascertain the will and preferences of all persons with disabilities, regardless of their method of communication.

Trigger warning: some of the materials utilised for research in this thesis contain ableist language and remarks.

*It is of the essence of the demand for
equality before the law that people should be treated
alike in spite of the fact that they are different.*

Friedrich August von Hayek

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TABLE OF ABBREVIATIONS

AAC	Augmentative and alternative communication
ADMCA	Assisted Decision-Making (Capacity) Act
Ad Hoc Committee:	Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities
CDM	Co-decision-maker
CRPD	United Nations Convention on the Rights of Persons with Disabilities
CSN	Communication Support Needs
DMA	Decision-making assistant
GC1	General comment No. 1 (2014) Article 12: Equal recognition before the law
ICSPM	Individuals Communicating Through Non-Speech Modalities
IDC	International Disability Caucus
SP	Support Persons
The Committee:	Committee on the Rights of Persons with Disabilities
UNGA	United Nations General Assembly

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1.

INTRODUCTION

1.1 WHAT IS LEGAL CAPACITY AND WHY IS IT IMPORTANT?

Legal capacity entails the right to be recognised before the law, and is a ‘legal shell through which to advance personhood in the lifeworld’, enabling persons to mould their own legal universe.¹ For many, it is a right synonymous with adulthood that is automatically awarded upon turning a certain age, and for other groups of persons, the right to legal capacity is a privilege. Throughout history, persons with disabilities have been deprived of their right to legal capacity through being placed in systems of ‘substitute decision-making’ where their legal capacity is removed and another person is appointed to make decisions on behalf based on the objective ‘best interests’ of the individual.² Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which requires states parties to ‘recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’,³ intends to instigate a paradigm shift towards a universalist understanding of legal capacity for all persons with disabilities, maintaining that all persons have an unequivocal right to legal capacity.⁴ The importance of universal legal capacity lies within

¹ G Quinn, ‘Personhood & Legal Capacity. Perspectives on the Paradigm Shift of Article 12 CRPD’ (Concept paper, HPOD Conference, Harvard Law School, 20 February 2010) 10.

² Committee on the Rights of Persons with Disabilities, ‘General comment No. 1 (2014) Article 12: Equal recognition before the law’ (19 May 2014) UN Doc CRPD/C/GC/1 (GC1) para 26.

³ Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD) art 12(2).

⁴ Quinn (n 1).

the purpose of the CRPD to ‘promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities’,⁵ as the denial of legal capacity consequently determines whether an individual is able to exercise a number of civil, political, economic, social and cultural rights; such as the right to liberty, the right to family life and access to justice.⁶

Article 12 aims to eradicate and replace substitute decision-making with ‘supported decision-making’, a regime that ‘comprises various support options which give primacy to a person’s will and preferences and respect human rights norms’.⁷ These systems should *never* amount to substitute decision-making regardless of the disability or respective characteristics of each individual. Article 12, therefore, introduces universal legal capacity that not only requires a complete reconceptualization of legal capacity in itself, but urges law and society to consider how disability relates to fundamental principles such as autonomy and agency.⁸ The priority to be given to the will and preferences of persons with disabilities may not seem revolutionary at first instance, but regimes of substitute decision-making rely upon assessments of ‘mental capacity’, which analyse the cognitive functioning of the individual. Being placed in a regime of substitute decision-making indicates that one lacks the mental capacity to act in one’s own self-interest or communicate one’s desired choices. As such, legal capacity is taken away and third parties are entrusted to make decisions on behalf of a person with a disability based on what they deem to be in their ‘best interest’.⁹ The CRPD not only defends legal capacity, it emphasises that States Parties ‘shall take all appropriate measures to provide access by persons with disabilities the support they may require in exercising legal capacity’.¹⁰ Importantly, this includes the ‘development and recognition of diverse, non-conventional methods of communication, especially those for non-verbal forms of communication to express their will and preferences’.¹¹

⁵ CRPD art 1.

⁶ G de Beco, *Disability in International Human Rights Law* (OUP 2021) 93.

⁷ GC1 (n 2) para 29.

⁸ L Series, ‘Comparing Old and New Paradigms of Legal Capacity’ (2014) 2014 *Elder Law Journal* 62, 63.

⁹ KB Glen, ‘Changing Paradigms: Mental Capacity, Legal Capacity Guardianship, and Beyond’ (2012) 44 *Columbia Human Rights Law Review* 93; AS Kanter, *The Development of Disability Rights Under International Law: From Charity to Human Rights* (Routledge 2014).

¹⁰ CRPD art 12(3).

¹¹ GC1 (n 2) para 17.

Communication is a basic need and a basic right of all persons, and any consideration of the quality of life of persons with disabilities must take into account the degree to which individuals are able to communicate, and thus participate, in the community they live.¹² Effective communication allows us to live independently, manage our affairs and assert our own free will in the world; however, persons with disabilities face communication barriers and subsequent exclusion from a society rooted in prejudice.¹³ Acknowledging universal legal capacity calls for new and inclusive policy frameworks that recognise linguistic and non-linguistic forms of communication, falling under the heading of augmentative and alternative communication (AAC). Behind the idea of giving effect to a person's will and preferences is the belief that all individuals, regardless of whether or not they have a disability, communicate in some way. However, the effectiveness and the interpretation of such communication varies with social and environmental factors.

1.2 PROBLEM STATEMENT, OBJECTIVES OF THIS THESIS AND RESEARCH QUESTIONS

The problem this thesis seeks to address is centred around the legal implementation of states parties' obligations under article 12. Specifically, it is focused on the obligations to implement systems of supported decision-making where the will and preferences of the individual are always the utmost priority, regardless of the individual's method of communication or whether they rely on AAC. The problem that this thesis is concerned with on a broader level is how states parties can ensure a genuine understanding of the will and preferences of all persons with disabilities in systems of supported decision-making, when many persons with disabilities use AAC in a range of unique ways that may be challenging to understand. In order to accurately address this, this thesis will specify the aforementioned problem and use the Assisted Decision-Making (Capacity) Act 2022 (ADMCA) in Ireland as a case

¹² NC Brady and others, 'Communication Services and Supports for Individuals With Severe Disabilities: Guidance for Assessment and Intervention' (2016) 121 *American Journal on Intellectual and Developmental Disabilities* 121, 122-23.

¹³ D Money and others, 'Inclusive Communication and the Role of Speech and Language Therapy Position Paper' (Royal College of Speech & Language Therapists 2016) 11.

study. The ADMCA was originally signed into law in 2015,¹⁴ and the new amended version titled the Assisted Decision-Making (Capacity) (Amendment) Bill 2022¹⁵ was introduced on 30 May 2022, and signed into law on 17 December 2022.¹⁶ The 2015 Act, coupled with the amended Acts, aims to give effect to the CRPD,¹⁷ and heavily reform the framework of legal capacity for persons with disabilities in Ireland through the development of systems of supported decision-making. Thus, the specific problem that will be addressed is *how can systems of supported decision-making under the ADMCA in Ireland ensure a genuine understanding of the will and preferences of all persons with disabilities, regardless of how they communicate individually?*

This thesis seeks to address the aforementioned challenges through the proposal of a modified version of the capability approach, a normative theoretical framework primarily developed by Amartya Sen and Martha Nussbaum as a re-conception of classic welfarist notions that the possession of goods and resources were adequate indicators of justice. Under the capability approach, the well-being of individuals is understood in terms of the various *functionings* and *capabilities* of different persons. Functionings represent the ‘parts of the state of a person - in particular the various things he or she manages to do leading a life’,¹⁸ such as the ability to be healthy, have shelter or be a part of a community. The capabilities of an individual thus reflect ‘the alternative combinations of functionings the person can achieve, and from which he or she can choose one collection (...) with the quality of life to be assessed in the terms of the capability to achieve valuable functionings’.¹⁹ The purpose of utilising this framework lies in its individualised approach to understanding different persons and their idiosyncrasies,

¹⁴ Assisted Decision-Making (Capacity) Act 2015 (ADMCA 2015).

¹⁵ Assisted Decision-Making (Capacity) (Amendment) Bill 2022 Dáil Bill (2022) 59 (ADMCA 2022).

¹⁶ Houses of the Oireachtas, ‘Assisted Decision-Making (Capacity) (Amendment) Bill 2022 – No. 59 of 2022 – Houses of the Oireachtas’ (30 May 2022). Please note at the time this thesis was written the ADMCA was undergoing debates and was signed into law as of 17 December 2022 as the Assisted Decision-Making (Capacity) (Amendment) Act 2022. The introduction has been revised to reflect this change, however the content of this thesis (which refers to the draft text) will not be edited as the sections of the ADMCA 2022 which are analysed have not undergone any significant changes.

¹⁷ The original 2015 Act did not explicitly reference the CRPD, but the amended acts specify the ADMCA gives further effect to the CRPD.

¹⁸ M Nussbaum and A Sen (eds), *The Quality of Life* (OUP 1993) 31.

¹⁹ *ibid.*

something that may be applied in understanding unique forms of communication or AAC for persons with disabilities. Specifically, this thesis will adapt the capability approach and argue it to be a useful guide for support persons (SP) within the ADMCA, namely ‘decision making assistants’ and ‘co-decision makers’, who can use it to decide on an implementation framework for appropriate methods of AAC. Though the framework may be widely applicable across disabilities, this thesis is primarily concerned with persons with intellectual disabilities.²⁰

Based on the problem and information above, the primary research question is: how might the capability approach be used in regimes of supported decision-making to discern the appropriate method of communication for each individual with a disability so that their will and preferences are understood? As such, the sub-questions to be addressed are: (1) what are the legal obligations of article 12 surrounding communication and will and preferences?; (2) what is the purpose and usefulness of using the capability approach as a framework to aid the implementation of the CRPD; and (3) how might the capability approach be used by Ireland in its implementation of the ADMCA?

1.3 SCOPE AND STRUCTURE OF THE THESIS

This thesis will firstly discuss legal capacity in chapter 2 as it was understood through the ‘medical model’ of disability, which holds disability to be an inherent trait of persons with disabilities that should be ‘fixed’; and outline the historical and contextual background of the former paradigm of substitute decision-making before the ratification of the CRPD. Following this, the development of the CRPD and article 12 will be discussed, concluded by a brief summary of criticisms of the new paradigm of universal legal capacity. Chapter 3 will then provide a

²⁰ Intellectual disability is commonly defined as neurodevelopmental impairments characterized by *limitations* in intellectual functioning and adaptive behaviour; K Lee, M Cascella and R Marwaha, ‘Intellectual Disability’, *StatPearls* (StatPearls Publishing 2022). This thesis recognises this definition falls within the medical model of disability, and will rather consider intellectual disability from the perspective of the social model which distinguishes impairments from disability. The impairments of persons with intellectual disabilities do not limit the individual, rather ‘disability’ and ‘limitations’ are the result of the interaction between intellectual impairments and societies/environments which do not provide for the full and equal participation of persons with disabilities. For further clarification, see sub-section 2.4.

comprehensive legal interpretation of the obligations in article 12 of the CRPD, employing the methodology found in the Vienna Convention on the Law of Treaties (VCLT),²¹ to enable understanding of the new paradigm of universal legal capacity that is introduced by the CRPD. As such, this thesis will discuss and explore the legal obligations created by the Committee on the Rights of Persons with Disabilities (the Committee) and article 12 in particular, and focus on interpretations of legal capacity surrounding will, preferences and communication. Chapter 4 will then provide a more comprehensive review of the capability approach and how it has been used to discuss the CRPD, disability, guardianship and public policy in the past. This will serve as a background for the creation of a framework which will apply the capability approach to the national case study of Ireland in this thesis. Furthermore, chapter 5 will provide a comparative analysis between article 12 of the CRPD and the ADMCA to understand the extent to which the ADMCA complies with the CRPD, and expand upon AAC, specific forms of AAC, and how they are used by persons with intellectual disabilities. Finally, chapter 5 will draw upon the findings from chapter 4 related to the capability approach and argue for use of the capability approach by decision-making assistants (DMA) and co-decision-makers (CDM) within the ADMCA. Chapter 6 will serve as a conclusion.

1.4 METHODOLOGY

1.4.1 *Article 12 of the Convention on the Rights of Persons with Disabilities*

A traditional method of legal analysis is that of doctrinal legal analysis, which examines the content of a legal opinion and conducts a systematic analytical study of existing laws or legal provisions and other relevant authoritative legal sources, such as *travaux préparatoires*, case law and academic sources.²² Chapter 3 will utilise the tools for interpretation contained in articles 31 and 32 of the VCLT to carry out

²¹ Vienna Convention on the Law of Treaties (adopted 22 May 1969, entered into force 27 January 1980) 1155 UNTS 331 (VCLT).

²² A Kharel, 'Doctrinal Legal Research' [2018] SSRN Electronic Journal 4; A Broderick, 'The Long and Winding Road to Equality and Inclusion for Persons with Disabilities The United Nations Convention on the Rights of Persons with Disabilities' (PhD, Maastricht University 2015) 13-14.

doctrinal legal analysis. The interpretive tools are, namely, the literal (textual) approach, the systematic (contextual) approach, the historical interpretive approach and the teleological (functional) approach.²³

This thesis will firstly employ the textual approach to interpret the text of article 12 of the CRPD in accordance with its ordinary meaning in good faith.²⁴ To complement textual analysis, supplementary documents pertaining to the interpretation of article 12 will be employed through the contextual approach drawn from article 31 of the VCLT. A primary supplementary document that will be used is the first general comment to the CRPD²⁵ (GC1), the use of which may be justified in accordance with article 31(3)(b) which holds that ‘any subsequent practice in the application of the treaty which establishes the agreement of the parties regarding its interpretation’ shall be taken into account, together with the context.²⁶ GC1 is controversial and differs from former international statements about human rights, resulting in objections to the Committee’s interpretation by states parties.²⁷ Though it may not be universally accepted, GC1 contains authoritative interpretive guidance for states parties by the Committee, the official UN committee tasked with overseeing the implementation of the CRPD, whose role and function is outlined in article 34 of the CRPD. As the Committee has stood by its interpretation, though states parties may disagree with GC1, it is maintained in this thesis that GC1 constitutes subsequent practice under article 31 of the VCLT. Both textual and contextual analysis will be further complemented by the teleological approach, additionally drawn from article 31 of the VCLT, and the historical approach found in article 32 of the VCLT. The teleological approach allows for evolutive or contemporaneous interpretation which takes account of evolving social and cultural changes which may impact or shift the object and purpose of legal provisions. It will thus be used to build upon the analysis of article 12 to understand its object and purpose, alongside the effect article 12

²³ VCLT arts 31-32.

²⁴ *ibid* art 31(1); Ammann O, ‘The Interpretative Methods of International Law: What Are They, and Why Use Them?’, *Domestic Courts and the Interpretation of International Law*, vol 72 (2019) 197.

²⁵ GC1 (n 2).

²⁶ VCLT art 31(3)(b).

²⁷ S Müller, ‘The influence of the UN Convention on the Rights of Persons with Disabilities on the German jurisdiction and legalisation regarding compulsory measures’ (2018) 86 *Fortschritte Der Neurologie-Psychiatrie* 485, 486.

and the CRPD Committee intend to achieve.²⁸ The historical approach allows recourse to ‘supplementary means of interpretation, including the preparatory work of the treaty’ where interpretation in accordance with article 31 leaves the meaning of certain provisions ‘ambiguous or obscure’.²⁹ This will be utilised throughout the interpretation of article 12 to supplement the understanding of the article by providing historical context, primarily through the discussion of debates between parties when drafting the CRPD to illuminate core aspects of article 12, its controversial reception from the start and its intended goals.

1.4.2 The Convention on the Rights of Persons with Disabilities and the Assisted Decision-Making (Capacity) Act

The methodology that will be used to interpret the ADMCA and its compliance with the CRPD is that of comparative legal methodology. Comparative legal methodology has been used in a number of ways to analyse and compare different legal systems or traditions, or different fields of law within one legal system. Hey and Mak contend comparative methodology has been employed to gain insight into other legal systems or find solutions for a particular legal system, and as regimes of international law strengthen, comparative legal research has expanded to include international law.³⁰ There is no firm agreement on the type of method to be followed in undertaking comparative legal analysis, and as such, there is room for interpretation insofar as expanding comparative research to the international field.³¹ Comparative international law has been defined as ‘identifying, analysing, and explaining similarities and differences in how actors in different legal systems understand, interpret, apply, and approach international law’.³² Concerning public international law and the interpretation/application of treaties, it has been argued the comparative analysis may be used to compare international and domestic legal systems to enrich the former and analyse how various principles and norms of international law are defined and applied

²⁸ Ammann (n 24).

²⁹ VCLT article 32.

³⁰ E Hey and E Mak, ‘Introduction: The Possibilities of Comparative Law Methods for Research on the Rule of Law in a Global Context’ (2009) 2(3) *Erasmus Law Review* 287.

³¹ MV Hoecke, ‘Methodology of Comparative Legal Research’ [2015] *Methodology of Comparative Legal Research, Law and Method* 1.

³² A Roberts and others, *Comparative International Law* (OUP 2018) 7.

across various legal systems.³³ In turn, this method of comparison may specifically provide interpretive guidance and clarification of certain norms or provisions through the analysis of how such norms have been applied domestically.³⁴ Comparative legal methodology will be used here to compare the content and obligations of the CRPD, particularly the notion of will and preferences under article 12, with the ADMCA, for the purpose of understanding the extent to which the ADMCA aligns with the CRPD.

³³ A Carcano, 'Uses and Possible Misuses of a Comparative International Law Approach' (2018) 54 QIL 21, 28-29.

³⁴ *ibid* 30; T Ginsburg, 'Objections to Treaty Reservations: A Comparative Approach to Decentralized Interpretation' in A Roberts and others, *Comparative International Law* (OUP 2018).

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2.

THE DEVELOPMENT AND IMPORTANCE OF ARTICLE 12

2.1 THE MEDICAL MODEL AND THE OLD PARADIGM

The notion of a paradigm shift originated from Thomas Kuhn, who formulated a scientific understanding of a paradigm, described as universally recognised achievements within science that provide both problems and solutions to communities of practitioners.³⁵ He conceived of a shift in paradigms that creates changes in the perception or evaluation of familiar data, and urges us to look at the role of external social, economic and intellectual conditions to reorient our understanding.³⁶ The notion of a paradigm shift has since been applied beyond science, encompassing any fundamental change to widespread thought and assumptions. As article 12 of the CRPD aims to provide universal legal capacity to all persons with disabilities and overhaul centuries of societal, legal and governmental norms, one may describe article 12 as bringing about a paradigm shift.³⁷

Legal systems of substitute decision-making formulated guardianship through policies of so-called benevolence, to ‘protect’ persons who had limited capacity, essentially allowing the state to act as a parent to those who were unable to care for themselves.³⁸ This principle, *parens patriae*, refers to the state’s authority and responsibility to protect the best interests of so-called ‘vulnerable persons’, going as far back as the 13th

³⁵ TS Kuhn, *The Structure of Scientific Revolutions* (3rd edn, University of Chicago Press 1996).

³⁶ Glen, ‘Changing Paradigms’ (n 9) 97-99.

³⁷ G Quinn, ‘Personhood & Legal Capacity. Perspectives on the Paradigm Shift of Article 12 CRPD’ (Concept paper, HPOD Conference, Harvard Law School, 20 February 2010) 10.

³⁸ AS Kanter, *The Development of Disability Rights Under International Law: From Charity to Human Rights* (Routledge 2014) 239.

century.³⁹ Throughout the following centuries, though the protective rationale embedded in *parens patriae* was still utilised, guardianship laws began to shift towards an increasingly medicalised and nuanced model of capacity based on ‘objective’ medical or scientific criteria.⁴⁰ As the medical profession gained power within the field of disability through the ability of medical professionals to both define and ‘cure’ so-called ‘deficiencies’, the medical field found itself in an advantaged position to construct and perpetuate discourse around disability as something that was inextricably linked to ‘soundness’ of body and mind.⁴¹ This ‘medical model’ had a dominant grip on the understanding of disability and the rights of persons with disabilities until the latter half of the 20th century, and was rooted in scientific understandings of disability as an ailment that is inherently biological and needs to be cured.⁴² As such, it relies on two normative categories, ‘persons with disabilities’ and ‘persons without disabilities’. Those falling into the category ‘persons with disabilities’ are considered to have a disability on the basis that they are essentially unable to function in the same capacity as so-called ‘normal’ people. On the other hand, under a medical model approach ‘persons without disabilities’ represent a standard of physical and mental functioning that is not inherently achievable for persons with disabilities.⁴³

³⁹ MI Hall, ‘The Vulnerability Jurisdiction: Equity, Parens Patriae, and the Inherent Jurisdiction of the Court’ (Social Science Research Network 2016) SSRN Scholarly Paper 2821231 6; The oldest source of *parens patriae* in English guardianship may be found in the Praerogativa Regis in 1290 which provided that the ‘king as father and guardian was bound to take care of those who by reason of their imbecility or want of understanding are incapable of taking care of themselves’ (AS Kanter, *The Development of Disability Rights Under International Law: From Charity to Human Rights* (Routledge 2014) 102 citing Barbara A Cohen and others, ‘Tailoring Guardianship to the Needs of Mentally Handicapped Citizens’ (1976) 6 MD L F 91, 92; M Donnelly, ‘Assessing Legal Capacity: Process and the Operation of the Functional Test’ (Social Science Research Network 2007) SSRN Scholarly Paper 1961205 144). *Parens patriae* derived from English law at the time settling in the American Colonies was maintained after the American Revolution, see *Late Corp of Church of Jesus Christ v United States* (1890) 136 US 1, 57 para 8 (JJ Monthie ‘The Myth of Liberty and Justice for All: Guardianship in New York State, (2017) 80 Albany Law Review 87 950). The notion of *parens patriae* as justification for guardianship legislation may be found throughout the 21st century in various jurisdictions, eg Canada (see *In Re F* [1990] 2 AC) and Israel (see Legal Capacity and Guardianship Law, 5722-1962, s 33(a)(4)). Moreover, it should be noted *parens patriae* is applied in many areas of the law and not limited to guardianship laws.

⁴⁰ Glen, ‘Changing Paradigms’ (n 39) 105.

⁴¹ I Brittain, ‘Perceptions of Disability and Their Impact upon Involvement in Sport for People with Disabilities at All Levels’ (2004) 28 Journal of Sport and Social Issues 429, 430.

⁴² JA Haeggele and S Hodge, ‘Disability Discourse: Overview and Critiques of the Medical and Social Models’ (2016) 68 Quest 193, 194-96.

⁴³ S Mitra, ‘The Capability Approach and Disability’ (2006) 16 Journal of Disability Policy Studies 236, 237; BA Areheart, ‘When Disability Isn’t Just Right: The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma’ (2008) 83 Indiana Law Journal 181, 186.

Due to these perceived ‘deficiencies’ or ‘abnormalities’, the supposed best path towards managing disability within society is taking steps to *eradicate* disability, so that persons with disabilities may exist within society in the same way persons without disabilities do.⁴⁴ As the medical model focuses on individual pathology and finding ways to prevent or cure disabilities, a central concern is accurate medical diagnosis of an individual’s disability, which would commonly be required (or at the very least referred to) by the state as a form of proof that this person, as indicated by their diagnosis, lacked mental capacity.⁴⁵ Accordingly, the right to legal capacity for persons with disabilities was based on the medical criterion of competency, framed by the notion that having a disability innately means lacking the decision-making abilities to exercise legal capacity on an equal basis with persons without disabilities.⁴⁶ The right to legal capacity under this model is then not an immediately deserved right, but something reminiscent of an ‘award’ for displaying signs or improvements towards ‘normalcy’.

At the core of the medical model is the complementary relationship between ‘legal capacity’ and ‘mental capacity’, two distinct concepts that became intertwined throughout the history of disability and guardianship law. Mental capacity refers to an individual’s decision-making ability, or the capability and cognitive skills an individual has to make decisions. Mental capacity varies greatly between persons with disabilities, as it is widely affected by the respective disability each person has, as well as socio-economic factors such as access to education and access to healthcare.⁴⁷ Assessments of mental capacity were frequently instrumental in determining whether an individual should be placed into substitute decision-making, with said assessments generally falling into three categories, the status approach, the outcome approach and the functional approach.

⁴⁴ Haegle and Hodge (n 42) 195.

⁴⁵ J Craigie and others, ‘Legal Capacity, Mental Capacity and Supported Decision-Making: Report from a Panel Event’ (2019) 62 *International Journal of Law and Psychiatry* 160, 161.

⁴⁶ D Marks, ‘Models of Disability’ (1996) 19 *Disability and Rehabilitation* 85, 86.

⁴⁷ A Arstein-Kerslake and E Flynn, ‘The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality before the Law’ (2016) 20 *The International Journal of Human Rights* 471; KB Glen, ‘Introducing a “New” Human Right: Learning from Others, Bringing Legal Capacity Home’ (2018) 49 *Columbia Human Rights Law Review* 98.

2.2 ASSESSMENTS OF MENTAL CAPACITY: STATUS, OUTCOME AND FUNCTIONAL

The status approach is a binary model of assessment that determines legal capacity solely based on the ‘status’ of an individual as having a disability, assessing legal capacity through medical diagnoses of cognitive impairments.⁴⁸ The status approach is thus based on a presumption of incapacity that coincides with the status of having a disability and is predicated on a medical diagnosis of impairment.⁴⁹ In other words, once an individual is determined to have a disability, that status alone is adequate to strip an individual of their legal capacity, and so the law outrightly presumes a lack of capacity.⁵⁰ The second approach, the outcome approach, similarly determines that once an individual has a disability, their decision-making is questioned. However, legal capacity is assessed based on prior patterns or decisions, and the extent to which they align with ‘normal’ decision-making.⁵¹ Capacity is thus assessed based on reasonableness, holding that an individual’s legal capacity will be called into question if they are revealed to have a pattern of ‘bad’ decision-making. A classic example of the outcome approach is an individual with a psychosocial disability (mental impairment) checking into a treatment facility, who later decides to end their treatment. Their decision to check themselves into the facility would likely not be questioned; however, their decision to leave the facility may be questioned and legal restrictions might be imposed.⁵² The third approach, the functional approach, differs in that disability alone does not equal ‘incompetence’, but a person with a disability is considered

⁴⁸ A Arstein-Kerslake and G Quinn, ‘Restoring the “Human” in “Human Rights”: Personhood and Doctrinal Innovation in the UN Disability Convention’ in C Gearty and C Douzinas (eds), *The Cambridge Companion to Human Rights Law* (Cambridge University Press 2012) 44.

⁴⁹ A Arstein-Kerslake and E Flynn, ‘Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity’ (2014) 10 *International Journal of Law in Context* 81.

⁵⁰ N Devi, J Bickenbach and G Stucki, ‘Moving towards Substituted or Supported Decision-Making? Article 12 of the Convention on the Rights of Persons with Disabilities’ (2011) 5 *Alter European Journal of Disability Research* 249, 253; A Dhanda, ‘Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future Symposium: The United Nations Convention on the Rights of Persons with Disabilities’ (2006) 34 *Syracuse Journal of International Law and Commerce* 429, 431.

⁵¹ Arstein-Kerslake and Quinn, ‘Restoring the “Human” in “Human Rights”’ (n 48) 44; Arstein-Kerslake and Flynn, ‘Legislating Personhood’ (n 49) 84.

⁵² Devi, Bickenbach and Stuck (n 50) 253; *ibid* 86; A Nilsson, ‘Who Gets to Decide? Right to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities’ (Commissioner for Human Rights of the Council of Europe 2012) Issue Paper 8.

incompetent if they cannot reach a certain threshold of ‘functioning’.⁵³ Under the functional approach, assessments of capacity are concerned with specific tasks or decisions, with a new assessment of capacity required for each relevant new decision. For example, under the functional approach, an individual may have the legal capacity to sign a contract, but may later be determined to lack the legal capacity to get married or execute a will.⁵⁴ As the functional approach is decision-specific, it has become increasingly popular because it allows for tailored restrictions of legal capacity. Moreover, it is thought to respect autonomy based on the view that functional tests are ‘value-neutral’, assessing the ‘internal processes of decision-making for their autonomous character rather than assessing the outcome of a decision against the assessor’s own values’.⁵⁵

2.3 THE OLD PARADIGM IN DOMESTIC AND INTERNATIONAL LAW

The prevalence of the rationale of the old paradigm, rooted in the protective ideals of *parens patriae* and medicalised ideas of disability, is evident in the domestic legislation of states and in international human rights pre-dating the CRPD. A pertinent example of domestic legislation embodying these principles is the Lunacy Regulation (Ireland) Act 1871,⁵⁶ which was in force for over a century until it was repealed by the ADMCA 2015 (now the Amended 2022 Act).⁵⁷ A ‘lunatic’ was defined as ‘any person found by inquisition idiot, lunatic or of unsound mind, and incapable of managing himself or his affairs’.⁵⁸ Under the Act, a person may be classified as a ‘lunatic’ or someone ‘incapable of managing oneself’, and effectively stripped of legal capacity by being

⁵³ Dhanda (n 50) 431.

⁵⁴ M Donnelly, ‘Assessing Legal Capacity: Process and the Operation of the Functional Test’ (Social Science Research Network 2007) SSRN Scholarly Paper 1961205 143.

⁵⁵ A Nilsson and L Series, ‘Article 12 CRPD: Equal Recognition before the Law’ in I Bantekas and others (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press 2018).

⁵⁶ Lunacy Regulation (Ireland) Act 1871 (1871 UKPGA c 22).

⁵⁷ Assisted Decision-Making (Capacity) Act 2015; M Carolan, ‘Repeal of 200-Year-Old Law Preventing Wards of Courts Marrying Is Welcomed’ (*The Irish Times*, 2 February 2021) <www.irishtimes.com/news/crime-and-law/courts/high-court/repeal-of-200-year-old-law-preventing-wards-of-courts-marrying-is-welcomed-1.4474113> accessed 5 May 2022.

⁵⁸ Lunacy Regulation (Ireland) Act 1871 preamble s 2.

deemed a ‘ward of court’. Classification of ‘wardship’ under the Lunacy Act was achieved through petitioning or applying to the High Court of Ireland, which would utilise medical evidence, requiring affidavits by the petitioner’s solicitor in addition to two supporting affidavits by registered medical professionals that indicated the ‘ward’ in question lacked mental capacity.⁵⁹ The Lunacy Act is just one of many examples of domestic legislation that allowed denial of legal capacity based on mental capacity, a principle that was additionally transcribed into international human rights law. Article 5 of the 1971 United Nations General Assembly (UNGA) Declaration on the Rights of the Mentally Retarded states that ‘a mentally retarded person has the right to a qualified guardian when this is required to protect his personal well-being and interests’.⁶⁰ The old paradigm is prominently reflected by the notion that the only right for persons with disabilities concerning legal capacity is the right to have a qualified individual exercise legal capacity on their behalf (though the right to legal capacity was provided for under international human rights law), again operating under the presumption that legal capacity has or will be denied to an individual with a disability, and the best option is to ‘protect’ them through substituted decision-making. The 1975 Declaration on the Rights of Disabled Persons further exemplifies these ideals, as it defines a ‘disabled person’ in a language that echoes the 19th-century act above, defining persons with disabilities as ‘any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual (...) as a result of deficiency, either congenital or not, in his or her mental or physical abilities’.⁶¹ Though guardians are not outrightly mentioned, persons with disabilities are still held to be persons with deficiencies, who are unable to care for themselves or function in comparison to a ‘normal’ person.⁶² Through the consistent distinction between persons

⁵⁹ Lunacy Regulation (Ireland) Act 1871 preamble s 15; Donnelly (n 54) 157. The requirement of the expertise of a medical professional, a signed affidavit of a medical professional, or a requirement of a medical certificate may be found in the Act in ss 4, 5, 6, 11, 22, 56, 57, 58, 103, 104, 115, 117.

⁶⁰ UNGA ‘Declaration on the Rights of the Mentally Retarded’ (adopted 20 December 1971) UNGA Res 2856 (XXVI).

⁶¹ UNGA ‘Declaration on the Rights of Disabled Persons’ (adopted 9 December 1975) UNGA Res 3477 (XXX) s 1.

⁶² AS Kanter and Y Tolub, ‘The Fight for Personhood, Legal Capacity, and Equal Recognition Under Law for People with Disabilities in Israel and Beyond’ (2017) 39 *Cardozo Law Review* 557, 569-72.

with disabilities and persons who are ‘normal,’ and the extent to which such a distinction compromises the right to legal capacity, we can see the permeance of the old medicalised paradigm of legal capacity within domestic frameworks and international human rights law up until the ratification of the CRPD.

2.4 THE DEVELOPMENT AND SIGNIFICANCE OF ARTICLE 12: A NEW PARADIGM OF UNIVERSAL LEGAL CAPACITY

Before the CRPD, none of the existing international human rights treaties specifically discussed disability (with the only exception being the UN Convention on the Rights of the Child).⁶³ It was not until 2001 that the UNGA accepted a proposal to begin negotiating an international convention to promote the human rights of persons with disabilities. Following a mandate for an Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (Ad Hoc Committee) to draft the CRPD and eight drafting sessions between 2002 to 2006, the CRPD was adopted by the UNGA on 13 December 2006.⁶⁴ Though it was drafted within five years, the CRPD was a result of two decades of advocacy by organisations for persons with disabilities, non-governmental organisations, individuals and governmental representatives; and is a covenant which embraces a new paradigm centred around the social model.⁶⁵ The social model, contrasted with the medical model, maintains that society imposes disability on persons who have ‘impairments’.⁶⁶ To clarify the distinction between ‘impairments’ and ‘disability’ within the social model, impairments are intellectual, cognitive, physical, sensory or psychosocial limitations, meanwhile disability is understood in terms

⁶³ Convention on the Rights of the Child (adopted 20 November 1989, entered into force 2 September 1990) 1577 UNTS 3; art 2 includes disability in its definition of discrimination, and art 23 is specifically concerned with children with disabilities, recognising their right to ‘enjoy a full and decent life in conditions which ensure dignity, promote self-reliance, and facilitate the child’s active participation in the community’.

⁶⁴ G de Beco, *Disability in International Human Rights Law* (OUP 2021) 16.

⁶⁵ Glen, ‘Changing Paradigms’ (n 39) 98.

⁶⁶ Haegele and Hodge (n 42) 197.

of exclusion from society.⁶⁷ For example, societal barriers which may facilitate disability can range from e.g. public buildings not having wheelchair-accessible ramps to discriminatory attitudes against persons with disabilities. Disability within the CRPD is, therefore, something that can be challenged through social change.⁶⁸ The CRPD Committee additionally relates the CRPD to a human rights-based model of disability in General comment No 6 to the CRPD.⁶⁹ The human rights-based model of disability ‘recognises that disability is a social construct and impairments must not be taken as legitimate grounds for the denial or restriction of human rights (...) hence, disability laws and policies must take the diversity of persons with disabilities into account’.⁷⁰ Thus, the CRPD rejects the medical model and rather reflects the social and human rights-based models of disability.

The new forward-looking perspective encapsulated by the social model and the human rights-based model, and the success of article 12, may be largely credited to the widespread involvement of persons with disabilities throughout the drafting of the CRPD. Particularly the International Disability Caucus (IDC), which was established at the first Ad Hoc Committee meeting in 2002, had a notorious and lasting impact. The IDC was open to the contributions of persons with disabilities, representative organisations and allies, providing a forum for persons with disabilities to voice their opinions and concerns and have those concerns represented at the UN level.⁷¹ It has been said that the Ad Hoc Committee’s meetings in drafting the CRPD were the most inclusive in the history of the UN, embodying the motto of the IDC – ‘nothing about us without us’ – with the largest number of representatives from civil society participating in meetings on the CRPD than any other UN instrument.⁷²

⁶⁷ A Broderick and D Ferri, *International and European Disability Law and Policy: Text, Cases and Materials* (1st edn, CUP 2019) 22.

⁶⁸ A Lawson and AE Beckett, ‘The Social and Human Rights Models of Disability: Towards a Complementarity Thesis’ (2021) 25 *The International Journal of Human Rights* 348, 349.

⁶⁹ Committee on the Rights of Persons with Disabilities, ‘General comment No. 6 (2018) on equality and non-discrimination’ (18 May 2018) UN Doc CRPD/C/GC/6 paras 3, 8 and 9. ⁷⁰ *ibid* para 9.

⁷¹ C de Bhailis and E Flynn, ‘Recognising Legal Capacity: Commentary and Analysis of Article 12 CRPD’ (2017) 13 *International Journal of Law in Context* 6, 8.

⁷² AS Kanter, ‘The Promise and Challenge of the United Nations Convention on the Right of Persons with Disabilities’ (Social Science Research Network 2007) SSRN Scholarly Paper 2109836 294 <<https://papers.ssrn.com/abstract=2109836>> accessed 25 April 2022; *ibid* 7.

During the ad hoc meetings, the IDC firstly argued that supported decision-making is the preferable model as it recognises equal treatment and the protection of human rights for persons with disabilities. Additionally, they maintained that supported decision-making was based on the *competence* of persons with disabilities, while substitute decision-making was based on incompetence, two perspectives that could not be reconciled.⁷³ Though these arguments were the foundation for the transition to a new paradigm, they also resulted in article 12 being one of the most hotly contested articles in the Convention. Different versions of article 12 may be found in the working group texts of the CRPD, one of which permitted substitute decision-making as a ‘matter of last resort’, were debated until the last second. The most notorious of the revisions concerned a footnote to clause (b) of article 12, which stated ‘in Arabic, Chinese and Russian, the term “legal capacity” refers to “legal capacity for rights,” rather than “legal capacity to act”⁷⁴ (which, after much deliberation, was finally removed at the eighth and final ad hoc session).⁷⁵ Arguments between countries on whether article 12 completely bans all forms of substitute decision-making persisted throughout the adoption of the CRPD by the UNGA, but it was ultimately the IDC that argued:

The Convention represents a paradigm shift that will have a substantial impact on the lives of millions of people with disabilities (...) underlined by the deletion of the footnote to Article 12, since the right to enjoy legal capacity on an equal basis in all aspects, including the capacity to act, is fundamental to basic equality and participation in all aspects of life.⁷⁶

Thus, following countless debates and gridlock, a social and human-rights based model of disability, which honoured the dignity of persons with disabilities and their right to exercise legal capacity, was enshrined in international law in the first international human rights treaty of the 21st century.⁷⁷

⁷³ Dhanda (n 50) 446-48.

⁷⁴ Ad Hoc Committee, ‘Interim Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities eighth session’ (2006) UN Doc A/AC.265/2006/4 <www.un.org/esa/socdev/enable/rights/ahc8intreporte.htm> accessed 5 May 2022; Dhanda (n 50) 442-51.

⁷⁵ Ad Hoc Committee, ‘Final Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities’ (2006); Ad Hoc Committee, ‘Working Text Article 12 Equal Recognition before the Law’ <www.un.org/esa/socdev/enable/rights/ahcstatachairtxt.htm> accessed 27 April 2022.

⁷⁶ UN Enable, ‘Statements Made on the Adoption of the Convention on the Rights of Persons with Disabilities’ <www.un.org/esa/socdev/enable/convstatementgov.htm> accessed 5 May 2022.

⁷⁷ Kanter and Tolub (n 62) 359; Nilsson and Series (n 55).

2.5 CONTROVERSY AND CRITICISM

Article 12 was included in the final text of the CRPD without stipulations that substitute decision-making could be a measure of last resort, and the CRPD Committee confirmed in GC1 that ‘support in the exercise must respect the will and preferences of persons with disabilities and should never amount to substitute decision-making’.⁷⁸ Moreover, ‘support’ is expressed to be a ‘broad term’ with ‘informal and formal support arrangements’, and persons with disabilities may choose one or more trusted SP or other forms of support such as ‘peer support or assistance with communication’.⁷⁹ These statements demonstrate a tension whereby, on the one hand, the Committee here is giving disability activists an ‘unequivocal expression of principle with which to challenge deeply ingrained paternalist norms’, while, on the other hand, arguably diminishing the ‘normative force of this aspect of the CRPD among States Parties who could legitimately point to limited data on the operation of legal frameworks for supported decision-making’.⁸⁰ With lofty requirements to overhaul centuries of legal practice and little practical guidance on how to implement such requirements, article 12 was subject to a plethora of reservations and interpretive declarations by states that affirmed the unwillingness of many states parties to solely allow supported decision-making.⁸¹ For example, Canada’s declaration and reservation to article 12 reads:

Canada declares its understanding that Article 12 permits supported and substitute decision-making arrangements in appropriate circumstances and in accordance with the law (...) To the extent Article 12 may be interpreted as requiring the elimination of all substitute decision-making arrangements, Canada reserves the right to continue their use in appropriate circumstances and subject to appropriate and effective safeguards.⁸²

⁷⁸ Committee on the Rights of Persons with Disabilities, ‘General comment No. 1 (2014) Article 12: Equal recognition before the law’ (19 May 2014) UN Doc CRPD/C/GC/1 (GC1) para 17.

⁷⁹ *ibid* paras 17-18.

⁸⁰ M Donnelly, R Harding and E Taşcıoğlu (eds), *Supporting Legal Capacity in a Socio-Legal Context* (Oñati International Series in Law and Society 2022) 20.

⁸¹ National University of Ireland and Centre for Disability Law and Policy Galway, ‘A Study on the Equal Recognition before the Law: Contribution towards the Council of Europe Strategy on the Rights of Persons with Disabilities’ (2017).

⁸² United Nations Treaty Collection, ‘Declaration and Reservation Made by Canada’ <https://treaties.un.org/pages/ViewDetails.aspx?chapter=4&clang=en&mtdsg_no=IV-15&src=IND#EndDec> accessed 5 July 2022.

Coinciding statements were additionally made by other states, such as the Netherlands and Ireland.⁸³

2.5.1 Assessments of mental capacity – discriminatory or necessary?

A pertinent line of criticism of article 12 regards the absolute division of mental and legal capacity, expressed by the Committee: ‘under Article 12 (...) perceived or actual deficits in mental capacity must not be used as a justification for denying legal capacity’.⁸⁴ The division between mental and legal capacity in the Convention can be accredited to a long history of mistreatment of persons with disabilities, who were deemed ‘incompetent’. This division was furthered by the emphasis of the social model which would argue that mental incapacity is a product of social, political and environmental factors rather than ‘mental deficiencies’.⁸⁵ In establishing universal legal capacity, the CRPD Committee maintains that ‘legal capacity is a universal attribute inherent in all persons by virtue of their humanity’⁸⁶ and to deny legal capacity in any circumstance is equal to a complete restriction of legal capacity. Dawson argues that the Committee is ‘exaggerating when it conflates denial of specific legal capacities with lack of recognition as a person before the law’, as the denial of legal capacity in specific circumstances would not *entirely* contravene the right to legal capacity.⁸⁷ For example, if the ability to possess a firearm is denied because of incapacity, it does not follow that an individual would lose their right to legal capacity as a whole. Rather, they would experience a selective loss

⁸³ The Netherlands declaration regarding article 12 states ‘The Kingdom of the Netherlands interprets Article 12 as restricting substitute decision-making arrangements to cases where such measures are necessary, as a last resort and subject to safeguards’. Ireland’s declaration and reservation on article 12 states ‘To the extent article 12 may be interpreted as requiring the elimination of all substitute decision making arrangements, Ireland reserves the right to permit such arrangements in appropriate circumstances and subject to appropriate and effective safeguards’. For a full list of all declarations and reservations see United Nations Treaty Collection, ‘Status of the Convention on the Rights of Persons with Disabilities’ <https://treaties.un.org/pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-15&chapter=4&clang=en> accessed 30 April 2022.

⁸⁴ GC1 (n 78) para 13.

⁸⁵ J Craigie, ‘A Fine Balance: Reconsidering Patient Autonomy in Light of the UN Convention on the Rights of Persons with Disabilities’ (2015) 29 *Bioethics* 398, 401.

⁸⁶ GC1 (n 78) para 18.

⁸⁷ J Dawson, ‘A Realistic Approach to Assessing Mental Health Laws’ Compliance with the UNCRPD’ (2015) 40 *International Journal of Law and Psychiatry* 70, 72.

of capacity while still maintaining their standing as a person before the law. This approach is closely tied to the functional model of capacity, which is based on time-limited assessments that fluctuate based on the situation. However, the Committee makes it clear that this approach is ‘discriminatorily applied to people with disabilities’ and ‘presumes to be able to accurately assess the inner-workings of the human mind’.⁸⁸ Thus, the Committee controversially maintains that the denial of even specific forms of legal capacity based on mental capacity is unacceptable and amounts to a full human rights violation. This absolutist position is theoretically progressive, yet it is neither nuanced nor pragmatic in its consideration of the many situations where the assessment of decision-making abilities could be relevant to the health, safety and enjoyment of rights for persons with disabilities. The sections below will consider ‘hard cases’ and two fields in which wholly negating the necessity of sufficient mental capacity is relevant and challenging: healthcare and criminal law.

2.6 HARD CASES, HEALTHCARE AND CRIMINAL LAW

Building upon the notion above that legal capacity is a universal right based on the will and preferences of the individual, questions arise regarding ‘hard cases’, or situations where universal legal capacity might put an individual at risk, rather than benefit them.⁸⁹ Arstein-Kerslake and Flynn lay out examples of situations where the new paradigm of legal capacity might cause more harm than good, such as where an individual is in a coma or vegetative state, or where an individual with a disability is displaying concerning behaviours of self-harm.⁹⁰ Under the framework of article 12, both individuals in these examples would technically have the right to exercise their own legal capacity, raising questions as to whether universal legal capacity should be unrestricted in all scenarios. Though the central focus of this thesis is on the notions of communication and will and preferences under article 12, criticisms and concerns regarding healthcare and criminal law will be addressed below. The purpose of the examples below is to briefly highlight the

⁸⁸ GC1 (n 78) para 15.

⁸⁹ Arstein-Kerslake and Flynn, ‘Legislating Personhood’ (n 49) 98.

⁹⁰ *ibid.*

potential dangers of a paradigm of legal capacity that prioritises the communication of will and preferences by an individual above all else.

2.6.1 *Healthcare*

Much of healthcare is based on the principle of informed consent, a legal embodiment of the idea that each individual has the right to make decisions about their own body and treatment, and the patient's understanding of the potential risks and rewards of proposed treatment underlies the principle itself.⁹¹ Sufficient mental capacity is necessary for informed consent, as consent obtained when a person is not competent to make a decision is not truly informed and therefore invalid.⁹² As such, there are situations where informed consent may be superseded by a necessary intervention. Expanding upon the 'hard case' above, what happens if an individual who is in a coma must undergo a necessary operation? When the situation occurs where persons with disabilities are deemed incompetent to make decisions regarding their treatment, the decision has traditionally fallen into the hands of guardians based on the best interest or substituted judgment standard.⁹³ The CRPD Committee's position would ban such intervention, raising questions about the adverse repercussions if all forms of interventions are banned. A primary concern is whether universal legal capacity would outrightly undermine the protection of informed consent and potentially affect certain human rights for persons with disabilities, eg the right to health, as they would be entrusted to permit or refuse medical treatment despite impaired decision-making.⁹⁴ Moreover, when someone exercises legal capacity, they assume responsibility for their decisions, entailing

⁹¹ TJ Paterick and others, 'Medical Informed Consent: General Considerations for Physicians' (2008) 83 *Mayo Clinic Proceedings* 313.

⁹² MC Freeman and others, 'Reversing Hard Won Victories in the Name of Human Rights: A Critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities' (2015) 2 *The Lancet Psychiatry* 844, 845.

⁹³ M Scholten and J Gather, 'Adverse Consequences of Article 12 of the UN Convention on the Rights of Persons with Disabilities for Persons with Mental Disabilities and an Alternative Way Forward' (2018) 44 *Journal of Medical Ethics* 226, 229; M Scholten, J Gather and J Vollmann, 'Equality in the Informed Consent Process: Competence to Consent, Substitute Decision-Making, and Discrimination of Persons with Mental Disorders' (2021) 46 *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine* 108, 109.

⁹⁴ M Bach, 'Inclusive Citizenship: Refusing the Construction of "Cognitive Foreigners" in Neo-Liberal Times' (2017) 4 *Research and Practice in Intellectual and Developmental Disabilities* 4, 13.

that if someone with impaired decision-making is entrusted to make healthcare decisions without a genuine understanding of the treatment or risks, they would bear responsibility for their decisions. In cases where negligence or human rights violations might occur, it would complicate the distribution of responsibility for such decisions, as technically the individual would have consented.⁹⁵ If universal legal capacity is to be achieved, the CRPD Committee must reconsider whether certain exemptions for legal agency might be permitted for the health and safety of the individual and address arguments.

2.6.2 *Criminal law*

A second area where a denial of legal capacity is *intended* to serve persons with disabilities is the use of the commonly dubbed ‘insanity defence’ in criminal law, whereby ‘insanity’ or diminished mental capacity may negate the criminal responsibility or culpability of an individual who commits a crime. Few principles are as stringently embedded in criminal jurisprudence as the principle that so-called ‘incompetent’ persons may not be put to trial or convicted in the same manner as ‘competent’ persons. Though the Committee has not addressed this, the OHCHR has stated that ‘recognition of the legal capacity of persons with disabilities requires abolishing a defence based on the negation of criminal responsibility because of the existence of a mental or intellectual disability’, and maintained that a disability-neutral approach which considers the *subjective* element of crime should replace the ‘insanity defence’ or other similar doctrines.⁹⁶ Disability-neutral restrictions then become very important, as such doctrines might utilise existing alternatives for diminished responsibility, such as necessity, duress or self-defence; or rely on other situational or behavioural criteria, such as dangerousness. All of these raise questions as to the protection of persons with disabilities. Kanter argues that under disability-neutral

⁹⁵ Scholten and Gather (n 93) 229.

⁹⁶ UNOHCHR, ‘Thematic Study by the Office of the United Nations High Commissioner for Human Rights on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities’ (2009) para 47 <<https://digitallibrary.un.org/record/647817>> accessed 2 May 2022; ML Perlin, “‘God Said to Abraham/Kill Me a Son’: Why the Insanity Defense and the Incompetency Status Are Compatible with and Required by the Convention on the Rights of Persons with Disabilities and Basic Principles of Therapeutic Jurisprudence’ [2015] SSRN Electronic Journal 487 <<http://www.ssrn.com/abstract=2683480>> accessed 5 May 2022.

laws ‘a person who is considered dangerous would be detained pursuant to a lawful authority, but not by the mental health system’, which would therefore reserve mental health systems for persons receiving treatment voluntarily, and would ‘likely result in an increase in the number of people with (...) a label of disability in jails and prisons’.⁹⁷ Another factor warranting consideration lies in the recognition of persons with disabilities as possessing equal criminal culpability, which may adversely increase the risk of persons with disabilities facing severe criminal sanctions, such as the death penalty. Moreover, such culpability may exacerbate the current challenges and human rights violations that detained persons with disabilities face, such as disproportionate violence and abuse, and a lack of adequate mental and physical health services.⁹⁸ The abandonment of concepts which utilise assessments of mental capacity in criminal law, such as *mens rea*, call fundamental legal principles into question, as they require assessment of the inner workings of the human mind. It has been argued by Dawson that this would violate the right to legal capacity.⁹⁹ Though ‘disability-neutral’ doctrines would supposedly replace such principles, ‘neutral’ doctrines are not an immediate remedy for institutional discrimination towards persons with disabilities; they are unknown territory and may be difficult to create and apply in a non-arbitrary fashion.¹⁰⁰ For example, if a ‘disability-neutral’ defence, such as a mistaken belief or duress, still considers elements linked to *mens rea*, are these defences still neutral and compliant with the CRPD?¹⁰¹ To be compliant with the CRPD under the Committee’s interpretation is thus to base criminal responsibility on observable, objective standards that overhaul all defences based on mental incapacity. However, such actions may consequently sacrifice the interests of persons with disabilities who commit otherwise criminal acts because of profoundly altered or diminished mental states brought on by their disability.

⁹⁷ Kanter (n 38) 144.

⁹⁸ S Enggist and others, *Prisons and Health* (World Health Organization Regional Office for Europe 2014) 153; E Flynn and others (eds), *Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories* (Routledge 2018) 19-20.

⁹⁹ Dawson (n 87) 73.

¹⁰⁰ Nilsson and Series (n 55) 17.

¹⁰¹ *ibid* 21; J Peay, ‘Mental Incapacity and Criminal Liability: Redrawing the Fault Lines?’ (2015) 40 *International Journal of Law and Psychiatry* 25, 30.

2.7 CONCLUSIONS ON CHAPTER 2

The purpose of this chapter was to provide background to article 12 and its drafting, as well as to present criticisms for the reader to consider before the detailed analysis of article 12 in the following chapter. To recognise the significance of article 12 and its interpretation, one must understand the stark contrast between the former paradigm/the medical model and the social model. Moreover, as the controversial interpretation of article 12 in GC1 is discussed at length in the following chapter, it is important to acknowledge the history of the varying arguments put forth by states to retain some form of substitute decision-making, as well as more conceptual criticisms of universal legal capacity.

3.

ANALYSING THE RIGHT TO EQUAL RECOGNITION
BEFORE THE LAW: A CLOSER LOOK AT ARTICLE 12

3.1 ANALYSIS OF ARTICLE 12

Building upon the previous chapter, this chapter will consist of a doctrinal legal analysis of article 12, utilising the methodological treaty interpretation framework of articles 31 and 32 of the VCLT outlined in chapter 1.¹⁰² The purpose of this chapter is primarily to answer the first research sub-question: what are the legal obligations of article 12 surrounding communication, will and preferences? Moreover, the analysis of article 12 is essential to understanding the obligations upon states parties to prioritise will and preferences and use a range of methods to communicate. Additionally, analysis here is important for the comparison between the ADMCA and CRPD in the following chapters. The text and interpretation of article 12(1)-(5) will be analysed by examining the central theme or principles of each article and, in turn, and how each of them contributes to universal legal capacity within article 12. The structure is as follows: (1) legal personality will be discussed through analysis of article 12(1); (2) legal capacity will be discussed through analysis of article 12(2) and article 12(5); (3) supported decision-making and communication will be discussed through analysis of article 12(3); and (4) safeguards for the support of legal capacity, and will and preferences will be discussed through analysis of article 12(4).

¹⁰² VCLT (1969) arts 31-32.

3.2 LEGAL PERSONALITY

Article 12(1) is a simple, clear and concise introduction that states that persons with disabilities have the right to legal personality, a prerequisite for legal capacity under article 12(2). The text of article 12(1)¹⁰³ reads ‘States Parties reaffirm that persons with disabilities have the right to recognition as persons everywhere before the law’.

A textual reading of article 12(1) does not define ‘legal personality’ in exact terms, however, the right to ‘recognition as persons before the law’ is understood as the right to legal personality. The text of article 12 directly stems from article 6 of the Universal Declaration of Human Rights and article 16 of the International Covenant on Civil and Political Rights,¹⁰⁴ according to the CRPD Committee, which provides that ‘everyone shall have the right to recognition everywhere as a person before the law’.¹⁰⁵ The text of article 12(1) thus builds upon pre-existing international provisions to specify and guarantee this right for all persons with disabilities without discrimination.¹⁰⁶

Interpreting article 12(1) within the context of the CRPD as a whole, the preamble to the CRPD does not mention legal capacity explicitly. However, both the preamble and the general principles contained in article 3 reference the importance of autonomy as a central component of the Convention, with the preamble stating the ‘importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices’.¹⁰⁷ We may see in its relation to the freedom of persons to make their own choices, autonomy is inextricably linked to the entirety of article 12, as one cannot truly be recognised as a person before the law unless autonomy is provided for and recognised by the State. Article 3 additionally affirms respect for

¹⁰³ CRPD art 12(1).

¹⁰⁴ Committee on the Rights of Persons with Disabilities, ‘General comment No. 1 (2014) Article 12: Equal recognition before the law’ (19 May 2014) UN Doc CRPD/C/GC/1 (GC1) para 1.

¹⁰⁵ Universal Declaration of Human Rights (adopted 10 December 1948) UNGA Res 217 A(III) (UDHR) art 6; International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (ICCPR) art 16.

¹⁰⁶ C de Bhailis and E Flynn, ‘Recognising Legal Capacity: Commentary and Analysis of Article 12 CRPD’ (2017) 13 *International Journal of Law in Context* 6, 7; EJ Kakoullis and K Johnson, *Recognising Human Rights in Different Cultural Contexts: The United Nations Convention on the Rights of Persons with Disabilities (CRPD)* (Springer Singapore Pte Limited 2020) 19-25.

¹⁰⁷ CRPD preamble paras (b) and (n).

individual autonomy and the freedom to make one's choices as a general principle of the Convention as a whole, further exemplifying the centrality of the recognition of legal personality for persons with disabilities to the CRPD and the overall paradigm of universal legal capacity.¹⁰⁸

To better understand legal personality, we must look to GC1 drafted by the CRPD Committee, which provides thorough contextual interpretive guidance beyond the text itself, though said interpretation has been met with both enthusiasm and criticism.¹⁰⁹ As previously mentioned, the status of legal personality as a 'prerequisite for the recognition of legal capacity' is directly taken from GC1, (rather than the text itself).¹¹⁰ Referring back to the *travaux préparatoires* of the CRPD, this distinction may be seen from early working group texts which read 'everyone shall have the right to recognition everywhere as a person before the law, *with* full legal capacity'.¹¹¹ It is important to recognise, however, that although the obligation of states parties to confer legal personality affirms that persons with disabilities may hold and exercise rights and duties, the conferral of legal personality itself does not specify which rights and duties are held, or how persons with disabilities may exercise them (this rather falls under the sphere of legal capacity).¹¹²

3.3 LEGAL CAPACITY

3.3.1 *Legal standing, agency and equality*

Article 12(2)¹¹³ builds upon article 12(1), with the text directly providing for universal legal capacity for persons with disabilities,

¹⁰⁸ CRPD art 3.

¹⁰⁹ PS Appelbaum, 'Protecting the Rights of Persons With Disabilities: An International Convention and Its Problems' (2016) 67 *Psychiatric Services* 366, 367; A Nilsson and L Series, 'Article 12 CRPD: Equal Recognition before the Law' in I Bantekas and others (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press 2018) 9.

¹¹⁰ GC1 (n 104) para 11.

¹¹¹ Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 'Chair's Draft Elements of a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities' (December 2003) art 11(1) (emphasis added).

¹¹² Nilsson and Series (n 109) 10-11.

¹¹³ CRPD art 12(2).

stating that ‘States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’.

A textual reading reveals the all-encompassing nature of legal capacity within the CRPD by indicating it should be enjoyed in ‘all aspects of life’. This being said, interpretation of article 12(2) demands greater contextual reference to ‘legal capacity’ itself, a concept which defines the enjoyment of human rights on a large scale, yet has no universally agreed-upon definition. Article 12(2) is only the second international human rights treaty to specifically refer to legal capacity, the first being article 15(2) of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) which accords women ‘in *civil matters*, legal capacity identical to that of men and the same opportunities to exercise that capacity’.¹¹⁴ Article 15(2) importantly guaranteed women the right to *perform* legally binding acts in a wholly equal manner to men, recognising both legal capacity and the need to avoid limitations on women’s legal capacity.¹¹⁵ Reading the text of article 12(2) with an understanding of article 15 of the CEDAW affirms that article 12(2) guarantees persons with disabilities the capacity to hold rights and to act upon those rights. Article 12(2) of the CRPD goes further, however, as article 15(2) of the CEDAW specifically accords this right to women in civil matters. GC1 additionally strengthens the right to legal capacity through stating that under article 12(2) legal capacity entails the capacity to ‘be a holder of rights’, ie have legal standing, and an ‘actor under the law’, ie have legal agency.¹¹⁶ Examples of legal standing include the right to seek medical assistance, apply for a passport or register to be on the electoral roll, for instance; while legal agency mandates that those actions be recognised by law.¹¹⁷ The CRPD Committee holds that the right to both legal standing and agency through legal capacity is a universal human right accorded to all persons simply by virtue of being human.¹¹⁸ It is further emphasised that for persons with disabilities it is often legal *agency* that poses a barrier to

¹¹⁴ Convention on the Elimination of All Forms of Discrimination Against Women (adopted 18 December 1979, entered into force 3 September 1981) 1249 UNTS 13 (CEDAW) art 15(2); GC1 (n 104) para 6 (emphasis added).

¹¹⁵ B Rudolf, MA Freeman and C Chinkin, *The UN Convention on the Elimination of all Forms of Discrimination against Women: a commentary* (OUP 2012) 391 (emphasis added).

¹¹⁶ GC1 (n 104) para 12.

¹¹⁷ *ibid.*

¹¹⁸ *ibid* para 14.

legal capacity for persons with disabilities, as laws may be in place to recognise that persons with disabilities have legal standing, yet states parties may still retain the authority to not recognise said actions because the person in question exercising their legal standing has a disability.

Article 12(2) guarantees legal capacity for persons with disabilities on an ‘equal basis with others’, though ‘equality’, like ‘legal capacity’, may be a slippery concept. The preamble to the CRPD recognises equality and barriers to equality which should, presumably, be addressed through rights such as those contained in article 12. The preamble considers equality in numerous ways, beginning with recognition of ‘the inherent dignity and worth and the equal and inalienable rights of all members of the human family’, as well as the recognition that disability ‘is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others’.¹¹⁹ This reflects the social model of disability, which frames inequality of persons with disabilities as the result of the interaction between societal barriers and impairments, indicating that states parties should recognise all barriers to inequality regarding the right to legal capacity for persons with disabilities both within the law and society. To analyse article 12(2) in accordance with article 31 of the VCLT and consider the greater context of the CRPD, one may refer to article 5 of the CRPD. Article 5 provides for the right of equality and non-discrimination, expressing that states parties must recognise ‘all parties are equal before and under the law and are entitled without any discrimination to the equal protection and benefit of the law’, and are guaranteed ‘equal and effective legal protection against discrimination on all grounds’.¹²⁰ Thus, the enjoyment of legal capacity on an equal basis with others under article 12(2) affirms that states parties must adopt a wide-reaching understanding of equality in both social and legal processes, as well as guarantee that states do not discriminate against persons with disabilities in their enjoyment of the right to legal capacity either directly or indirectly.¹²¹

¹¹⁹ CRPD preamble paras (b) and (e).

¹²⁰ *ibid* art 5.

¹²¹ Nilsson and Series (n 109) 11-13.

3.3.2 *Mental versus legal capacity*

Aside from the provisions regarding legal agency, standing and equality, GC1 makes it abundantly clear that mental capacity, or lack thereof, may never act as a restriction to legal capacity.¹²² This has been discussed in the previous chapter, so this sub-section will only briefly explore this issue, although the significance of this statement by the CRPD Committee should not be understated. This is arguably the most controversial, yet revolutionary, facet of article 12(2), and for the purpose of contextual interpretation, it must be recognised that the CRPD Committee holds that the ways in which people make decisions, and their varying levels of cognitive ability, should not be used to either access or deny legal capacity.¹²³ In other words, the CRPD Committee again maintains that *recognising* legal capacity for persons with disabilities on an equal basis for persons with disabilities means that no matter the extent to which an individual's decision-making abilities may be impaired, and no matter the context or purpose of said decisions, states parties will be in violation of article 12 if legal capacity is denied. GC1 goes further to describe mental capacity as 'highly controversial in and of itself', holding it 'is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon' and rather contingent on social and political contexts.¹²⁴ Analysing and interpreting article 12(2) in accordance with the VCLT, we may understand article 12(2) reflects the ultimate goal of article 12, which is to provide legal capacity to *all* persons with disabilities regardless of impairment.

3.3.3 *Legal capacity and economic rights: Article 12(5)*

A textual reading of article 12(5)¹²⁵ outlines specific rights concerning legal capacity and financial affairs, all of which represent societal and economic powers that have frequently been denied to persons with disabilities under the medical model of disability.¹²⁶ Article 12(5) reads as follows:

¹²² GC1 (n 2) para 13.

¹²³ de Bhailis and Flynn (n 106) 10.

¹²⁴ GC1 (n 104) para 14.

¹²⁵ CRPD art 21(5)

¹²⁶ V Della Fina, R Cera and G Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities : A Commentary* (Springer 2017) 267; GC1 (n 104) para 23.

Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Thus, the rights drawn from a textual interpretation are the rights to (i) own or inherit property (and to not be arbitrarily deprived of one's property), (ii) control one's own financial affairs and (iii) have equal access to bank loans, mortgages and other forms of financial credit. One might argue the rights listed are implicit under article 12(1)-(2), however, restrictions to financial control are worth separate treatment, as they have the ability to truly hinder independent living and legal capacity.

As article 12(5) clarifies that persons with disabilities may not be denied the right to own and inherit property or be arbitrarily deprived of their property,¹²⁷ right to control one's own financial affairs as a central component of legal capacity is affirmed. The provisions of specific financial rights emphasise the extent to which under systems of substitute decision-making persons typically lose all of their capacity to manage their financial affairs or only retain the capacity to make specific financial decisions, with the other decisions being transferred to a guardian.¹²⁸ Outside of formal financial matters, controlling one's finances affects everyday actions, such as the ability of an individual to purchase the food or clothing they desire. It is a right that guarantees access to legal capacity in everyday matters, though it should be noted that the Committee outlines exceptions, namely bankruptcy and criminal conviction (though said restrictions cannot be based on personal characteristics such as disability).¹²⁹ Moreover, article 12(5) includes the right to have equal access to bank loans, mortgages and other forms of financial credit. Access to loans and other services may be restricted for persons with disabilities for a number of reasons, particularly through

¹²⁷ Nilsson and Series (n 109) 36.

¹²⁸ A Nilsson, 'Who Gets to Decide? Right to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities' (Commissioner for Human Rights of the Council of Europe 2012) Issue Paper 8, 9-10; *ibid* 38.

¹²⁹ GC1 (n 104) para 32.

discrimination by financial institutions themselves.¹³⁰ The specific provision of a right to access various forms of financial credit is an important tool in furthering the inclusion of persons with disabilities under the social-contextual model of disability, as it obligates states parties to minimise discrimination by financial institutions. This, in turn, would aid in increasing the number of persons with disabilities who could take out mortgages on homes or apply for loans to start businesses, among many potential examples.

Overall, the Committee maintains that states parties must take legislative, administrative, judicial and other practical measures to ensure the rights of persons with disabilities in financial and economic affairs, on an equal basis with others.¹³¹ Where a person with a disability is not able to wholly exercise their own legal capacity in financial affairs, ‘the approach of denying persons with disabilities legal capacity for financial matters must be replaced with support to exercise legal capacity, in accordance with Article 12 paragraph 3’.¹³²

3.4 SUPPORT, SUPPORTED DECISION-MAKING AND COMMUNICATION

Article 12(3)¹³³ is concerned with states parties’ obligations to provide access and support for legal capacity, provisions which are essential to the maintenance of legal agency. It reads ‘States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’.

A textual reading of article 12(3) is clear in expressing that states parties have a firm obligation, firstly, to ensure that persons with disabilities may exercise legal capacity and, secondly, that they provide support mechanisms for persons with disabilities to exercise their legal capacity. Article 12(3) emphasises the state’s obligations to respect and fulfil,¹³⁴

¹³⁰ Nilsson (n 128).

¹³¹ GC1 (n 104) para 23.

¹³² *ibid.*

¹³³ CRPD art 12(3).

¹³⁴ The tripartite obligations under international human rights law include (1) the obligation to respect, entailing the duty for states interfering or diminishing the enjoyment of human rights, (2) the obligation to protect, which obligates states to protect persons against abuses of human rights, and (3) the obligation to fulfil, which asks states to take positive action to facilitate the enjoyment of human rights; OHCHR, ‘International Human Rights Law’ (OHCHR) <www.ohchr.org/en/instruments-and-mechanisms/international-human-rights-law> accessed 6 May 2022.

two of the three core obligations assumed by states when becoming parties to treaties under international human rights law. Article 12 is no exception to this, as the CRPD Committee firmly asserted that states parties ‘have an obligation to respect, protect and fulfil the right of all persons with disabilities to equal recognition before the law’.¹³⁵ These provisions are relatively direct; however, what begs contextualisation and guidance under article 31 of the VCLT is what type of measures and support are actually (1) appropriate and (2) required of states parties.

3.4.1 Article 12(3) and the obligation to support

To contextualise article 12(3), it is stated in GC1 that support ‘is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity’.¹³⁶ This statement solidifies that support may come through actions or policies of states, as well as through informal familial or friendly relationships.¹³⁷ Moreover, such support ‘must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making’.¹³⁸ With regard to both formal and informal support arrangements, the question arises as to the extent to which the rights, will and preferences of persons with disabilities may be safeguarded in casual arrangements that fall under ‘informal’ support. Conversely, formal support mechanisms may be able to have more effective safeguards regarding the rights, will and preferences of individuals, however, it may not be as personal as informal arrangements.¹³⁹ Support itself is not neatly defined within GC1, which reflects an understanding that support may vary through time and implementation of article 12, emphasising the constantly evolving nature of disability contained in paragraph (e) of the preamble. Though there is no firm definition of support in GC1, examples of support mechanisms are provided, namely requirements

¹³⁵ GC1 (n 104) para 24.

¹³⁶ *ibid* para 17.

¹³⁷ AS Kanter, *The Development of Disability Rights Under International Law: From Charity to Human Rights* (Routledge 2014) 237; A Arstein-Kerslake and E Flynn, ‘The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality before the Law’ (2016) 20 *The International Journal of Human Rights* 476.

¹³⁸ GC1 (n 104) para 17.

¹³⁹ Arstein-Kerslake and Flynn, ‘The General Comment on Article 12’ (n 137) 476.

that public and private actors, such as banks and financial institutions, ‘provide information in an understandable format (...) in order to enable persons with disabilities to perform the legal acts required to open a bank account, conclude contracts or conduct other social transactions’.¹⁴⁰ Despite these examples, such a broad understanding allows for the growth and development of ‘support’ mechanisms, though all support should firmly respect the rights, will and preferences of persons with disabilities. Interestingly, support was originally understood in the earlier texts the way ‘safeguards’ are understood in the final text. To clarify this, at the fifth ad hoc session, the provision regarding support expresses that states parties shall ensure ‘that where support is required (...) the assistance provided is proportional to the degree of support required and tailored to the person’s circumstances (...) respects the will and preferences of the person and is free from conflict of interest and undue influence’.¹⁴¹

Through analysing article 12(3) with historical reference to earlier drafts of the CRPD, in accordance with article 31 of the VCLT, we may understand that the notion of support evolved greatly throughout the drafting process. This resulted in a significant aspect of the new ‘paradigm’ of universal legal capacity under article 12, the obligation to implement regimes of supported decision-making. The sub-section below will specifically address regimes of supported decision-making.

3.4.2 Supported decision-making

Though the text of the CRPD itself does not specifically outline or even include the term ‘supported decision-making’, a framework of support which may be drawn from the contextualisation of article 12(3) is that of regimes of supported decision-making. Such regimes allow persons with disabilities to choose ‘one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support,

¹⁴⁰ GC1 (n 104) para 17.

¹⁴¹ UN Enable, ‘Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its fifth session’ (24 January-4 February 2005) UN Doc A/AC.265/2005/2 paras 20-21.

advocacy (...) or assistance with communication'.¹⁴² As the provisions for supported-decision making followed the statement that support may never amount to substitute decision-making, the interpretation of states parties' obligations to 'support' provided by the Committee outlines two ambitious obligations for states parties: (1) to institute regimes of supported decision-making and (2) to abolish all forms of substitute decision-making. As discussed in chapter 2, the notion that full legal capacity for persons with disabilities cannot coexist with systems of substitute decision-making was led by persons with disabilities during the drafting process of the CRPD and met with opposition by states who argued at many points that substitute decision-making may be utilised in specific situations. Though many states have maintained systems of substitute decision-making, GC1 maintains and furthers the sentiments of the IDC. The CRPD Committee asks states to repeal such regimes, calling upon states parties to 'review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences'.¹⁴³

3.4.3 The significance of communication

The disparity between substitute and supported decision-making lies in the irrefutable primacy of the notion of 'will and preferences'. Where GC1 outlines that support may include choosing trusted SP, it additionally states they 'may call on other forms of support such (...) as assistance with communication'.¹⁴⁴ Under substitute decision-making, where an individual with a disability may not be able to communicate in a manner comparable to those without disabilities, guardians or other relevant persons would represent the interests of said individual and communicate on their behalf. GC1 provides clarification of what 'support' may entail, particularly the inclusion of 'diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will

¹⁴² GC1 (n 104) para 17.

¹⁴³ *ibid* para 26.

¹⁴⁴ *ibid* para 17.

and preferences'.¹⁴⁵ In recognising the importance of communication, the CRPD Committee affirms the importance of expressing oneself as a basic human right, and as a human need to share opinions, emotions and thoughts in a way that can shape one's life.¹⁴⁶ Communication, and assistance with communication, are not solely based on a contextual interpretation using GC1, but may be found in the context of the CRPD itself. Firstly, article 4(g)-(i) of the CRPD, concerning general obligations for states parties, firmly create obligations regarding communication, holding that states parties are: (1) to promote the research, development and availability of information/communication technologies, as well as mobility aids, assistive technologies suitable to persons with disabilities, etc; (2) to provide accessible information, support services and facilities to persons with disabilities regarding the use of the aforementioned technologies and (3) promote the training of professionals/staff working with persons with disabilities to provide the aforementioned services and assistance.¹⁴⁷ Furthermore, drawing on the context in the CRPD that supports article 12, an inclusive and forward-looking understanding of communication is presented in the definition of communication in article 2 as:

languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.¹⁴⁸

The language within article 2 of the CRPD additionally includes spoken, signed and non-spoken languages.¹⁴⁹ Supporting persons with disabilities to communicate thus requires states to adapt their standards and methods of communication to suit all persons with disabilities so that they may exercise their legal capacity, meaning states parties are obliged to develop and utilise forms of communication which go beyond 'conventional' language. GC1 further maintains 'a person's

¹⁴⁵ GC1 (n 104) para 17. .

¹⁴⁶ J Bornman, 'Preventing Abuse and Providing Access to Justice for Individuals with Complex Communication Needs: The Role of Augmentative and Alternative Communication' (2017) 38 *Seminars in Speech and Language* 321, 322.

¹⁴⁷ CRPD art 4.

¹⁴⁸ *ibid* art 2.

¹⁴⁹ *ibid*.

level of support needs, especially where these are high, should not be a barrier to obtaining support in decision-making’,¹⁵⁰ and ‘a person’s mode of communication must not be a barrier to obtaining support in decision-making, even where this communication is non-conventional, or understood by very few people’.¹⁵¹

Further historical reference to the *travaux préparatoires* reveals the inclusion of communication from early on in the drafting process. The most significant example of this is Japan’s proposal to include a subparagraph in article 12 (then article 9) at the third ad hoc session, which held that states parties should:

take appropriate and effective measures to eliminate physical and communication barriers and to reduce understanding difficulty of persons with disabilities in order to exercise all the rights in judicial procedure which are provided in the International Covenant on Civil and Political Rights.¹⁵²

Many civil society actors fully supported Japan’s proposal, with Inclusion International stating that it ‘touched upon the spirit of the Convention’.¹⁵³ Although the term ‘communication’ did not find its way into the text of article 12 of the CRPD itself, through contextual and historical analysis using the interpretive tools provided in articles 31 and 32 of the VCLT, the importance of communication as a form of support is undeniable and fundamental towards realising the new paradigm of supporting the will and preferences of persons with disabilities, and the transition away from substitute decision-making.

3.5 SAFEGUARDS, WILL AND PREFERENCE, AND INTERPRETATION

The text of the first sentence of article 12(4) directly reflects the state’s duty to protect the right to universal legal capacity, as it asks states to have safeguards in place to act pre-emptively to prevent abuse. Article 12(4)¹⁵⁴ reads:

¹⁵⁰ GC1 (n 104) para 29(a).

¹⁵¹ *ibid* para 29(c).

¹⁵² Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, ‘Daily summary of discussions related to Article 9 on its third session’ (26 May 2004).

¹⁵³ *ibid*.

¹⁵⁴ CRPD art 12(4).

States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

This is a standard request of states parties under international human rights law; however, what such safeguards require carries important weight with regard to the interpretation of the rest of article 12. The purpose of safeguards, as interpreted from the text itself, may be outlined as follows: safeguards which exist to (i) respect the rights, will and preferences of the person, (ii) ensure there is no conflict of interest and (iii) ensure there is no undue influence.¹⁵⁵ In the sub-sections that follow, these elements will be analysed.

In regard to safeguards respecting the rights, will and preferences of the person, GC1 clarifies that 'the primary purpose of these safeguards is to ensure the respect the person's rights, will and preferences (...) In order to accomplish this, the safeguards must provide protection from abuse on an equal basis with others'.¹⁵⁶ While the utmost importance of will and preferences within the new paradigm has been discussed previously, article 12(4) goes further and requires protective, considerate and effective measures to ensure that all persons with disabilities are able to express their will and preferences. However, it begs the question of what measures are necessary to ensure the rights, will and preferences of persons with disabilities? While GC1 does not clarify any measures, it states that article 12(4) must be read in conjunction with the entirety of article 12 and the CRPD as a whole.¹⁵⁷ Importantly, as the Committee articulates that safeguards expressed in article 12(4) must protect from abuse on an equal basis with others, reference can be made to other provisions of the treaty which discuss 'equality' within the CRPD.

¹⁵⁵ W Martin and others, 'Essex Autonomy Project Three Jurisdictions Report Towards Compliance with CRPD Art. 12 in Capacity/Incapacity Legislation across the UK' (Essex Autonomy Project 2016) 38.

¹⁵⁶ GC1 (n 104) para 20.

¹⁵⁷ GC1 (n 104) para 20.

Article 5 guarantees that ‘States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds’.¹⁵⁸ Thus, the obligation to implement ‘appropriate and effective safeguards’ to protect the rights, will and preferences of persons with disabilities is wide-reaching, concerned with inequality and discrimination at all levels, insofar as the denial of the expression of their will and preferences is concerned. Moreover, while there are no specific provisions in the text of the CRPD explaining the term ‘safeguards’, one aspect that is clear is that safeguards shall never override the will and preferences of an individual, and never result in a restriction of legal capacity. GC1 additionally maintains that after significant efforts have been made, if it is not practicable to determine the will and preferences of an individual, the “‘best interpretation of will and preferences” must replace the “best interests” determinations’.¹⁵⁹ The next sub-section elaborates on this point.

3.5.1 What is the best interpretation of will and preferences?

In transitioning towards universal legal capacity, the replacement of the ‘best interests’ framework for that of will and preferences again maintains the eradication of substitute decision-making. This is important because during the drafting process of the CRPD, the requirement to ensure ‘safeguards’ left some participants wondering whether some safeguards might amount to a restriction of legal capacity in certain cases. For example, a suggestion by India was that ‘in exceptional circumstances where legal safeguards are necessary, the appointment of third parties as legal guardian/surrogate may be made in the best interests of persons with disabilities’.¹⁶⁰ A similar proposal was made by Canada, which suggested that ‘States Parties shall provide by law for a procedure with appropriate safeguards for the appointment of a personal representative to exercise legal capacity on the adult’s behalf’.¹⁶¹ Naturally, these proposals did not find their way into the

¹⁵⁸ CRPD art 5.

¹⁵⁹ GC1 (n 104) para 21.

¹⁶⁰ Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, ‘Daily summary of discussions related to Article 9 on its third session’ (n 152) para 1.

¹⁶¹ *ibid* para 4.

text or interpretation of the CRPD. However, they reveal the original understanding of ‘safeguards’, and the rejection of such notions in ushering in respect for the rights, will and preferences of persons with disabilities above all else. Interestingly, the earlier draft of GC1 did not include the principle of ‘best interpretation’ of will and preferences; rather, it was included following a proposal by the Canadian Association of Community Living to recognise that will and preferences cannot always be determined with certainty.¹⁶²

While GC1 does provide clarity as to the interpretation of article 12, the requirement that states make the ‘best interpretation of will and preferences’ is a vague and a significant task that places a large amount of reliance upon both communication and systems of supported decision-making to discern what the ‘best interpretation’ of will and preferences is. This gives rise to a plethora of questions, like does ‘best interpretation’ refer to a *process* of interpretation, or the *outcome* of such a process? Skowron asks where it is ‘not practicable to determine’ will and preference, is that taken to refer to a process of determination which has already failed, or to a process that could not be completed in the first place? How does one interpret what they cannot determine?¹⁶³ These questions will not be specifically addressed throughout the rest of this thesis, however, they are presented as important background considerations for the continuing discussion of will and preferences, communication and article 12. One response to the ‘best interpretation’ principle in GC1 is presented by Arstein-Kerslake and Flynn, who suggest that the appointment of an outside decision-maker might be an option, as they can (i) attempt all forms of communication and (ii) speak with those close to the individual who may be able to help interpret communication and provide insight into the individual’s will and preferences.¹⁶⁴ Although they acknowledge that the establishment of ‘best interpretation’ is difficult, they maintain that the use of such a process with the ultimate goal of ensuring respect for will and preferences is what distinguishes supported decision-making from the former paradigm of substitute decision-making.¹⁶⁵ Here, the

¹⁶² P Skowron, ‘Giving Substance to “the Best Interpretation of Will and Preferences”’ (2019) 62 *International Journal of Law and Psychiatry* 125, 126.

¹⁶³ *ibid* 126.

¹⁶⁴ Arstein-Kerslake and Flynn, ‘The General Comment on Article 12’ (n 137) 478; Martin and others (n 155) 35.

¹⁶⁵ Arstein-Kerslake and Flynn, ‘The General Comment on Article 12’ (n 137).

understanding of ‘best’ interpretation translates to a process that aims to obtain the most accurate interpretation of will and preferences, rather than ‘best’ having its ordinary meaning of a superior or preferable choice in some way. It is recognised that sometimes one’s will and preferences may remain unknown despite significant efforts, and that SP within regimes of supported decision-making, eg DMA and CDM under the ADMCA (both of which will be discussed in detail in chapter 5), may be required to make a decision based on what they can garner from the ‘best interpretation’. However, even where the will and preferences of an individual with a disability might be ‘unknowable’, the position of the CRPD Committee is that it is always possible to arrive at *some* understanding of what the individual may want.¹⁶⁶

Skowron, on the other hand, emphasises the accuracy of the ‘best interpretation’, how the substance of the interpretation operates, what presumptions it relies upon and what effect it may have on the person.¹⁶⁷ This reasoning draws from an understanding that the ‘best interpretation’ principle is ‘a call to include people facing serious communication issues in everyday practices’, acknowledging the difficulty that persons with disabilities face in eg rebutting incorrect interpretations if they cannot adequately communicate.¹⁶⁸ The importance of determining that will and preferences, *even* where it is not practicable, should always be taken into account, and it is a fundamental aspect of universal legal capacity. Particularly, it is fundamental to the Convention’s guiding principle to ensure ‘full and effective participation in society on an equal basis with others’.¹⁶⁹ Thus, the accuracy and the substance of the interpretation are important norms when determining the ‘best interpretation’ of will and preferences that should be evaluated against the full array of rights within the CRPD.

3.5.2 *Conflict of interest and undue influence*

Article 12(4) provides that safeguards should be free from both conflicts of interest and undue influence. While GC1 does not elaborate on ‘conflict of interest’, we may understand from a textual reading

¹⁶⁶ Arstein-Kerslake and Flynn, ‘The General Comment on Article 12’ (n 137) 484-45.

¹⁶⁷ Skowron (n 162) 131.

¹⁶⁸ *ibid.*

¹⁶⁹ CRPD art 3.

of article 12(4) that the CRPD is recognising conflicts of interest will indeed arise. In this regard, states parties should be prepared to cope with conflict of interest and ensure the rights, freedoms and genuine expression of the will and preferences of persons with disabilities.¹⁷⁰ With regard to undue influence, GC1 acknowledges that ‘all people risk being subject to “undue influence”, yet this may be exacerbated for those who rely on the support of others to make decisions’.¹⁷¹ Where persons with disabilities are placed into systems in which their legal capacity, and will and preferences, may be construed by multiple parties, undue influence is a prominent concern, as the basis of universal capacity is an *authentic* expression of will and preferences. The CRPD defines ‘undue influence’ within systems of supported decision-making as something that occurs ‘where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation’.¹⁷² According to Gooding, the clarification of undue influence within the context of article 12 is useful in tasking states parties to develop safeguards that monitor or assess the quality of interaction between parties in systems of supported decision-making, as well as ensure the prevention of undue influence.¹⁷³ It further recognises that the relationships required for the implementation of the new paradigm of supported decision-making have the potential for undue influence, abuse or exploitation, which should be acknowledged and prevented.¹⁷⁴ States are thus tasked with developing safeguards to protect against undue influence and conflict of interest, yet the protection offered must always respect the rights, will and preferences of the person, ‘including the right to take risks and make mistakes’.¹⁷⁵

¹⁷⁰ Martin and others (n 155) 48.

¹⁷¹ GC1 (n 104) para 22.

¹⁷² *ibid.*

¹⁷³ P Gooding, ‘Navigating the “Flashing Amber Lights” of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns’ (2015) 15 Human Rights Law Review 45, 57.

¹⁷⁴ M Donnelly, R Harding and E Taşcıoğlu (eds), *Supporting Legal Capacity in a Socio-Legal Context* (Onati International Series in Law and Society 2022) 70.

¹⁷⁵ GC1 (n 104) para 22.

3.6 SUMMARY AND CONCLUSION OF FINDINGS ON ARTICLE 12

Article 12 as a whole lays down legal personality, legal capacity and frameworks of support which require alternative methods of communication, along with frameworks of supported decision-making and safeguards. Each of these factors contribute to the overall paradigm of universal legal capacity and must be recognised by states parties if they aim to provide equality for all persons with disabilities before the law. Overall, the universal recognition of legal capacity for persons with disabilities, in addition to rights and obligations generated by the entirety of article 12, is central to the purpose and enjoyment of the rights within the CRPD. The guiding principles of the CRPD include autonomy, dignity, the freedom to make one's own choices and the ability to fully participate in society without discrimination, none of which can be genuinely achieved if legal personality, agency and standing are not recognised.¹⁷⁶ The opportunity for persons with disabilities to not only exercise legal capacity, but be actively supported by the state, is crucial to achieving 'full and effective participation and inclusion in society'.¹⁷⁷

¹⁷⁶ CRPD art 3.

¹⁷⁷ *ibid* art 1; Della Fina, Cera and Palmisano (n 126) 266.

4.

THE CAPABILITY APPROACH, DISABILITY AND POLICY

4.1 CAPABILITIES AND LEGAL CAPACITY

Following the analysis of article 12 above, this chapter will explore the capability approach in order to answer the second sub-research question, namely, what is the purpose and usefulness of using the capability approach as a framework to aid the implementation of the CRPD? Expanding on the brief overview in the introduction, this chapter provides a cohesive overview of the capability approach, and an analysis of how it has been drawn on within disability, guardianship and policy. The purpose of this theoretical exploration is to provide a foundation for the following chapter, which will put forth the capability approach as a framework to determine the appropriate mode of communication within Ireland's ADMCA 2022.

4.2 THE CAPABILITY APPROACH: SEN AND NUSSBAUM

The capability approach was first articulated from an economic perspective by economist philosopher Amartya Sen in a lecture titled 'Equality of What?' in which he rejected notions of justice developed by utilitarianism, welfarism and Rawlsian notions of equality by asserting that possession of goods and resources were inadequate indicators of justice. In criticising Rawls' 'difference principle',¹⁷⁸ Sen remarks:

¹⁷⁸ Rawl's difference principle is the second principle in a theory of social distribution that states any inequality that is permitted should only be permitted on the basis that it benefits the least favoured in society; L Premchand, 'Social Justice and Rawls' Difference Principle' (2017) 9 Essex Student Journal <<http://publications.essex.ac.uk/esj/article/id/17/>> accessed 3 July 2022.

If people were basically similar, then an index of primary goods may be quite a good way of judging advantage. But, in fact, people seem to have very different needs varying with health, longevity, climatic conditions, location, work conditions, temperament, and even body size (...) judging advantage purely in terms of primary goods leads to a partially blind morality.¹⁷⁹

This leads Sen to conclude that what is arguably missing from prior conceptions of justice is some notion of ‘basic capabilities’, ie a person being able to do certain things.¹⁸⁰ Recalling the explanations provided in chapter 1, ‘functionings’ represent ‘parts of the state of a person – in particular the various things he or she manages to do leading a life’,¹⁸¹ while capabilities of an individual represent ‘the alternative combinations of functionings the person can achieve, and from which he or she can choose one collection (...) with the quality of life to be assessed in the terms of the capability to achieve valuable functionings’.¹⁸² The total set of the combinations of functionings an individual could achieve, including the combination which the individual is achieving, is the ‘capability set’.¹⁸³ Functionings and capabilities are understood as the well-being of individuals, which Sen expands upon through the consideration of freedom and achievement. Moreover, he provides a distinguishable ‘agency’, which is additionally considered from the lens of both freedom and achievement.¹⁸⁴ Well-being concerns the quality of a person’s being, wellness, personal advantage and personal welfare, thus ‘well-being freedoms’ refer to the freedom to advance or promote one’s well-being.¹⁸⁵ Agency freedom, on the other hand, constitutes the freedom to achieve whatever the individual as an agent desires to achieve. Agency achievement is thus the realisation of goals and values an individual wants to pursue regardless of whether or not they have implications for well-being.¹⁸⁶ Separately, well-being achievement evaluates the state of *wellness* of a person’s being.¹⁸⁷ Through the delineation of capabilities, functionings, well-being and agency, Sen’s initial theories have laid out a broad framework that has been widely developed, most notably by Martha Nussbaum through her refined rendition of the capability approach.

¹⁷⁹ A Sen, ‘Equality of What?’ (Stanford University 22 May 1979) 216.

¹⁸⁰ *ibid* 218.

¹⁸¹ M Nussbaum and A Sen, *Quality of Life* (OUP 1993) 31.

¹⁸² *ibid*.

¹⁸³ T Burchardt, ‘Capabilities and Disability: The Capabilities Framework and the Social Model of Disability’ (2004) 19 *Disability & Society* 735, 738.

¹⁸⁴ A Sen, ‘Well-Being, Agency and Freedom: The Dewey Lectures 1984’ (1985) 82 *The Journal of Philosophy* 169.

¹⁸⁵ D Crocker and I Robeyns, ‘Capability and Agency’ in CW Morris (ed), *Amartya Sen* (CUP 2009) 62-63.

¹⁸⁶ *ibid*.

¹⁸⁷ Nussbaum and Sen (n 181) 36.

Nussbaum's version of the capability approach may be described as a (partial) theory of justice, rooted in philosophical Aristotelian and Marxian ideas of human flourishing and dignity.¹⁸⁸ Dignity, and a life that is worthy of dignity, serve as the focal point of Nussbaum's approach,¹⁸⁹ which she uses to justify a list of ten central capabilities. Nussbaum's central capabilities are intended to lay out a framework of goals that may be specified further by societies and represent what she considers to be the essential pre-requisites to living a life with dignity.¹⁹⁰ The ten 'central capabilities' are:

1. LIFE.
2. BODILY HEALTH.
3. BODILY INTEGRITY.
4. SENSES, IMAGINATION, AND THOUGHT.
5. EMOTIONS.
6. PRACTICAL REASON. Being able to form a conception of the good and to engage in critical reflection about the planning of one's life.
7. AFFILIATION.
 - * Being able to live with and toward others (...) to engage in various forms of social interaction.
 - * Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin.
8. OTHER SPECIES.
9. PLAY.
10. CONTROL OVER ONE'S ENVIRONMENT.
 - * POLITICAL. Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association.
 - * MATERIAL. Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.¹⁹¹

¹⁸⁸ NG Saigaran, P Karupiah and PS Gopal, 'The Capability Approach: Comparing Amartya Sen and Martha Nussbaum' (USM International Conference on Social Sciences, Penang, 2015) 191.

¹⁸⁹ MC Nussbaum, *Frontiers of Justice : Disability, Nationality, Species Membership* (Harvard UP 2006) 74.

¹⁹⁰ *ibid* 75.

¹⁹¹ *ibid* 76-77; MC Nussbaum, 'Capabilities and Human Rights' (1997) 66 *Fordham Law Review* 273, 287-88. Please note the full description of many of the capabilities has been shortened, for a complete description refer to the sources provided.

It is important to note that Nussbaum herself has contended that the list is open-ended and subject to modification. It is this ‘fixed’ list of capabilities where Sen and Nussbaum diverge in their conceptions of the capability approach, with Sen contending that ‘to have a fixed list (...) is to deny the possibility of fruitful public participation on what should be included and why’.¹⁹² Furthermore, Nussbaum’s list and account of the capability approach is more political, as she equates the denial of central capabilities as a denial of basic justice, constituting an affront to one’s dignity.¹⁹³ The list is meant to be a focus for political planning,¹⁹⁴ as the list in the context of ‘political liberalism’ is specifically linked to political goals.¹⁹⁵ As such, her approach is meant to provide a philosophical underpinning of basic constitutional principles and core human entitlements that should be ‘respected and implemented by the governments of all nations, as a bare minimum for what human dignity requires’.¹⁹⁶

Considering article 12 of the CRPD, the central capabilities relate to having control over one’s environment from both political and material perspectives, using practical reason and planning one’s own life, and the ability to be treated with dignity without discrimination, particularly align with the rights provided for in article 12. The central capabilities closely reflect additional human rights provided in the CRPD, such as the right to equality and non-discrimination under article 5, which we again may relate to the capability of affiliation. Despite these similarities, Nussbaum maintains her conception of the capability approach is a *species* of a human rights approach,¹⁹⁷ meanwhile Sen distinguishes capabilities from human rights maintaining that capabilities are much broader.¹⁹⁸

¹⁹² A Sen, ‘Capabilities, Lists, and Public Reason: Continuing the Conversation’ (2004) 10 *Feminist Economics* 77, 77.

¹⁹³ J-S Gordon, J-C Pöder and H Burckhart (eds), *Human Rights and Disability: Interdisciplinary Perspectives* (Routledge 2016) 45.

¹⁹⁴ Nussbaum, ‘Capabilities and Human Rights’ (n 191) 286.

¹⁹⁵ MC Nussbaum, ‘Women’s Capabilities and Social Justice’ (2000) 1 *Journal of Human Development* 219, 223.

¹⁹⁶ *ibid* 222; Nussbaum, *Frontiers of Justice* (n 189) 70.

¹⁹⁷ *ibid* 78.

¹⁹⁸ Gordon, Pöder and Burckhart (n 193) 42.

4.3 THE CAPABILITY APPROACH, DISABILITY AND THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The interrelatedness of disability and capabilities lies in the consideration of persons' needs and wants beyond resources in a way that is inclusive of varying physical, political and socio-economic idiosyncrasies. Since its inception, examples of disability have been cited within the capability approach, and though Sen's perspectives do not reflect the social model of disability, he argues for the consideration of capabilities and conversion factors by stating 'a person who is disabled may have a larger basket of primary goods and yet have less chance to lead a normal life (or pursue her objectives) than an able-bodied person with a smaller basket of primary goods'.¹⁹⁹ As the capability approach has widened, it has been used to both define and understand disabilities from all angles. Mitra, for example, argues that the capability approach may be used as a framework with which to understand disability, stating that disability may be analysed as either deprivation of capabilities or deprivation of functionings.²⁰⁰ On the other hand, Riddle and Bickenbach use disability as a lens with which to offer a critical engagement with the capability approach and assess its adequacy in evaluating human justice.²⁰¹ A full exploration of the rich body of literature pertaining to capabilities and disability is outside the breadth of this thesis. However, despite the fact the frameworks above do not specifically pertain to the CRPD, the perspectives of disability discussed above are provided as brief examples of how the capability approach can be used to view disability, which should be briefly considered as we move on to the sections below which explore the capability approach and (1) the social model of disability/CRPD and (2) guardianship.

¹⁹⁹ A Sen, *Development as Freedom* (Anchor Books 1999) 74.

²⁰⁰ S Mitra, 'The Capability Approach and Disability' (2006) 16 *Journal of Disability Policy Studies* 236, 237.

²⁰¹ C Riddle and J Bickenbach, *Disabilities and Justice: The Capabilities Approach in Practice* (Lexington Books 2014).

4.3.1 *The social model and the Convention on the Rights of Persons with Disabilities*

The compatibility of the social model of disability and the capability approach lies in the consideration of external, environmental and societal factors which contribute towards a person's being. Where the capability approach rejects utility in favour of capabilities, the social model rejects medicalised notions of disability as a 'defect', and both shift the focus away from what people are or have – to what people are able to do or be. Through these considerations, both have the potential to re-conceive how society and policy interact with disability. Under the capability approach, the functionings within the capability set are not weak potential opportunities per se, or merely opportunities that are not restricted by the state, but real opportunities where an individual possesses the resources, knowledge and ability to achieve the functioning in question, *as well* as the social, economic and environmental factors to facilitate the individual realising said functioning.²⁰² Since the capability approach (particularly Nussbaum's) focuses on the state's or third parties' omissions or acts towards persons, it emphasises the state's fundamental responsibility to ensure basic capabilities and the ability of all to be fully functioning.²⁰³ If groups of persons, such as persons with disabilities, are prevented from attaining full functioning then it is the state and society at fault, and to this degree, the capability approach as a framework certainly complements the social model of disability.²⁰⁴ This being said, the interrelatedness of the social model and the capability approach has been explored in a number of ways, with some asserting the compatibility of the two, and others maintaining the capability approach can go beyond the social model. Though the focus of this sub-section is on the social model, it should be noted that the human rights-based model of disability, which is acknowledged by the CRPD Committee as underpinning the CRPD,²⁰⁵ has also been argued to go beyond the social model.²⁰⁶ In this sense it may also be comparable to the capability

²⁰² Burchardt (n 183) 738.

²⁰³ C Baylies, 'Disability and the Notion of Human Development: Questions of Rights and Capabilities' (2002) 17 *Disability & Society* 725, 735.

²⁰⁴ *ibid.*

²⁰⁵ Committee on the Rights of Persons with Disabilities, 'General comment No. 6 (2018) on equality and non-discrimination' (18 May 2018) UN Doc CRPD/C/GC/6 paras 3, 8 and 9.

²⁰⁶ T Degener, 'Disability in a Human Rights Context' (2016) 5(3) *Laws* 1, 3.

approach and the CRPD, as it ‘focuses on the inherent dignity of the human being’, and places the individual at the centre of all decisions which may affect said individual, locating the ‘main “problem” outside the person and in society’.²⁰⁷

Burchardt draws upon a number of similarities between the social model and capability approach, such as the consideration of the autonomy of persons with disabilities.²⁰⁸ It is argued in disability research that the identification of a disadvantage or restriction of ‘autonomy’ for persons with disabilities is commonly measured through the assessment of ‘normal’ daily activities, ie the extent to which a person with a disability is able to do the same things or access the same resources as someone without disabilities on a daily basis. Both the social model and the capability approach would criticise this measurement due to the primary recognition of disadvantage through barriers related to the individual’s impairment itself, along with financial resources and rights. The approach concerning the ‘limitation of normal daily activities’ assumes a problematic concept of ‘normalcy’, which is additionally at odds with the social model.²⁰⁹ Moreover, both the social model and the capabilities framework recognise the necessity of removing societal barriers in promoting well-being and addressing discrimination as a central component of these barriers.²¹⁰

In addition to comparison of the similarities between the social model and the capability approach, Terzi argues that ‘the capability approach advances the theorization of impairment and disability at both theoretical and political levels of analysis, and allows for a comprehensive evaluation of disability in the just design of social and institutional arrangements’.²¹¹ As the capability approach provides an egalitarian framework that determines entitlement based on capability sets rather than biological or societal conceptions of disability, it allows a multidimensional and relational understanding of disability.²¹² On a political level, the capability approach promotes a participatory democratic process in determining capabilities, discrimination and disadvantage, as Sen has provided that

²⁰⁷ G Quinn and others, *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability* (UN 2002) 14.

²⁰⁸ Burchardt (n 183).

²⁰⁹ *ibid* 741.

²¹⁰ *ibid* 744-45.

²¹¹ L Terzi, *Justice and Equality in Education: A Capability Perspective on Disability and Special Educational Needs* (Continuum 2008) 85.

²¹² *ibid*.

the persons most affected by decisions should be involved in the decision-making process. This may be specifically related to the human-rights based model of disability, as the CRPD Committee states the human rights model calls for ‘participation’, described as a ‘dimension to reaffirm the social nature of people and social groups and the full recognition of humanity through inclusion in society’.²¹³ Thus, the capability approach may align with theories of disability through its promotion of a positive and active role for persons with disabilities in determining relevant capabilities through democratic processes.

Building upon this relationship between the capability approach and the CRPD, Harnacke explores the extent to which the capability approach provides ethical support for the rights within the CRPD, ultimately concluding that the capability approach (specifically Nussbaum’s approach) *supports* the rights within the CRPD, but is not able to guide the implementation process because the CRPD lacks clear justification of capabilities.²¹⁴ Though this thesis does not specifically endorse this position, the following chapter will propose that the capability approach may be used as a *supplementary* guide for assistant decision-makers and CDM within the ADMCA. It will not be argued that the capability approach may be used as a framework to directly implement the CRPD, but rather where the CRPD is being implemented, the capability approach may complement said framework for implementation. Returning to Harnacke’s interpretation, insofar as support for the CRPD is concerned, she recognises the paradigm shift of the CRPD where persons with disabilities are no longer objects that benefit from social welfare, but persons who are deserving of rights in the same capacity as everyone else.²¹⁵ As Nussbaum takes the position that human rights are best understood as capabilities to be provided by the state, the capability approach makes no distinction between rights, eg considering rights to be either ‘positive’ or negative’. The CRPD additionally integrates all rights with no guidance about which rights belong to a specific group per se.²¹⁶ Furthermore, Harnacke takes the position that both the capability approach and CRPD adopt a social model of disability, and both recognise society

²¹³ General comment No 6 (n 205).

²¹⁴ C Harnacke, ‘Disability and Capability: Exploring the Usefulness of Martha Nussbaum’s Capabilities Approach for the UN Disability Rights Convention’ (2013) 41 *Journal of Law, Medicine and Ethics* 768, 769.

²¹⁵ *ibid* 774.

²¹⁶ *ibid*.

is just if ‘the state guarantees for all citizens the social basis of their capabilities, regardless of existing impairments’.²¹⁷ Despite this, it is argued that the capability approach *cannot* guide the implementation of the CRPD, because the reality of the implementation of CRPD requires prioritisation of certain rights and capabilities, something the capability approach does not offer.

Conversely, others argue the capability approach could ‘make a substantial contribution to the evolving discourse around the implementation of development efforts as a specific pathway to the realisation of disability rights guaranteed throughout the CRPD’.²¹⁸ The specific manner or extent to which the capability approach could guide implementation is not explored. However, a rather general position is taken that, regardless of whether the capability approach aids or answers issues related to the implementation of the CRPD, many of the theoretical considerations surrounding human rights, capabilities and disability, as well as conclusions drawn from the capability approach, have great relevance for disability advocates, persons working in disability rights and persons/states developing disability rights in both domestic and international fields.²¹⁹ The justifications behind this stance are, firstly, the fact the capability approach ‘promotes the universal aspect to basic capabilities that are valued by all’.²²⁰ As Sen insists that persons with disabilities need more resources to achieve a ‘good life’, the capability approach insists upon both equality and equity to achieve substantial opportunities and rights. In line with the CRPD, the capability approach would hold that existing barriers to the realisation of a ‘good life’ and opportunities for persons with disabilities must be removed and replaced with adequate opportunities and assistance. This may be related to communication within the context of article 12, as the ability to express will and preferences requires both adequate opportunities to communicate will and preferences, as well as assistance in communicating will and preferences. Moreover, it has maintained ‘the possibility for [persons with disabilities] to live a life they value also

²¹⁷ Harnacke (n 214) 774-75.

²¹⁸ R Lang and others, ‘Implementing the United Nations Convention on the Rights of Persons with Disabilities: Principles, Implications, Practice and Limitations’ (2011) 5 *Alter* 206, 216.

²¹⁹ *ibid* 217.

²²⁰ *ibid*.

relies on social solidarity within a given social context'.²²¹ Throughout various societies and cultures, persons with disabilities experience relationships with communities, families, etc that are able to influence their choices, potentially limiting their rights. Conversely, such societal relationships could assist persons with disabilities by providing the opportunity for persons with disabilities to achieve a 'good life'. For these reasons, the authors maintain that conceptual similarities and considerations of societal barriers within both the capability approach and the CRPD have the potential to aid (at least some aspects) of the implementation of the CRPD. This sentiment pertains to the following chapter, as the capability approach will be argued to aid the specific obligations in the CRPD surrounding communication.

4.3.2 *Guardianship*

Nussbaum specifically addresses guardianship within the capability approach, though her position varies at points from that of the CRPD. She holds that 'most states protect (at least some of) the capabilities of people with mental impairments through forms of guardianship'.²²² Persons with mental impairments are then restricted from exercising legal capacity, eg being unable to vote, even where there might not be any impairment that would make voting an unrealistic goal. Even where states offer partial/temporary guardianship, there is uncertainty about which options lead to unnecessary discrimination and disempowerment for persons with disabilities, and what options might maximise autonomy.²²³ It should be noted, Nussbaum's argument here is in a work from 2006, the same year that the CRPD was passed; however, she does review laws that protected legal capacity up to that point. Namely, laws in Sweden, Israel and Germany, which she asserts form an example of what the capability approach would offer and favour as a template in this area. Since 1994, a Swedish law offers mentorship that does not alter the civil rights of the mentee, and since 1999 an Israeli law states that persons with disabilities have the right to equal and active participation in all spheres of life, and supports human rights for persons with disabilities to live with autonomy and dignity.²²⁴ Moreover,

²²¹ Lang and others (n 218).

²²² Nussbaum, *Frontiers of Justice* (n 189) 195.

²²³ *ibid.*

²²⁴ *ibid* 196.

a German law from 1992 offers a procedural approach to guardianship with safeguards (eg personal interviews and appeal procedures), and recognises different principles that protect persons with disabilities, namely (1) the principle of necessity, which bars guardianship where the individual can manage with other support, (2) the principle of flexibility, which limits the scope of a guardian's authority, (3) the principle of self-determination, which permits power of attorney rather than a guardian and (4) the principle of rights preservation, which aims to prevent legal incapacitation in such a way where an individual under guardianship is not immediately deprived of rights, eg the right to vote.²²⁵ Nussbaum maintains that:

If we combine the underlying vision of human dignity and equality in the Israeli law with the general principles asserted in the German law and the flexible structure of legal and social categories embodied in the Swedish law, we have a good example of what the capabilities approach would favour as a template for reform in this area. More practical legal and political work clearly needs to be done to flesh all this out further.²²⁶

It is laws such as those cited by Nussbaum that seemingly reflect laws which the CRPD ultimately wants states to adopt under article 12. In contrast to article 12, Nussbaum does not stand against guardianship, but takes the position that guardianship is not a matter of dealing with 'incompetence' but 'a way of facilitating access to all the central capabilities'.²²⁷ As such, the norm should be that persons with disabilities should be able to choose the relevant functioning, and we should strive for a form of guardianship that is tailored to assist persons with disabilities where it is needed, 'in a way that invites the person to participate as much as possible in decision-making and choice'.²²⁸ In this way, Nussbaum defends guardianship, yet the manner of 'guardianship' she describes arguably resembles the position of many states parties to the CRPD that believe in both supported and substitute decision-making, and closely reflects the provisions of the ADMCA (though this position is contrary to the position of the CRPD Committee).²²⁹

²²⁵ Nussbaum, *Frontiers of Justice* (n 189) 198.

²²⁶ *ibid.*

²²⁷ *ibid.* 199.

²²⁸ *ibid.*

²²⁹ The ADMCA provides for ADM, CDM and decision-making representatives (which constitute a form of substitute decision-making), all three will be discussed in further detail in the following chapter.

Nussbaum addresses guardianship again in a later work, using the previously mentioned example of the right to vote for persons with disabilities. Here, three situations are laid out: (1) Case A where a person with a disability has the full cognitive and physical ability to vote but is unable to because of social arrangements, putting them in a position of ‘combined capability’, (2) Case B where a person cannot exercise the functions to vote even with a special arrangement but may be able to communicate their preferences to a guardian, who is able to exercise this functioning on their behalf and (3) Case C where the person’s ‘cognitive disability is so profound that she cannot communicate her wishes about whom to vote for to a guardian’.²³⁰ Regarding Case B, Nussbaum expresses the view that she is considering cases where the person does have views which may be communicated to a group of specific individuals, but may not be ‘comprehensible to the world at large’.²³¹ The supposition here again resembles the provisions requiring states parties to provide support under article 12(3); however, within the new paradigm of universal legal capacity, *all* persons with disabilities would be able to express themselves through varying modes of communication. She holds Case A to be ‘easy’ as equal respect here merely requires the funding to facilitate persons’ full inclusion in citizenship. Case B is also regarded as ‘conceptually’ easy, as the person can form a view and have another individual exercise the function of voting on their behalf.²³² Both Case A and Case B require some form of guardianship-like intervention, as a person with a disability would need assistance regarding voting or understanding the ballot, that role is ‘best played by a person of choice, whether a legally official guardian or (...) trained election officials who can assist those unable to bring a guardian’.²³³ Case C represents a more extreme example, one of a large group of citizens that are excluded and disqualified from the basic functions of citizenship. Here, equal respect requires the guardian to exercise the functions on behalf of the person and in their interest. Consequently, we see an application of the capability approach where persons with disabilities are unable to exercise legal capacity because they cannot achieve certain capabilities, which calls for state assistance and varying forms of guardianship.

²³⁰ MC Nussbaum, ‘The Capabilities of People with Cognitive Disabilities’ (2009) 40 *Metaphilosophy* 331, 334-37.

²³¹ *ibid* 334-35.

²³² *ibid.*

²³³ *ibid.*

The discussion of the capability approach above considers measures with which to evaluate the state's responsiveness to the specific needs of citizens with disabilities, particularly those pertaining to legal capacity. The full realisation of the right to legal capacity for persons with disabilities has the potential to be a powerful vehicle for the expansion of capabilities for all persons with disabilities. In opposition to Nussbaum's stance above, it may be argued that guardianship and restriction of legal capacity relegates persons with disabilities from being subjects, ie being deserving of full enjoyment of all human rights; to objects, in a manner that restricts various functionings and thus diminishes an individual's capability set. Simply put, if persons with disabilities are placed under guardianship and lose their legal capacity, their 'capability set' is heavily restricted to the areas of life the law cannot regulate.²³⁴ Furthermore, the capability set of an individual under guardianship may be reduced further by the decisions the guardian makes, and there is seldom room for capacity expansion as the person in question becomes dependent on guardians and other relevant caregivers. The denial of legal capacity thus significantly reduces the capability set of persons with disabilities, renders capability expansion difficult and creates a greater risk for other human rights violations through the removal of legal agency and standing. Equally important is the consideration that frameworks of supported decision-making seek to provide assistance to persons with disabilities in exercising their legal capacity in a way that does not restrict them, allowing persons with disabilities to maintain their freedom of choice and therefore have increased 'functionings' and 'capability sets'.²³⁵ Under guardianship regimes, where an individual might be deemed unable to make a decision, their ability to make a decision would be restricted as a whole, and many of their capabilities, particularly the capability to control one's environment, are denied. Conversely, within systems of supported decision-making under article 12 of the CRPD, even individuals with severe disabilities could still indicate their will and preferences regarding all life matters and maintain their capability to control their environment through having an individual understand and represent their preferences, rather than acting on their behalf.

²³⁴ A Arstein-Kerslake, 'Cognitive Disability and the Capabilities Approach: Exploring a Human Right to Individual Development' (Human Development and Capabilities Association Annual Conference, Jakarta, 2012) 10.

²³⁵ *ibid.*

4.3.3 *The capability approach and policy*

As we may recall from chapter 2, the medical model historically informed policy regarding disability, particularly legal capacity. Nowadays, the capability approach is progressing as a way of informing critical social policy.²³⁶ As a widely applicable yet individualised framework concerned with people on a personal level, it has practical relevance for the drafting and implementation of policy, and the implementation of disability policies based on the CRPD. This subsection below will draw on existing proposals for a revised capability approach, which will serve as a conceptual basis for the next chapter.

How might the capability approach affect public policy? Trani and others have argued for the construction of a community-based framework based on the capability approach that is able to provide assistance to policymakers in formulating and drafting policies, as well as expand the choices and freedoms of persons with disabilities.²³⁷ The framework laid out is based on several suppositions, the first of which is that for all persons, especially persons with disabilities, public policies affect how resources are converted into capabilities. The conversion of such resources depends upon both internal factors and the internal powers of an individual (eg physical condition, language capabilities) to convert resources into individual functionings.²³⁸ External factors, on the other hand, pertain to societal and environmental factors that either enable or block functionings, and are often dependent upon the capabilities of others.²³⁹ In order to shift policy to adhere to the new paradigm of universal legal capacity, we need to analyse the success and goals of policy in light of the expansion of the capability set of persons, and the functionings they may achieve as a result of said policy. For example, where the goal of a policy is to achieve universal legal capacity in alignment with article 12, this policy can be analysed through the success of the expansion of the capability set, eg further expansion of the ability to access assistance in communication, to achieve the resultant functioning of the expression of will and preferences.

²³⁶ M Carpenter, 'The Capabilities Approach and Critical Social Policy: Lessons from the Majority World?' (2009) 29 *Critical Social Policy* 351, 363.

²³⁷ J-F Trani and others, 'Disabilities through the Capability Approach Lens: Implications for Public Policies' (2011) 5 *Alter* 143, 144-45.

²³⁸ *ibid* 145; A Austin, 'Turning Capabilities into Functionings: Practical Reason as an Activation Factor' (2018) 19 *Journal of Human Development and Capabilities* 24, 29.

²³⁹ *ibid*.

Disability is understood here as a deprivation of capabilities ‘through the means of various personal characteristics, including the impairment itself, available resources, and environmental circumstances’.²⁴⁰ This view of disability creates a framework for forming social arrangements that create more opportunities for persons with disabilities; with a new policy framework aimed at allowing the full participation of persons with disabilities in society.²⁴¹ Furthermore, it demands a radical change in the way data regarding persons with disabilities is collected and analysed, and takes a community rather than an individualised approach to better understand capabilities. The community approach taken here is relevant for frameworks of supported decision-making, as it argues that, for persons with disabilities (particularly those with ‘severe’ intellectual disability), the ‘caregivers’ assistance is often crucial. Consequently, the capability set of these persons is ‘shaped by their conversion factors, as well as by their parents’ or caregivers’ capabilities’.²⁴² The framework proposed by Trani and others importantly frames analysis around a ‘community capability set,’ a comprehensive set of valued functionings determined by a given community that should be open to all members of society, that is considered for analysis and policy (constituting of an aggregate of individual, collective²⁴³ and social²⁴⁴ capability sets). Capability here begins with a consideration of the aforementioned capability sets, and considers a plurality of conversion factors which may be social (eg social norms), personal (eg disability, skills) or environmental (eg communication structure), all of which may be directly affected or implemented through policy.²⁴⁵ In other words, the factors which allow a community to convert a set of means into functionings will be considered from social, personal, environment and policy-based perspectives. For example, factors such as societal

²⁴⁰ Mitra (n 200) 237; Trani and others, ‘Disabilities through the Capability Approach Lens’ (n 237) 149; J-F Trani and others, ‘Disability as Deprivation of Capabilities: Estimation Using a Large-Scale Survey in Morocco and Tunisia and an Instrumental Variable Approach’ (2018) 211 *Social Science & Medicine* 48, 49.

²⁴¹ A Buchanan, ‘Choosing Who Will Be Disabled: Genetic Intervention and the Morality of Inclusion’ (1996) 13 *Social Philosophy and Policy* 18, 38-45; Trani and others, ‘Disabilities through the Capability Approach Lens’ (n 237) 149.

²⁴² Trani and others, ‘Disabilities through the Capability Approach Lens’ (n 237) 145.

²⁴³ Comprised of the capabilities of given groups within the community (eg non-governmental organisations, trade unions). A pertinent example of this within the context of this thesis would be the IDC (*ibid* 30).

²⁴⁴ Supplementary capabilities resulting from social interaction; depend on sharing capabilities with others who acquire similar capabilities (*ibid*).

²⁴⁵ Trani and others, ‘Disabilities through the Capability Approach Lens’ (n 237) 151.

barriers, an individual's respective impairment and communication skills, the structure of that communication and the policy which aims to implement article 12 would be considered for the 'functioning' of persons with intellectual disabilities being able to express their will and preferences. Revisiting article 12 of the CRPD, the consideration of such a 'community capability set' and the range of conversion factors constitutes a powerful capabilities framework that seemingly incorporates the fundamental ideals of the social model through such community-based considerations, in contrast to the commonly individualised capability theories. The authors contend that the 'achieved functionings of individuals have an influence on the capability set of the community as a whole [and] the achieved functionings are the outcome of an ongoing process that either expands, or reduces the capability set of the community'.²⁴⁶

Essentially, where policies are being implemented to 'expand capabilities' of persons with disabilities, in order to rectify their deprivation of functionings, policy-makers or other relevant persons (such as ADM and CDM) should go beyond the expansion of capabilities at a political level. Rather, policies should additionally consider the individual, social and environmental factors that are unique to different communities. To give an example of this, where policies are being implemented to eg expand the ability for persons with disabilities to express their will and preferences in systems of supported decision-making, the policy should not solely be concerned with prior conceptions of legal capacity and how prior policies and political systems deprived persons with disabilities of their legal capacity. Rather, it would consider these political factors, in addition to individual factors, eg specific impairments of various persons/communities, social factors, eg the social discrimination persons with disabilities experience, and the environmental factors, such as the ability for persons with disabilities to access education. Finally, the authors outline several considerations which are relevant to the content of the following chapter. Importantly, the actual operational application of the capability approach with regard to policy requires further specifications and resources in order to be genuinely effective. There needs to be forms or standards to measure valued capabilities, agency and the choices of individuals

²⁴⁶ Trani and others, 'Disabilities through the Capability Approach Lens' (n 237) 152.

and communities; as well as information allowing the identification of resources, constraints, availability of commodities and achieved functionings.²⁴⁷

4.4 CONCLUSIONS ON THE CAPABILITY APPROACH

Let us return to the second research sub-question: what is the purpose and usefulness of using the capability approach as a framework to aid the implementation of the CRPD? Each section was intended to provide theoretical considerations with which to understand the purpose of the capability approach in discussing and implementing article 12, and as a framework for disability as a whole. Additionally, its purpose was to exemplify that the capability approach has already been used as a framework to understand guardianship specifically. The final revised capability approach, presented above, served to enable understanding of how the capability approach can inform disability policy. It will be referred to in the next chapter regarding the ADMCA, specifically concerning how to use the capability approach to understand and determine various methods of communication.

²⁴⁷ Trani and others, 'Disabilities through the Capability Approach Lens' (n 237) 154.

5.

COMMUNICATION AND THE CAPABILITY APPROACH:
IRELAND'S ASSISTED DECISION-MAKING (CAPACITY) ACT

5.1 INTRODUCTION TO THE ASSISTED DECISION-MAKING (CAPACITY) ACT

Systems of supported decision-making have begun to burgeon across legal systems, with Ireland being a prominent example. This chapter revisits the interpretation of article 12 outlined in chapter 3, particularly article 12(3), and undertakes a comparative analysis with Ireland's new ADMCA 2022.²⁴⁸ The analysis here will serve to illustrate the extent to which the ADMCA is in line with article 12, including the Committee's interpretation of that article. Specifically, the obligations pertaining to will and preferences, and communication, within the CRPD and the ADMCA will be compared, and followed by a discussion of a framework that would help relevant SP under the system in implementing the Act's obligations regarding will and preferences. Overall, this chapter will serve to answer the third sub-research question: how might the capability approach be used by Ireland in its implementation of the ADMCA?

²⁴⁸ The ADMCA 2022 consists of the original Assisted Decision-Making (Capacity) Act 2015 (ADMCA 2015); as well as the amendments contained in the Assisted Decision-Making (Capacity) (Amendment) Bill 2022 Dáil Bill (2022) 59 (ADMCA 2022).

5.2 ARTICLE 12 AND THE ASSISTED DECISION-MAKING (CAPACITY) ACT: IS THE ASSISTED DECISION-MAKING (CAPACITY) ACT COMPLIANT WITH THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES?

The ADMCA is an act from 2015 that was introduced to replace the centuries-old Lunacy Regulations (Ireland) Act 1871,²⁴⁹ and end status-based determinations of incapacity that placed persons with disabilities under wardship. As mentioned in chapter 1, the ADMCA 2015 has since been amended. Firstly, the Assisted Decision-Making (Capacity) (Amendment) Bill 2021 was proposed, and the amended 2021 version was meant to be commenced in June 2022. Since then, the 2021 Bill has become the Assisted Decision-Making (Capacity) (Amendment) Bill 2022, which was signed into law as the Assisted Decision-Making (Capacity) (Amendment) Act 2022.²⁵⁰ The analysis undertaken in this chapter is concerned with the ADMCA 2022, which refers to both the original ADMCA 2015 (where it was not amended) and the ADMCA 2022 amendments.

As demonstrated in chapter 3, article 12(1) confers ‘legal personality’ which serves as a pre-requisite for article 12(2), containing the universal right to legal capacity. Legal capacity under article 12(2) maintains that all persons with disabilities have a universal right to exercise both legal agency and standing, with the CRPD Committee stating that no determinations of mental capacity (or incapacity) may be used to restrict legal capacity. As the ADMCA repeals the Lunacy Act and terminates the wardship system in Ireland, it is undoubtedly a progressive piece of legislation that signifies the transition toward the new paradigm envisaged under article 12.²⁵¹ Despite the termination of wardship, both assessments of mental capacity and systems of substitute decision-making are maintained in the ADMCA, although they are heavily reformed. Section 3 of the ADMCA, titled ‘person’s capacity to be construed functionally’, states:

²⁴⁹ Lunacy Regulation (Ireland) Act 1871 (1871 UKPGA c 22).

²⁵⁰ Assisted Decision-Making (Capacity) (Amendment) Bill 2022 Dáil Bill (2022) 59 (ADMCA 2022); Assisted Decision-Making (Capacity) (Amendment) Act 2022. Please note at the time this thesis was written the ADMCA 2022 was still undergoing debate, however this sub-section has been revised upon the passing of the ADMCA 2022 on 17 December 2022.

²⁵¹ For the termination of wardship, see ADMCA 2015 s 54 with 2022 amendments.

For the purposes of this Act, a person's capacity shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time.²⁵²

As capacity is construed functionally, a presumption of incapacity in one instance will not prevent an individual from being regarded as having the capacity to make decisions on the same matter, or other matters, at a different time.²⁵³ Recalling chapter 3, the CRPD Committee maintains that even functional assessments are not compliant with article 12. However, even where capacity is restricted the principle of will and preferences, as articulated in article 12(4) of the CRPD, is still of central importance and takes precedence over 'best interests'. The priority of will and preferences is reflected within the functional assessments of the ADMCA, as it deems a person lacks legal capacity if he/she is unable to:

- (a) To understand the information relevant to the decision
- (b) To retain information long enough to make a voluntary choice
- (c) Use or weigh that information as part of the process of making the decision, or
- (d) To communicate his or her decision (whether by talking, writing, using sign language, assistive technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party.²⁵⁴

Thus, capacity is not restricted on the basis of disability. Rather, it is restricted on a case-by-case basis, depending on the individual's understanding of a decision and all of its effects, as well as the individual's ability to communicate their decision or preference through a variety of methods. Furthermore, the reference in the foregoing provision regarding the use of alternative forms of communication, which is in line with article 12(3) and the CRPD as a whole, is reiterated in section 3(3) which provides that:

²⁵² ADMCA 2015 s 3(1).

²⁵³ *ibid* s 3(5)-(6).

²⁵⁴ *ibid* s 3(2)(a)-(d).

A person is not to be regarded as unable to understand the information relevant to a decision if he or she is able to understand an explanation of it given to him or her in a way that is appropriate to his or her circumstances (whether using clear language, visual aids or any other means).²⁵⁵

Furthermore, though substitute decision-making is not outrightly prohibited, the principles under the Act that apply before and during an ‘intervention in respect of relevant persons’ clarify that there shall be no intervention unless *all practicable steps* have been taken to aid the relevant person in making a decision, and it must be *necessary* to do so having regard to the individual circumstances of the relevant person.²⁵⁶ Where these conditions are satisfied, the ‘intervener’ in question must permit and encourage the participation of the relevant person, and ‘give effect, in so far as is practicable, to the past and present will and preferences of the relevant person, in so far as that will and those preferences are reasonably ascertainable’.²⁵⁷ Recalling the Committee’s interpretation of article 12(1)-(2) of the CRPD, the ADMCA still fails to implement universal legal capacity, particularly as it retains functional assessments of capacity as well as substitute decision-making (which will be discussed further in this chapter). Nonetheless, it is progressive in its rejection of discriminatory status-based thresholds with regard to capacity (despite its application of functional assessments). Even where persons are placed in supported decision-making, there is still a mandate to take ‘all practicable steps’ before any determination of incapacity is made, to place ‘will and preferences’ at the centre of decision-making, and to take account of varying communicative abilities when determining a person’s capacity, and will and preferences.²⁵⁸

5.2.1 Supported decision-making: Decision-making assistants and co-decision-makers

Revisiting the interpretation of article 12(3) in GC1, to provide ‘support’ in exercising legal capacity, it may be recalled that ‘support’ can constitute regimes of supported decision-making. Furthermore, article

²⁵⁵ ADMCA 2015 s 3(3).

²⁵⁶ *ibid* s 8(3)-(5).

²⁵⁷ *ibid* s 8(7)(b).

²⁵⁸ M Donnelly, R Harding and E Taşcıoğlu (eds), *Supporting Legal Capacity in a Socio-Legal Context* (Oñati International Series in Law and Society 2022) 21.

12(4) requires safeguards in the exercise of legal capacity. The ADMCA certainly satisfies the obligation to create regimes of supported decision-making, as it sets out ‘decision making assistants’ and ‘co-decision makers’.²⁵⁹ Despite this, the ADMCA still provides for substitute decision-making under the title ‘decision-making representatives’. In part 3 of the ADMCA, article 10 states that:

a person who has attained the age of 18 years and who considers that his or her capacity is in question or may shortly be in question may appoint another person who has also attained that age to assist the first-mentioned person in making one or more than one decision on the first-mentioned person’s personal welfare or property and affairs, or both.²⁶⁰

The language of article 10 is significant, as it recognises the legal capacity of the ‘appointer’ and allows them to recognise their own limitations with regard to their capacity. It also allows them to appoint an individual they select to assist in manners they choose or various individuals to work jointly or severally at the discretion of the appointer.²⁶¹ The appointer may revoke or modify the decision-making agreement between the two at any time.²⁶² The DMA may be anyone over the age of 18 who the appointer feels they can trust, insofar as they do not fall under the categories of persons ineligible to be assistants.²⁶³ One pertinent safeguard is the fact that the decision-making agreement between the parties is subject to regulation by the minister who may provide for the inclusion of specification of the personal welfare, property and affairs of the appointer. Moreover, the minister may require the inclusion of a statement by the appointer that he/she ‘*read and understands the information*’ as to the effect of making the appointment or that such information has been explained to the appointer, by a person other than the proposed decision-making assistant’.²⁶⁴

Recalling the references to varying forms of communication in earlier parts of the ADMCA, the requirement that the appointer understands the information is not limited to mere verbal expression but accounts

²⁵⁹ Please note ‘enduring powers of attorney’ and ‘advance healthcare directives’ are also provided for under the Act, but for our purposes will not be discussed.

²⁶⁰ ADMCA 2015 s 10(1); see also ADMCA 2022 s 8.

²⁶¹ ADMCA 2015 s 5.

²⁶² ADMCA 2015 s 10(4)(d)(i)-(ii)

²⁶³ See ADMCA 2015 s 11.

²⁶⁴ ADMCA 2015 s 10(4)(d)(i)-(ii); ADMCA 2022 amendment 8 (emphasis added).

for variations in communicative abilities, a notion emphasised in GC1. The functions of a DMA are moreover limited to those specified in the decision-making agreement, and allow the assistant to ‘assist’ the appointer in obtaining and explaining relevant information pertaining to a relevant decision.²⁶⁵ Furthermore, the assistant must ‘ascertain the will and preferences of the appointer on a matter the subject or to be the subject of a relevant decision and assist the appointer to communicate them’.²⁶⁶ Thus, the specific formation of a DMA under the ADMCA is a framework for supported decision-making that adheres to the interpretation and standards of the CRPD within GC1, as the relevant person or appointer is the individual who ultimately retains control over their decisions and capacity. Considering safeguards under article 12(4), the ADMCA does specifically create safeguards for the ‘appointer’ against the DMA that are compliant with article 12(4). Specifically, a DMA may be disqualified under section 13 of the 2015 Act, and have complaints lodged against them under section 15, in addition to the ability of the appointer to remove them from their position at any given moment.

The second fundamental system of supported decision-making under the ADMCA is that of a CDM under part 4 of the Act. Whereas the details of the appointment of a DMA is unspecified, beyond being an individual over 18 whom the appointer trusts, a CDM may be ‘a relative or friend of the appointer who has had such personal contact with the appointer over such period of time that a relationship of trust exists between them’,²⁶⁷ and who is able to perform their functions under the decision-making agreement. Similar to a DMA, there must be a formal co-decision-making agreement between the parties, but the co-decision-making agreement will not take effect until it is registered in accordance with the Act and meets all the requirements of the registration.²⁶⁸ Co-decision-making is thus subject to more scrutiny compared to DMA (which require no registration); however, this is because the decision is made *jointly* between the appointer and the CDM, whereas DMA simply *aid* the appointer in making a decision. Though the framework of co-decision-making is compliant with article

²⁶⁵ ADMCA 2015 s 14(1)(a)-(b), ADMCA 2022 amendment 11.

²⁶⁶ ADMCA 2015 s 14(1)(c).

²⁶⁷ *ibid* s 17(2).

²⁶⁸ For applications and requirements of registration see ADMCA 2015 ss 21-22.

12 in some aspects, the notion that a decision made by the appointer is not merely facilitated, but made together with the CDM, suggests that the ADM framework is more aligned with article 12 than the CDM framework. This being said, the ADMCA accordingly mandates statements and applications which heavily align with the goals of article 12 of the CRPD. Firstly, the application for registration of the co-decision-making agreement must be accompanied by statements that the appointer understands the implications of the agreement and that they may revoke the agreement, and has either read and understood the information within the agreement, *or* has had the information explained to them in a manner they can understand.²⁶⁹ The CDM must also make a statement that they understand their specified functions and agree to act within the guiding principles of the ADMCA, and further that they understand the revocation, nullity or variation of the agreement between the parties.²⁷⁰ Where co-decision-making agreements deviate from the CRPD is through the mandate of a statement by a medical practitioner or healthcare professional containing their opinion regarding whether the appointer has the ‘capacity to make a decision and enter the co-decision-making agreement’ and whether they have the ‘capacity to make the relevant decisions specified in the co-decision-making agreement with the assistance of the co-decision-maker’.²⁷¹ Moreover, upon registration of the agreement, the director of the decision support service²⁷² may review and require further information concerning whether the CDM is suitable, or whether the agreement is in accordance with the will and preferences of the appointer, and ultimately reject the agreement if they find it is not in accordance with the will and preferences of the appointer.²⁷³

For the purpose of interpreting the compliance of the ADMCA with article 12, particularly the interpretation of article 12 provided in chapter 3, it is essential to look at the functions of a CDM. Moreover, we must consider whether they align with the obligations to prioritise

²⁶⁹ ADMCA 2015 s 22(4).

²⁷⁰ *ibid.*

²⁷¹ *ibid* s 21(4)(f).

²⁷² The appointment and functions of the Director may be found in sections 94-103 of the ADMCA 2015.

²⁷³ ADMCA 2015 s 22(1)-24(2).

the will and preferences of persons with disabilities, and the obligation to use alternative forms of communication. The most relevant CDM function related to this is section 19(b),²⁷⁴ which states the CDM shall ‘ascertain the will and preferences of the appointer on a matter the subject of, or to be the subject of, a relevant decision and assist the appointer with communicating the appointer’s will and preferences’²⁷⁵ This closely resembles the function of the ADM under section 14(1)(c). Insofar as the obligations under article 12(3), there is an explicit obligation to assist the appointer in communicating, which under the CRPD would constitute a wide range of different forms of communication. The functions under section 19 do not clarify this, but revisiting section 3 which states an individual may be deprived of their capacity if they cannot communicate their decision through talking, writing, assistive technology or other means, we may infer that that section 19(b) would include the aforementioned forms of communication.²⁷⁶ Considering ‘safeguards’ in accordance with article 12(4), under section 27 of the ADMCA the CDM is additionally required to prepare and submit reports to the Director regarding the *performance* of their functions. Thus, the CDM is subject to regular scrutiny and may have complaints lodged against them under section 30, if they do not act in accordance with the will and preferences of the appointer, for instance.²⁷⁷ Similarly to decision-making agreements, the co-decision-making agreement may be subject to variation or revoked,²⁷⁸ however, it must be noted that both the CDM and the appointer have the power to revoke or modify the agreement.

Overall, we may conclude the 2015 Act, coupled with the Amended 2022 Amendment Bill, reflects a significant advancement in expanding and recognising the legal capacity of all persons with disabilities and ensuring that will and preferences is at the centre of capacity-related decisions.²⁷⁹ The extent to which the will and preferences of the appointer is the basis of agreements regarding supported decision-

²⁷⁴ ADMCA 2015 s 19(1)(b).

²⁷⁵ *ibid* (emphasis added).

²⁷⁶ For a full list of the functions of a CDM see ADMCA 2015 s 19.

²⁷⁷ ADMCA 2015 s 30(1)(c).

²⁷⁸ *ibid* ss 28-29.

²⁷⁹ BD Kelly, ‘The Assisted Decision-Making (Capacity) Act 2015: What It Is and Why It Matters’ (2017) 186 *Irish Journal of Medical Science* 351.

making exemplifies the ADMCA's commitment to the obligations outlined in the CRPD, particularly as under the previous wardship system there was no obligation to adhere to will and preferences. Moreover, the ability of appointers to define, alter and terminate their own supported capacity arrangements showcases respect towards the individual's legal capacity even where they need support arrangements. Where the Act fails to fulfil the obligations within the CRPD, particularly as interpreted under GC1, is in its retainment of functional assessments of mental capacity. Flynn, who worked with a civil society coalition which influenced the development of the ADMCA, articulated that the retention of functional assessments was the biggest missed opportunity of the new Act, and risked undoing all the progress of transitioning away from the 'best interests' principle.²⁸⁰ In her view, this retention might result in more people being deprived of their capacity than under the 'archaic' wardship system. In contrast to the framework of decision-making representatives under the ADMCA, she rather purports adults should always choose their preferred support arrangement, with 'last resort appointment of a decision-making representative [being] reserved for situations in which the person's will and preferences remained unknown, after significant efforts to support the person and to discover her will and preferences have been made'.²⁸¹ This is undoubtedly the ideal model under the CRPD, but the retention of supported decision-making under the title 'decision-making representatives', which arise as a result of a court's declaration of incapacity under the ADMCA, does vary from older models of substitute decision-making.²⁸² Decision-making representatives still contradict the CRPD; however, it should be noted this is a *reformed* framework of supported decision-making which still considers the individual's will and preferences, and firstly attempts to provide supported decision-making. To expand upon this, a declaration may be made whereby 'the relevant person the subject of the application lacks capacity, *unless* the assistance of a suitable person as a CDM is made available to him or her',²⁸³ as well as where 'the subject of the application lacks capacity, *even if* the assistance of a suitable person

²⁸⁰ M Donnelly and C Gleeson (eds), *The Assisted Decision-Making (Capacity) Act 2015: Personal and Professional Reflections* (Health Service Executive 2021) 111.

²⁸¹ *ibid.*

²⁸² ADMCA 2015 ss 37-38.

²⁸³ *ibid* s 37(1)(a) (emphasis added).

as a co-decision-maker were made available to him or her'.²⁸⁴ Again, this is not in compliance with the CRPD, however, there is an attempt to blend the old and the new conceptions of guardianship. Moreover, the decision-making representative shall, 'insofar as this is possible, ascertain the will and preferences of the relevant person on a matter the subject of, or to be the subject of, a relevant decision and assist the relevant person with communicating such will and preferences'.²⁸⁵

5.2.2 Conclusion on analysis of the Assisted Decision-Making (Capacity) Act and the Convention on the Rights of Persons with Disabilities

Although these provisions above align with the view held by many states parties that substitute and supported decision-making can exist within a complementary system that is still centred around will and preferences,²⁸⁶ it is far from a perfect alignment with the interpretation under GC1 by the CRPD Committee. This being said, the notion of the will and preferences of persons with disabilities in exercising legal capacity is re-stated and re-emphasised time and time again within the ADMCA, demanding a reconsideration of 'appropriate' forms of communication both within the CRPD and relevant domestic legislation such as the ADMCA. Practical difficulties arise when working with persons with disabilities who might have a range of impairments and communication difficulties. As disability is an ever-evolving concept, it is difficult to place persons with certain disabilities or impairments into various categories of communication and communicative abilities. Despite this, there are a number of methods of communication being developed and utilised to both aid and understand persons with disabilities who have no standardised language or system available to them which will be discussed in the section below.²⁸⁷

²⁸⁴ ADMCA 2015 s 37(1)(b) (emphasis added).

²⁸⁵ *ibid* s 41(1).

²⁸⁶ Please refer back to chapter 2 section 5 for clarification.

²⁸⁷ It should be noted that the communication methods referred to are not exclusive to persons with intellectual disabilities and may be employed across varying disabilities, however many are widely used by persons with intellectual disabilities and caretakers.

5.3 PEERING THROUGH THE LENS OF COMMUNICATION: HOW SHOULD WILL AND PREFERENCES BE DETERMINED?

DMA and CDM under the ADMCA are prime examples of persons tasked under the Act to meet standards to utilise alternative forms of communication. Despite this, there is little guidance in the Act, beyond demanding the primacy of will and preferences, and maintaining that communication includes clear language, visual aids and ‘any other means’. This section will answer the third sub-research question of this thesis, namely, how might the capability approach be used by Ireland in its implementation of the ADMCA? Below it is argued that the capability approach may be utilised by DMA and CDM under the ADMCA in determining how to communicate with appointers or relevant persons with disabilities when said persons rely on aided modes of communication. As such, the framework laid out below is specifically concerned with persons with intellectual disabilities who are non-speaking and use aided AAC to express their will and preferences.

5.3.1 Communication support needs and the importance of augmentative and alternative communication

Before delving into the use of the capability approach in frameworks of supported decision-making under the ADMCA, it is important to address the factors behind communication for persons with intellectual disabilities, all of which contribute to the capabilities, functionings, conversion factors and well-being of persons with disabilities. Persons with intellectual disabilities commonly have ‘communication support needs’ (CSN) and might need assistance in developing their communication skills and expressing themselves. A study from a sample of 601 adults with intellectual disabilities in Ireland found that 57.9% experienced difficulties with communication, with 23.5% of cases reflecting communication difficulties of a severe nature.²⁸⁸ While the individual profile of each person’s communication skills is unique, certain impairments may be associated with particular patterns of difficulties, eg persons with Down Syndrome typically have

²⁸⁸ M Smith and others, ‘Communication Difficulties in Adults with Intellectual Disability: Results from a National Cross-Sectional Study’ (2020) 97 *Research in Developmental Disabilities* 103557.

limited speech intelligibility.²⁸⁹ Recent developments have classified communicative abilities into AAC, a useful framework for understanding varying communicative abilities through different ‘modalities’, which are broken down in the chart below with examples.²⁹⁰

Unaided Modalities	Aided Modalities
<ul style="list-style-type: none"> • sign language • manual signs from language systems/ vocabularies • natural gestures and pre-linguistic behaviour, ie facial expressions, vocalisation • body movements 	<ul style="list-style-type: none"> • use of external technologies, eg computers, tablets • non-electronic communication board with eg symbols, pictures, drawings, printed words

The intellectual disability itself and the ‘severity’ of the intellectual disability are key factors in the choice of modalities. Persons with ‘severe-profound intellectual disabilities’²⁹¹ tend to function at a ‘pre or proto-symbolic level, relying primarily on “non-speech modalities” (which may be aided but are commonly unaided) – such as facial expressions, movements, vocalisations, body posture or muscle tone’.²⁹² This does not mean that said persons have zero speech or language abilities. However, their abilities might be limited or not be their preferred mode of expression. Where an individual primarily relies upon non-speech modalities that are unaided, these forms of communication are often highly individualistic and rely upon partners who are familiar with the individual, for interpretation purposes. The environment and resources available to an individual, as well as the ‘partners’ in communication define what modes of communication are developed, responded to,

²⁸⁹ Smith and others (n 288) 2.

²⁹⁰ J Sigafoos and others, ‘Augmentative and Alternative Communication (AAC) in Intellectual and Developmental Disabilities’ in JK Luiselli and AJ Fischer (eds), *Computer-Assisted and Web-Based Innovations in Psychology, Special Education, and Health* (Academic Press 2016) 257 <www.sciencedirect.com/science/article/pii/B9780128020753000103> accessed 1 July 2022.

²⁹¹ Please note the classification of disabilities as ‘severe’ is rooted in medicalised assessment, which measures the extent to which ‘deficits’ in functionings impair the individual’s cognitive skills and ability to go about daily life. Severe disabilities here are considered from a social perspective, ie disabilities are ‘severe’ as a result of environmental and societal factors which are particularly restrictive due to the intensity of an individual’s impairments.

²⁹² Sigafoos and others (n 290); C Griffiths and M Smith, ‘Attuning: A Communication Process between People with Severe and Profound Intellectual Disability and Their Interaction Partners’ (2016) 29 *Journal of Applied Research in Intellectual Disabilities* 124, 125.

interpreted and perceived as successful communicative interactions.²⁹³ For example, an adult with ‘severe’ intellectual disabilities might typically communicate frustration by moving their head from side to side in culmination with clapping their hands. Families and caretakers who are familiarised with this mode of communication would recognise it to represent frustration, understand they are expressing discontent, and remedy the situation where appropriate. Another example is where an individual is limited in their speech ability but is able to effectively communicate through the use of singular words, such as being able to respond to ‘yes’ or ‘no’ questions or using simple words, eg the word ‘bed’ to express the desire to go to sleep. The use of singular or limited language is likely easier for an unfamiliar party to understand, and although such language skills may be innate, they are often aided through education or speech therapy.

5.3.2 Communication support needs and the capability approach

Due to the varying CSN of persons with intellectual disabilities, and the individualistic nature of communication in many cases, the assessment of communication is dependent upon information about the individual as a whole, including aided/unaided communication abilities, motor abilities, sensory abilities, living environment, educational resources, etc, which we may understand to be their ‘capabilities’. The objective of such assessment is to understand the potential to achieve valuable functionings, which – for the purpose of this thesis – may be the effective expression of an individual’s will and preferences, within the broader exercise of legal capacity. Beyond functionings, however, assessment of AAC in the context of legal capacity is fundamentally concerned with the quality of life of persons with disabilities, as a direct relationship may be found between communication and quality of life, as communication difficulties may affect the health, psychological and social well-being of an individual.²⁹⁴ Moreover, studies conducted regarding children with disabilities and CSN found the degree of communication support offered by families

²⁹³ Smith and others (n 288).

²⁹⁴ JC García and others, ‘Communication Support Needs in Adults with Intellectual Disabilities and Its Relation to Quality of Life’ (2020) 17 International Journal of Environmental Research and Public Health 7370, 7371-2.

directly impacted the quality of life of the individual and the family.²⁹⁵ Importantly, assessments of communication must be multi-faceted and address receptive and expressive communication, and go beyond formal assessments – to include informal assessments that consider the individual and the context in which they live and communicate.²⁹⁶ As such, communication assessment should be dynamic and prompt feedback in order to identify barriers in institutional approaches and measure the *quality* of communicative interactions between the assessor and the individual.²⁹⁷ All of these factors suggest the capability approach to be a useful framework of assessment in determining the CSN of persons with disabilities, as understanding CSN requires consideration of all the factors concerning a person’s being, abilities and environment. This brings us to the final sub-research question, how can the capability approach be used by Ireland in its implementation of the ADMCA?

5.3.3 How should the Assisted Decision-Making (Capacity) Act be implemented?

Throughout the development, passing and amending of the ADMCA, frameworks for the implementation of the Act have been laid out by professionals and academics. Teague has outlined an Active Implementation Framework, laying out four key components to implementing the ADMCA: (1) integrated team approaches to implementation, (2) support (ie persons with disabilities should receive support from their families and staff members to understand assisted decision-making), (3) communication, asking stakeholders to learn barriers to implementing assisted decision-making and identifying strategies to overcome the barriers and (4) time (ie effective implementation will take a long time).²⁹⁸ Howard considers different factors in implementing the communication requirements of the

²⁹⁵ M Schertz and others, ‘Family Quality of Life among Families with a Child Who Has a Severe Neurodevelopmental Disability: Impact of Family and Child Socio-Demographic Factors’ (2016) 53–54 *Research in Developmental Disabilities* 95.

²⁹⁶ NC Brady and others, ‘Communication Services and Supports for Individuals With Severe Disabilities: Guidance for Assessment and Intervention’ (2016) 121 *American Journal on Intellectual and Developmental Disabilities* 121, 7.

²⁹⁷ *ibid.*

²⁹⁸ NC Brady and others, ‘Communication Services and Supports for Individuals With Severe Disabilities: Guidance for Assessment and Intervention’ (2016) 121 *American Journal on Intellectual and Developmental Disabilities* 121, 7. 123-26.

ADMCA that prevent effective communication, the first being the ‘communication environment’. These include noise levels, the availability of objects/photos/technology that the individual is known to use, etc.²⁹⁹ Communication partners constitute the second factor, meaning that staff should be required to use and apply varying forms of communication, taking time to uncover respective CSNs and creating opportunities to support each person in expressing their will and preferences.³⁰⁰ Both of these frameworks may be useful for the implementation of the Act at a policy-wide level and to provide broad instruction for DMA and CDM regarding factors they should consider in obtaining the will and preferences of persons with disabilities generally. However, *genuine* communication with persons who have CSN and use AAC demands a more detailed application of all the considerations above on a more personal level. This is where the capability approach presents itself as an applicable and useful framework for understanding CSN, because it facilitates personalised assessments of the capabilities, functionalities and well-being of persons. For these reasons, the capability approach will be proposed below as a framework for individual use by DMA and CDM in understanding communication under the ADMCA. Specifically, it will be proposed as a guide to fulfil the obligations under the Act and accompanying implementation frameworks.³⁰¹ To clarify this, let us say upon commencement of the Act, the four-part framework outlined above by Teague is accepted as an implementation guide for supported decision-making arrangements. Under the third ‘communication component’, namely the task to identify and overcome communication barriers, a DMA or CDM might feel lost as to how to identify and overcome these barriers, and seek a guide to understand these barriers in the first place. This is the proposed usefulness of the capability approach within the ADMCA.

²⁹⁹ Brady and others (n 298) 129-31.

³⁰⁰ *ibid.*

³⁰¹ It is recognised that persons beyond CDM and DMA have obligations regarding communication under the ADMCA, however the use of the capabilities approach here is specifically concerned with the responsibilities of CDM and DMA.

5.4 SUPPORT PERSONS, THE CAPABILITY APPROACH AND COMMUNICATION

5.4.1 A capability framework for the Assisted Decision-Making (Capacity) Act

As the capability approach is a broad normative framework that takes many forms, for a consideration of a capability approach that is pragmatic enough to assist DMA and CDM it must be significantly refined and adapted. Firstly, to argue for the use of eg Nussbaum's capability approach here would mandate quite far-reaching expectations of conducting assessments and culminating rather extensive data on every person, their CSN, their capabilities/functionings and other relevant social/environmental factors. While all of these factors should ultimately be considered by DMA and CDM (SP), there must be a framework to understand capabilities at a broader level which may be narrowed down, for the purpose of efficiency and feasibility. Rather, Trani's construction of a community-based framework will be drawn on, as it is premised upon analysing the success of a policy through consideration of whether the policy has allowed for the expansion of the capability set or functionings of the persons who are the subject of a policy.³⁰² The framework is not adopted in whole, but key factors from this framework will be drawn on below to shape a modified capability approach to communication under the ADMCA.

The first factor is that for persons with disabilities who rely upon caregivers, the capabilities of caregivers influence the conversion sets of the person with disabilities, and such 'external capabilities' play a role in ensuring basic capabilities for persons with disabilities.³⁰³ Substituting the term caregiver with SP (though they may often also be caregivers), is important because this framework aims to account for varying capabilities of SP in understanding AAC, and provide assistance in expanding relevant capabilities for the benefit of persons with disabilities. Second is the idea of 'community capability', as the aggregation of 'various individual capability sets, the collective capability set of the community and the social capability set', as well as the related plurality of conversion factors, may be affected/implemented

³⁰² See chapter 4 section 4.3.3 for further detail.

³⁰³ J-F Trani and others, 'Disabilities through the Capability Approach Lens: Implications for Public Policies' (2011) 5 Alter 143, 145.

through policy.³⁰⁴ Here, the set of valued functionings determined by a community that should be available to all is the ability to exercise legal capacity generally and the ability to communicate one's will and preferences. The consideration of community capabilities here aims to inspire policy-makers to consider environmental/social/individual factors when drafting and implementing policy, but we will use the idea of 'community capability' to inform SP in determining effective methods of communication. The idea is that what individuals can do, in our case individuals with disabilities, affects the capability set of an entire community, and the functionings that are achieved either expand or reduce the capability set of a community. Whether this community capability-set expands or not depends on cooperation within the community or with other communities.

For the purposes of this thesis, the community specifically refers to persons with intellectual disabilities and CSN. The capabilities of said individuals refer primarily communication using AAC, specifically varying non-speech modalities. The functioning to be achieved is the expression of the will and preferences of the individuals with intellectual disabilities, which would expand the capability set of the community through allowing them to exercise legal agency in a greater capacity. This expansion is based on cooperation and understanding with other communities, being the SP within systems of supported decision-making under the ADMCA. Here, the aim is to expand the capability set of persons with intellectual disabilities and CSN, to allow them to express their will and preferences under the ADMCA. This is dependent upon the abilities of SP to understand their mode of non-speech modality and interpret their wishes accordingly. Thus, the capability set of persons with disabilities with intellectual disabilities and CSN to express their will and preferences is dependent upon the ability of the SP to understand them, and the ability of the SP to understand the relevant individual relies upon the consideration of the capabilities and functionings of persons with intellectual disabilities and CSN. While all of these considerations might appear to be theoretical, the section below will provide a concrete illustration of this application of the capability approach within the ADMCA.

³⁰⁴ J-F Trani and others, 'Disabilities through the Capability Approach Lens: Implications for Public Policies' (2011) 5 *Alter* 143, 145.

5.4.2 The Assisted Decision-Making (Capacity) Act and the capability approach: An illustration

Let us say that the implementation of the ADMCA is well underway. There is an individual tasked with being an SP for persons within a community, consisting of persons who have an intellectual disabilities, high CSN and communicate primarily through the use of non-speech modalities. This community will hereby be referred to as ICSPM (individuals communicating through non-speech modalities). The implementation framework provided to the SP is that outlined above, of identifying and deconstructing barriers to communication. The modalities here are specifically the unaided and aided non-speech modalities of facial expressions, movements, vocalisations, body posture or muscle tone, the use of singular words or phrases and non-electronic communication boards. Although we know SP may be (and are likely to be) persons who have a close personal relationship and are entrusted by the appointer, we will focus on persons who do not have an established personal relationship with the appointer but are nonetheless appointed to be SP. Since the requirements outside of being close persons are rather vague, this could constitute a number of people, ranging from persons within the government to disability specialists who have been assigned to this role by the appointer. This specification is due to the fact that persons who are close to the appointer will likely have a solid ability to understand non-speech modalities, and this framework is intended to help persons unfamiliar with the individual's AAC.

In this scenario, the 'community capability set' on a larger scale is the ability to express one's will and preferences in the exercise of legal capacity as determined by the CRPD, CRPD Committee and ADMCA. On the smaller scale, the 'community capability set' is the ability of ICSPM to communicate their will and preferences to their SP. Despite the goal to expand legal capacity, many persons who fall into the ICSPM community, and are currently under frameworks of supported decision-making within the Act, are at a great risk of being denied capacity by way of assessment determining they are unable to communicate their decisions, and subsequent court orders appointing decision-making representatives. As the ICSPM must exercise their own capacity to mandate the appointment of another individual as SP, the fact that they are under a supported decision-making regime in the first place exemplifies that they are able to communicate in some form,

but the interpretation of will and preferences beyond this appointment becomes a challenge. This could be for a number of reasons, eg the appointment of an SP was facilitated by a close family member who is able to ascertain the individual's preference, but is unable to be a SP for some reason or another.

Simply because an *outright* specific analysis of each individual's capabilities is not feasible does not mean that the lens of the capability approach cannot be applied and utilised in this situation. Considering the ICSPM, the SP chooses to employ the capability approach to design a framework to ascertain the will and preferences of individuals within the ICSPM. Though the capabilities vary for each individual, all the persons in this scenario are shown to have the capabilities allowing for communication through non-speech modalities. The issue in realising this communication is a lack of understanding by the SP, influenced by a variety of conversion factors which the SP aims to analyse in order to realise necessary communication. The conversion factors the SP may consider range from personal factors such as likes, dislikes and the distinct impairments of an individual within the ICSPM, to educational opportunities, home environment, so on and so forth. Thus, the analysis of conversion factors to realise the communication of will and preferences must firstly occur at a wider level, considering social and environmental factors of ICSPM generally, such as the societal barriers, educational resources and the home environment of ICSPM. This may then lead to the consideration of more personal factors, such as the individual's impairment, likes or dislikes, which may allow the SP to understand the relevant individualised communication style, and identify/deconstruct barriers to communication as tasked. This will be expanded upon and illustrated below.

Firstly, although persons within ICSPM have the capability to communicate through non-speech modalities, they all face profound societal barriers which deem their method of communication to be 'illegitimate' because it does not follow a specific identifiable pattern or language. Since existing social norms dictate that persons who use non-speech modalities are not able to genuinely communicate, the result is they are often deprived of the ability to make their own decisions and express their wants, and are thus deprived of the ability to exercise capacity because of these societal barriers. Social norms, though pervasive, do vary across societies and may be overcome in many circumstances, particularly depending on environmental

conversion factors, such as access to public education for persons with disabilities. Where ICSPM were wholly blocked by the aforementioned societal barrier and deemed within their own environment as unable to genuinely communicate, there is a chance they would not even fall into ICSPM as they could have been prevented from developing any concrete AAC. Thus, the SP understands that all these individuals' capabilities and functionings may be limited by societal barriers, but the 'level' of the societal barriers faced by the individual, together with their environmental conversion factors, have allowed these individuals to develop non-speech modalities which may be understood by other parties. There are many environmental conversion factors to be considered, but the SP focuses on factors related to (1) education and (2) home environment. Environmental factors determine the point where the capabilities of individuals within ICSPM may begin to differentiate. The SP may begin by looking generally at the educational resources or level of education of different ICSPM members. This is where factors will become more individualised, which will allow for personal assessment, as there could be eg 50% of ICSPM who attended basic schooling programmes for persons with disabilities, 25% who were never placed in such programmes and 25% who were placed in exceptional private programmes and had additional speech aids. From the consideration of these environmental factors, the SP is able to delineate that those who attended basic schooling and exceptional programmes are more likely to be able to communicate through non-electronic communication boards and the use of singular words or phrases, because they have had educational resources to develop these communicative abilities. Thus, for the remaining 25% who were never able to access educational resources but are still within ICSPM, the SP understands they should initially pay particular attention to the home environment of these members, because it is likely they utilise facial expressions, body movements and posture which has been understood and interpreted by family members or other close persons through time to a point where it constitutes a method of AAC. Analysing broader capabilities within a community framework has therefore allowed the SP to narrow down community-wide capabilities (in our case, the capability for the ICSPM to communicate through non-speech modalities) and conversion factors (such as social and environmental factors mentioned above) to the point where more individualised analysis is feasible, which allows them to develop the capabilities to ascertain the will and preferences of ICSPM.

Continuing with the previous example, the SP is designated as a CDM for an ICSPM member, who the SP determines has had very few educational resources. The SP, rather than firstly attempting to employ limited verbal communication or use communication boards in ascertaining the will and preferences of this individual, understands they must take all practicable steps to familiarise themselves with the relevant expressions or body language of the individual. Alternatively, they must consult with or refer to a relevant person who is acquainted with the individual and may have an understanding of whether this specific AAC is possible. Through either taking concrete steps to understand the individual's mode of AAC or consulting close persons who may aid the SP in their interpretation, the specific capabilities and coinciding functionings of the individual's communication skills can become apparent. Here, if the SP, based on the analysis of environmental factors (eg the educational factors mentioned above) initially consults close persons who clarify that if the individual eg claps their hands multiple times it means they are satisfied, the SP may form a fundamental basis for assessing the communication capabilities of the individual more efficiently than if they first employed the use of singular words or communication boards (which are more ideal for unfamiliar persons as they are commonly easier to interpret). This, in turn, expands the capability set of the SP to understand specified modes of AAC, which then affects the capabilities of the aforementioned individual.

5.5 CONCLUSIONS ON CHAPTER 5

The original capability approach has been re-framed above for the purposes of supported decision-making under the ADMCA. This was done by suggesting that capabilities and varying conversion factors be considered at a community-wide level, which may then be narrowed down. This, in turn, would allow for the capabilities of different individuals with disabilities to express themselves through AAC to be realised as a 'functioning' of being able to express one's will and preferences. Conversely, from the position of the SP, the development and use of this revised capability approach here to discern appropriate communication may result in the expansion of the SPs' capabilities to work with and understand various AAC of persons with (intellectual) disabilities. This directly impacts the ability of the SP to ascertain the

will and preferences of the individual, which we may hold here to be a functioning.

There are many drawbacks, criticisms and considerations which may arise from the framework above. One may hold that the consideration of capabilities at a community-wide level is useless if the assessment will be individualised later on. Others may argue this framework to be unnecessary, as it may reflect basic common sense to consult close persons to the individual and consider the various factors influencing one's communicative abilities in ascertaining their will and preferences. All things considered, the purpose and use of this capabilities framework is rooted in the idea that the transition towards universal legal capacity demands that social, environmental and personal factors be taken into account. This means moving away from medicalised denominations of eg 'speaking' or 'non-speaking,' and looking at capabilities (specifically those related to the language abilities of persons with disabilities), as arising as a result of the factors and persons that make up the life of each individual. In implementing the new paradigm of universal legal capacity, the framework above may be a useful tool for persons tasked with being SP for individuals who use AAC and who, to put it simply, are not sure where to start. The understanding of disability within such a framework demands that government, policy and society shift in how they perceive and interact with persons with disabilities. Though it may seem minute, the consideration of such personalised capabilities and factors within a larger policy is a significant advancement away from the medical disability classifications of the past.

CONCLUSION

Let us return to the primary research question of this thesis, namely, how might the capability approach be used in regimes of supported decision-making to discern the appropriate method of communication for each individual with a disability so that their will and preferences are understood? We may conclude that the capability approach has the potential to aid SP in frameworks of supported decision-making. This is because it allows for an understanding of the resources, abilities and needs of persons with disabilities through considering capabilities and conversion factors. In the framework illustrated in the previous chapter, the capability approach facilitates an understanding of how persons with disabilities may communicate through looking at the conversion factors pertaining to their society, environment and personal life.

For persons with CSN, understanding their will and preferences requires an ongoing process that develops alongside the individual as they expand their capabilities and interact with the world. This ‘process’ is new to all parties, as the CRPD is ushering in a new understanding of disability, which requires policy-makers and society alike to ponder what disability is, why disability arises, and how persons with disabilities are restricted because of their differences. Legal capacity under article 12 is at the forefront of this process, as it recognises the choices and thoughts of all persons with disabilities should be respected under the law, no matter how they might be communicated. As states parties aim to respect, protect and fulfil the human rights of persons with disabilities on an equal basis with others, persons tasked with implementing said rights must be provided with tools to learn about and understand disability and its unique nature, just as persons with disabilities must be provided with the tools to exercise their rights, and express their will and preferences. In this manner, the dynamic and interdependent

relationship between legal capacity and communication is revealed through the centrality of will and preferences.

Communication is often constrained by sole reference to expression through verbal language, although the ability of humans to communicate extends far beyond learned verbal communication. Communication is not rooted in systematic language, but an understanding of persons and what they desire to express. To quote Noam Chomsky, ‘a language is not just words. It’s a culture, a tradition, a whole history that creates what a community is. It’s all embodied in language’.³⁰⁵ For persons with disabilities, the ability to communicate and be understood is so more than expression. Rather, it represents the extent to which persons and communities can develop their own cultures and languages in the face of discrimination.

³⁰⁵ A Makepeace, *We Still Live Here: Âs Nutayuneân* (2011).

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