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European Master's Degree in Human Rights and Democratisation
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ADJUSTING OUR LENSES

The Right to Equal Legal Capacity for People with Disabilities

*"We're paying the highest tribute you can pay a man.
We trust him to do right. It's that simple".*

Harper Lee, To Kill a Mocking Bird.

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Abstract

Will the realisation of equal legal capacity in practice lead to greater participation and empowerment of people with disabilities in exercising decision-making about their lives?

This thesis addresses the implementation and practice of supported decision-making according to Article 12 of the Convention on the Rights of Persons with Disabilities, CRPD, and identifies factors that might help in the establishment of this new system of Legal Capacity support. The legal framework of the UN CRPD Article 12: Equal recognition before the law and the general comment on Article 12 are presented, illustrating the legal obligation on States in the implementation of systems to realise this right, with particular reference to the right to support when exercising legal capacity. Changes in national legislation are underway in some countries to bring systems of supported decision making into being and participation of persons with disabilities and human rights advocates have played key roles in influencing the development of legislation. Supported decision-making arrangements in place in a selected number of countries are analysed to identify current applications of supports in exercising legal capacity with a specific focus on persons with intellectual disability. The right to supports that are effective to enable people with disability to exercise their right to decision making about their lives will be important along with awareness raising amongst all people, in the evolution of systems of supported decision-making and the legal framework surrounding them. The conclusions from the thesis aim to inform this transitional journey.

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List of Abbreviations

ADACAS	Act Disability, Aged and Carer Advocacy Service (Canberra Australia)
CERMI	Spanish Committee of Representatives of people with disabilities
CDLP	Centre for Disability Law and Policy, (National University of Ireland, Galway)
COE	Council of Europe
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled People's Organisation
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights,
EU	European Union
FRA	European Union Agency for Fundamental Rights
ICCPR	International Covenant on Civil and Political Rights
ICF	International Classification of Function
OHCHR	Office of the High Commissioner of Human Rights
MDAC	Mental Disability Advocacy Centre
OPA	Office of Public Advocate (South Australia)
RSBC	Representation Agreement Act British Columbia (Canada)
UN	United Nations
UDHR	Universal Declaration of Human Rights
WFOT	World Federation of Occupational Therapy
WHO	World Health Organisation

1 Introduction

The right to make decisions about one's life is closely associated with human dignity and freedom. In human rights terminology, if this right is taken away, the person is not considered to be a "person" in the eyes of law (legal personality) and can be considered not to be truly free, deprived of all other rights and susceptible to injustice without legal remedy.¹ Throughout life, people make decisions and those decisions that involve contracts or formal consent, require recognition of the person before the law, both in terms of legal recognition as a person before the law and for one's decisions to be legally recognised. Legal capacity has been described as the law's recognition of the validity of a person's choices². In human rights law, the right to be recognised as equal before the law is in Article 16 of International Covenant on Civil and Political Rights, ICCPR, which expresses the right as "everyone shall have the right to recognition everywhere as a person before the law". This right is denied to persons with disabilities when their legal capacity is removed by legal proceedings. The appointment of a guardian who substitutes for the person, described as plenary guardianship, allows substituted decision-making to take place. This happens in situations where it is perceived as protecting the person with disabilities and is established practice worldwide, often carried out by those surrounding the persons with disabilities without questioning its validity, discriminatory nature and the consequences it can have. The consequences can vary from the imposition of a lifelong label such as "person of unsound mind" in order to meet requirements of court proceedings³ to forced sterilization or detention in inhuman conditions with no possibility to reverse the situation.

The Convention on the Rights of Persons with Disabilities, (CRPD), and its Optional Protocol, adopted in New York in 2006 with United Nations (UN) resolution 62/170, coming into force in 2008, has provided an internationally agreed legal directive which challenges the practice of denial of legal capacity of persons with disabilities and

¹ Office of the United Nations High Commissioner for Human rights, 2005, p. 4.

² Amnesty International Ireland 2012, *A citizen's Jury on Legal Capacity Law*, p. 20.

³ *Lunacy Regulation (Ireland) Act, 1871*.

proposes that substituted decision making be replaced by supported decision making.

The Article on legal capacity in the CRPD, Article 12, reaffirms that persons with disabilities have the right to recognition everywhere as persons before the law, and is viewed as core to the convention itself, in that it endorses that recognition of legal capacity is linked to other rights such as liberty, access to health, private and family life, voting rights and that it is core to the principles of the convention; “*respect for the inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons*”.⁴ It was one of the most hotly contested articles during the drafting process of the Convention⁵ and the need for the monitoring body of the CRPD, the CRPD Committee, to provide States with guidance on its implementation, through the drafting of the first general comment on the CRPD, is indicative of its complexity and the challenge it presents to current legislation and policies in States.

The contentious debate at the UN CRPD negotiations reflects the challenge which goes beyond the legal system to the core of society and attitudes towards persons with disabilities within all practices of life. The hope is that this change in the legal system will have an expanding impact on all aspects of life in terms of the recognition of the human dignity and freedom in both the making of and validity of decisions about one’s life.

1.1 Main research questions

This thesis aims to explore the question: will the realisation of equal legal capacity in practice, lead to greater participation and empowerment of people with intellectual disabilities in exercising decision-making about their lives. The first part of answering this question is; are national legislative reforms, both those proposed and those enacted, compliant with CRPD Article 12 in achieving the expected goal of equal recognition for

⁴ CRPD Article 3 General Principles.

⁵ Dhanda, Amita, (2006-2007), p 429.

people with disability before the law and secondly, do the proposed supported decision-making models enable those persons with disabilities that require them, to exercise decisions-making in all aspects of life?

1.2 Research Methodology

The research methodology in the thesis is interdisciplinary, combining traditional legal interpretive analysis with thematic analysis, from a qualitative research approach. Thematic analysis is considered a valuable methodology when examining studies with different designs⁶ in this case legal texts, academic literature and research reports, pertaining to legal capacity for persons with disabilities. The analysis follows a thematic structure, with themes derived from the essential requirements of the CRPD Article 12 on Legal Capacity. Initial exploration of the legal sources with oversight from the academic literature and disability representative groups' reports, resulted in the deduction of five main themes, then used to analyse the sources of evidence. Discussion forms part of the analysis and is interwoven through the body of the thesis in order to induce conclusions to the research questions posed, provided at the end.

The five themes identified correlate with the main research question and component sub questions, regarding 1) the right to legal capacity in both recognition of and in the exercising of this right; 2) the absolute shift from substituted decision-making to supported decision-making; 3) the question of mental capacity in the denial or adjustment of legal capacity; 4) the supports to exercising legal capacity and 5) safeguards to ensure the respect of this right.

1.3 Structure of research and Sources

The structure of the thesis is built on initially establishing the theoretical background to the change in legal capacity, to give a broad context to the path that persons with

⁶ Dahan-Oliel, Noemi, Shikako-Thomas, Keiko, Majnemer, 2011, p. 427.

disabilities are on, towards the realisation of legal capacity on an equal basis with others in all aspects of life.

The primary legal source is the UN Convention on the Rights of Persons with Disabilities, Article 12 in particular and recent soft law in the form of General Comment no 1 (2014), providing the background to the obligations on States with regards to legal capacity. Other legal sources influencing developments in legal capacity at a European regional level are included.

Analysis is conducted on two sample legislative texts from Europe, the Civil Code of Catalonia in Spain, introducing the system of Assistance in 2011, and the proposed draft legislative reform of the Assisted Decision-Making (Capacity) Bill of 2013 in Ireland. Sources from international academic literature and disability representative group reports are consulted and incorporated in the thematic analysis.

Analysis of the legal texts is then complemented with analysis of sources of research findings from projects conducted in Australia and Canada, where outcomes of models of supported decision-making for people with disabilities have been explored. This second analysis follows the same thematic approach as that carried out on the legal texts, to examine the application of this proposed change in respect of the outcomes for the lives of people with disabilities. Particular emphasis has been made on finding sources that include the voice of those for whom this legal and social change can make real difference, people with disabilities.

The need for awareness about the changes in legal capacity across all sectors of society has been called for, particularly those with most influence in the current power dynamics that exist in aspects of some persons with disabilities lives, whether it is those in financial or business professions, government departments, or health professions. In this instance, academic and professional sources from the profession of Occupational Therapy are examined to identify influences reflective of the changes that Article 12 on legal capacity proposes.

The final conclusions provide a succinct compilation of the findings of the analysis which may serve to guide developments in legislative reforms, research, policy developments and practice, on the ongoing journey towards equal legal capacity for people with disabilities.

1.4 Limitations of research

Limitations of the research include the limited focus on people with intellectual disabilities. Denial of legal capacity predominantly impacts on people with intellectual disabilities and people who experience mental health problems and the issues are crosscutting in some respects and very different in other respects.⁷ This research limits its focus to people with intellectual disabilities⁸. A small amount of research of a participatory nature is available to determine the outcomes of new approaches to supported decision-making, which results in exploration of available studies from Canada and Australia, while the primary focus from the legal perspective is on new and proposed legislative reforms in two case samples in Europe. The scope of the research does not expand to address the topic across differences in cultures, economics, and policies, impacting people with disabilities.

⁷ European Agency on Fundamental Rights, (FRA) 2013, p. 42.

⁸ The term people with disabilities is generally applied throughout the text of the thesis, primarily referring to experiences pertaining to legal capacity and people with intellectual disabilities or significant physical and intellectual disabilities.

2. Theoretical Background

2.1 The journey towards supported decision-making and equal rights for persons with disabilities

The fact that people with disability can be denied legal capacity (the capacity to be holder of rights and the power to exercise those rights) is indicative of the discriminatory practice that takes place today in States across the world. Serious human rights violations take place when persons are denied legal capacity, taking away the basic right to be able to make decisions about their lives, when treatments are forced upon people against their will, when people are detained in inhuman conditions and rendered invisible to the world⁹. Structural violence against persons with disabilities results from social, political and economic systems, leading to denial of rights, exclusion, dependency and can enable direct violence in forms such as forced detention, forced treatments, sterilisation and in extreme cases death, as was found in the European Court of Human Rights judgment of June 2013 (Nencheva v. Bulgaria) where the Bulgarian Government was held responsible for the deaths of 15 children and young adults who died at in institution in Bulgaria during the winter of 1996/1997.¹⁰

Rodrigo Jimenez describes the violence experienced by people with disability as invisible and tolerated by law, media, and other institutions; *“The way in which people with disabilities experience violence is not only made invisible, but is also publicly tolerated by laws, mass media, the church, education and other institutions that justify and confer legitimacy on it.”*¹¹.

The legitimacy of discrimination by legal and medical institutions, often in the guise of protective or medical reasons, resulted in large institutional settings to incarcerate persons with disabilities away from society, with many still operating in States today¹².

⁹ WHO, World Report on Disability, 2011.

¹⁰ Nencheva v. Bulgaria. ECtHR Judgement 18 June 2013.

¹¹ Jimenez, Rodrigo, 2011, p. 404.

¹² She, Peiyun, and Stapleton, David, C., 2006 and Mansell J, Knapp M, Beadle-Brown J and Beecham J

The history of how different cultures and societies have viewed differences in human characteristics in terms of disability involves a complex web, which is addressed differently depending on sociological, economical, medical, political and philosophical theories applied. James Charlton, a disability activist, attempts to untangle these theories in terms of the development of disability rights movements in ‘Nothing about us without us: Disability Oppression and empowerment.’ Charlton moves beyond the narrow geographical documentation of the disability rights movement stemming from the civil rights movement in North America, to document disability activism in parts of Asia, South America, Africa and Europe. He presents some common threads to the campaigns of the disability rights organisations he encountered, including; empowerment and human rights; independence and integration; self help and self determination, while also making the case for a fundamental re-ordering of global priorities and resources based on equality, respect, and control of resources by the people and communities that need them.¹³

Disability organisations, such as Inclusion International, advocate and campaign through giving voice to the people with disabilities in terms of their experiences of discrimination but also their guidance to governments and communities on how attitudes, resource control and distribution and legal and policy reform can all contribute to realizing rights for people with disabilities to live interdependent lives.¹⁴ The Human Rights mechanisms of the UN may not be position to address world re-ordering of resources particularly in political and economic terms, but the UN CRPD does challenge priorities and advocates for people and communities to seek and have control of multi-dimensional resources within their communities. The rights paradigm, enshrined in CRPD Article 12 but also prevalent throughout the Convention, can be considered a reordering of resources to enable people to fully participate in their communities.

(2007).

¹³ Charlton, James, I., 2000.

¹⁴ Inclusion International, 2014.

The development of the social model of disability during 1970s and 1980s challenged and altered the previously dominant medical approach to disability. This has resulted in new approaches within medical and social services such as the World Health Organisation's inclusion of environmental factors influencing disability (in the International Classification of Function, ICF)¹⁵. The shift from predominantly focusing on the person and their impairment to a broader concept that involves the interaction of the person with environment, gives disability a new framework which allows for interventions and supports to be used to overcome barriers to participation and equality. This is a new way of analysing the needs of a person with disability, to take the lead from the person and their wishes, to not only focus on interventions related to impairments but to also investigate interventions that focus on environmental contexts. The environment can be changed to be more inclusive both through physical alterations but of equal, if not more importance, attitudinal changes. This approach, based on an individual-complaint model, on its own cannot hope to achieve an end to discrimination, just as human right legislation has been criticised for its reliance on individuals taking action to enforce rights, (when considering the failure to achieve disability rights through legal mechanisms is under discussion.)¹⁶

Health and rehabilitation intervention is only one aspect that should be accessible to persons with disabilities without discriminatory barriers, all other aspects of life, education, employment, relationships, social, leisure and political aspects require a multi-pronged approach to addressing discrimination and achieving accessibility.

Disability discrimination in the form of societal attitudinal barriers is built on layers of reinforced perceptions, habits, and structural power dynamics, that anti-discrimination policies and laws only begin to scratch at the surface. Recognition of the value in the role that each tool aimed at addressing discrimination can play, prevents defeatism setting in. The fundamental change that the implementation of the right to legal capacity can be a driver for, if it is implemented true to the CRPD article 12 and the General

¹⁵ WHO International Classification of Function (ICF) replaced previous medical classification systems with a function based system which includes Person – activity – and environment and how they interface with each other.

¹⁶ Pooran, Brendan, Wilkie, Cara, 2005, p. 27.

Comment, is to provide communities with an example of where the elimination of discrimination based on status of disability can take place and where diversity is addressed in a manner which demonstrates social solidarity can be given precedence to enable people with disabilities achieve their rights.¹⁷ This includes elimination of status-based discrimination on medical or other professional diagnosis or assessment terms, including functional assessment of decision-making capabilities. In line with the changed view of disability, if assessment is required, it should be focused on the level of support that the person may require to achieve the outcome, in this case to exercise their right to legal capacity. This provides opportunity to embrace existing and new ways of utilising supports within communities, as an approach to overcome discrimination and achieve rights for people with disability. This approach of focusing on supports rather than status or functional capabilities, if implemented successfully in the legal arena, could lead example to influence other areas such as access to education or employment for persons with disabilities.

The general view held about disability is changing from a lens of pity or charity, instead requiring a rights based viewpoint, which has been called for by disability rights campaigners, endorsed by the World Health Organisation and legally framed in the Convention on the Rights of Persons with Disabilities (CRPD). The experience of disability is varied depending on multiple factors; the individual characteristics of the person, interacting with the social and environmental factors that create barriers or enable living. Societal perceptions can be addressed with the altered, rights based perspective: disability is a human condition influenced by social and environmental factors - what if attitudes and the environment were different, barriers removed and access to supports in place, would the experiences of persons with disabilities be different?

¹⁷ Quinn, Gerard, equates assisted decision-making to “*a form of social solidarity, a reliance on social supports to exercise my formal freedoms*” 2009, p. 16.

2.2 The United Nations Convention on Rights of Persons with Disabilities. A Legally Binding Instrument and its impact

In the process of negotiating the need for a specific convention to address the rights of persons with disabilities, a comprehensive analysis of the existing United Nations human rights instruments in the context of disability was conducted by a number of experts and published by the Office of the High Commissioner of Human Rights (OHCHR) in 2002.¹⁸ The link between disability and poverty and social exclusion was emphasized in this report, with the inclusion of the stark statistic of only 2 per cent of children with disability in some parts of the world receiving any education or rehabilitation.¹⁹ The failure of the existing Human Rights instruments to address the rights of persons with disabilities, including those conventions addressing civil and political, economic, social and cultural rights and those that could potentially address intersecting rights of children, women and minority persons with disabilities, was addressed in terms of the “invisibility” of people with disabilities. The values inherent in the human rights discourse emphasising the human dignity and freedom of all persons / citizens of the world were not interpreted as the problem in this OHCHR report:

*“The problem is not the values themselves or the system of basic freedoms that they postulate but the fact that they are either not applied or are applied differently to people with disabilities. This is a legacy of the past, when people with disabilities were often virtually invisible citizens of many societies. They have been marginalized in nearly all cultures throughout history. A common reaction (on the part of both the general public and policy-makers) was either pity or revulsion. There was a tendency to take the relative (or sometimes absolute) invisibility of persons with disabilities for granted or to accept it as “natural”.*²⁰

¹⁸ Quinn, Gerard, Degener, Theresia, eds, 2002.

¹⁹ Quinn, Gerard, Degener, Theresia, eds, 2002, p. 11.

²⁰ Quinn, Gerard, Degener, Theresia eds, 2002, p. 23.

A wide range of disability representative organisations were involved in the drafting of the CRPD, and its optional protocol which was adopted in New York in 2006 and came into force in May 2008.²¹ A sustained involvement of persons with disability was sought in the monitoring of the national implantation of the convention in States, as described in Article 33 of the CRPD.²² The International Disability Caucus, formed out of disability representative groups, petitioned for a definition of disability to be included and while no agreement on a final definition was reached, the inclusion is credited to the participation of the disability representative groups.²³ The final definition or *open description*, as it has been described²⁴, is as follows in the preamble of the CRPD “*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*”²⁵

The unique and powerful element of the Convention is the mandate it imposes on States that have ratified it, to implement the rights and duties included in it. This is an important aspect that gives the movement towards the realization of rights of persons with disabilities a strong position which can be used to mobilise and change current practices and attitudes towards people with disabilities. This includes in State and private spheres of welfare, health, employment, education, community and social contexts and in the legal sphere of contracts, businesses, banks and within all realms of life. The CRPD offers a changed outlook on disability, which ratifying States have an obligation to express in their legislation, policies and resource allocations. The rights enshrined in the CRPD are not considered to be new rights, but the changed outlook that the CRPD offers is that of the viewpoint or understanding of disability, not to be considered a welfare problem, instead it offers a rights viewpoint as a way to consider the situations of people with disability.²⁶

²¹ Woodburn, Hannah, 2013. p 75.

²² CRPD Article 33(3) “*Civil society, in particular persons with disabilities and their representative organisations, shall be involved and participate fully in the monitoring process*”.

²³ de Burca, Grainne, 2010, p 10.

²⁴ Schulze, Marianne, 2010, p. 27.

²⁵ CRPD, Preamble.

²⁶ Marquez Carrasco, Carmen, 2008, p. 60.

The mandatory nature of the convention is a paradigm shift in how we view disability, with the power of law enforcement behind it. Addressing the current discriminatory practices within legal institutions in terms of denied legal capacity could be considered an essential first step in ensuring States act on the mandate given by the CRPD, while the realization of other rights within the CRPD should not be required to wait while States grapple with how to address legislation to enable Article 12. The rights enshrined within the CRPD are inextricably linked and the realization of some can result in realization of others, with perhaps the individual's or the most pressing need within communities, indicating the lead as to which aspects States need to address most urgently. Institutionalisation and deprivation of liberty or forced sterilization, for example, might be pressing needs for States to change legislation or policies on. These and other rights are linked to the right of the person to decide themselves, inherent in the changes required with Article 12, where the will and preference of the person are paramount over best interests. This is reflected in the general principles of the Convention, listed in Article 3, the first principle includes the freedom to make one's own choices.²⁷ The change envisaged in the minds of some of the advocates behind Article 12 is enshrined in the idea that "substituted decision-making" and such terms as "plenary guardianship" need to be eradicated, so that a new language and a new way of thinking can be allowed to develop.²⁸

²⁷ CRPD Article 3 lists the general principles of the convention, the first 3(a) "*respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons*".

²⁸ Quinn, Gerard, 2010, p. 18.

3. Legal Framework

3.1 The United Nations Bodies and Instruments that address legal capacity

The right to equal recognition before the law is in the Universal Declaration of Human Rights (UDHR) (Article 6). The United Nations International Covenant on Civil and Political Rights (ICCPR): Article 16 states *“Everyone shall have the right to recognition everywhere as a person before the law.”*

Considered a civil and political right, no specific Article on legal capacity or equal recognition before the law is included in the International Convention on Economic, Social and Cultural Rights (ICESCR), however non-discrimination principles are enshrined in the ICESCR and its general comment 5 notes the need for comprehensive anti-discrimination legislation to address the legal situation of persons with disabilities around the world.²⁹

The Convention on the Elimination of All forms of Discrimination against Women (CEDAW) is the first convention to specifically refer to legal capacity in Article 15 which expresses the explicit right that women have legal capacity equal to men and the same opportunities to exercise that capacity.³⁰

The UN Special Rapporteur on Torture has given strong voice to the link between denial of legal capacity and torture and ill-treatment of persons with disabilities in several reports, including in 2008 and 2013.³¹

²⁹ Quinn, Gerard, Degener, Theresia eds, 2002.

³⁰ CEDAW Article 15.

³¹ Quinn, Gerard, Degener, Theresia, eds 2002.

3.2. United Nations Convention on the rights of persons with Disabilities and Article 12, Equal Recognition before the law

The process of negotiation of Article 12 was heavily focused on the debate as to whether the article on legal capacity should include a defined split in the understanding of legal capacity, between the right to recognition as legal subject of law and capacity to exercise this right. Proposals made during the negotiations included some that had such limitations in the exercising of rights within them, as to reverse the rights of persons with disabilities, threatening the validity of the entire convention.³² A number of countries submitted reservations in respect of this and the maintenance of substituted decision-making regimes for specific circumstances of exercising rights, when the final agreed text of the Article did not include this distinction³³.

The final text of the article does not explicitly state the need to abolish the use of substituted decision-making (plenary or full guardianship), to be replaced by supported decision making, while analysis in academic publications, the UNCRPD committee responses to State party reports, and the General Comment no 1 (2014) have proclaimed that this is required in order to meet the full compliance with the CRPD Article.³⁴ The text of Article 12 is as follows:

Article 12. Equal Recognition before the law

- 1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.*
- 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.*
- 3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.*
- 4. State Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in*

³² Quinn, Gerard, 2009, p 14.

³³ Wildeman, Sheila, 2013, p. 60.

³⁴ Eilionoir Flynn and Anna Arstein-Kerslake, 2014, p. 102.

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.

5. 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.'

3.3. States obligations to implement CRPD and Article 12

State reports and the CRPD Committee responses to date has shown that those States that have submitted reports do not have clarity on full compliance with implementation of Article 12 of the CRPD.³⁵ Spain submitted in the initial state report to the CRPD Committee in 2010 for example, that the existence of guardianship statutes met with compliance with Article 12(3)'s requirement to provide access to supports and that incapacity could be applied in a situation where a person could not act unaided.³⁶ The CRPD Committee has described the situation as “*a general failure (by State parties) to understand that the human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making.*”³⁷

³⁵ Dinerstein, Robert D, 2012, p. 8.

³⁶ State Report of Spain to CRPD 2010 p 11 Para 53: Article 12 (3) *requires States parties to take appropriate measures to provide persons with disabilities with the support they may require in exercising their legal capacity. This obligation appears to be met in Spanish legislation by the institutions for the guardianship and protection of persons and property in general or exclusively for that of persons with disabilities. These institutions are governed by Parts IX and X of Book I of the Civil Code, which govern deprivation of capacity (articles 199 to 201), guardianship (articles 215 to 285), curatorship (articles 286 to 293), the Legal Defender and the de facto custodian (articles 303 and 304).*

³⁷ General Comment 1 (2014) p. 1.

States are obliged to review and introduce changes to relevant legislation and policies to implement the requirements of the CRPD.³⁸ With regards to Article 12 of the CRPD, the General Comment no 1 (2014) explicitly outlines the requirements on States in their obligation (part III of the General Comment) and in the implementation at a national level (part V of the General Comment). The relationship of Article 12 with other articles of the Convention is also included in the General Comment, giving important emphasis on the inextricable link between rights in the convention, which States need to consider in their reforms towards implementing the Convention within national laws and policies.³⁹

Similar monitoring systems for States that have ratified the Convention are applied, as with other UN Conventions, in terms of State reporting to the CRPD Committee which has been established to monitor implementation and compliance with the Convention. Regional systems can also influence States in their implementing of national legislative and policy reforms, such as the European Regional framework, including the European Union, which has ratified the CRPD. Monitoring of national implementation involves the establishment of focal points within governments (Article 33(1) of CRPD) and the involvement of civil society and persons with disabilities through their representative groups in the national implementation and monitoring (Article 33(3) of CRPD).

3.4 CRPD General Comment no 1 (2014) Article 12: Equal Recognition before the law

The General Comment on Article 12 of the CRPD was adopted on the 8th of April 2014, after 5 years of consultative work involved in the drafting process, with a comprehensive draft general comment in circulation from September 2013. There were

³⁸ CRPD Article 4 General Obligations includes 4.1 State Parties undertake (a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention; (b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities.

³⁹ General Comment no 1 (2014) part IV Relationship with other provisions of the Convention.

a total of seventy-three submissions on the final draft of the general comment from Disabled Persons Representative Organisations, Human Rights Organisations, individuals and the European Union Agency for Fundamental Rights.⁴⁰

General Comments are interpretations of individual human rights in human rights treaties, which are produced and adopted by the UN treaty bodies/committees. While not legally binding, with no ratification system, they are considered legally authoritative in their capacity to address issues of interpretation.⁴¹

The General Comment consists of five parts including; Introduction; Normative content; Obligations of State parties; Relationship with other provisions of the CRPD and Implementation at national level. The text of the General Comment will be analysed in the context of the clarity of guidance it provides to State parties, using two sample legislative texts from Ireland and Catalonia, Spain in chapter 4.

3.5 Overview of European regional legal framework relating to equal legal capacity

3.5.1 EU ratification of CRPD

The CRPD is the first International Convention that the European Union has ratified, with the specific and unique provision of Article 44 of the CRPD, enabling regional integration organisations such as the EU, African Union (AU) and Organisation of American States (OAS) to accede to the Convention, a provision not in place in any previous international Convention.⁴²

⁴⁰ Submissions publishes on OHCHR website

<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>.

⁴¹ Gerner, Paula, Kyriakakis, Joanna, O'Byrne, Katie, 2013, p. 7.

⁴² CRPD Article 44 and EU ratification of the CRPD through Council Decision 2010/48/EC formally adopted on 26th November, 2009.

The competencies of the EU as a legal body and the EU member State's national competencies are split, such that some aspects of the Convention can be applied to the operations of the bodies and institutions of the EU itself, some aspects require EU member States to pass legislation based on EU directives, such as anti-discrimination directives, and some aspects the EU does not have direct competency on, such as legal capacity, while it is argued that restrictions on legal capacity based on discriminatory practices fall within EU competency.⁴³ *M.X. v Health Services Executive*, 23 November 2012, a High Court case taken in Ireland, one of the 11 countries in the EU which had signed but not ratified the CRPD⁴⁴, did not succeed in the claim that Article 12 of the CRPD has direct applicability under EU legal order due to the EU ratification of the CRPD.⁴⁵ The judge in this case, while rejecting the argument of legal applicability, did refer to the guidance the CRPD provides in the area of legal capacity and the right to assisted, as opposed to substituted, decision making for persons with disability.⁴⁶

The Charter of Fundamental Rights of the European Union, which entered into force with the Lisbon Treaty of 2009, has specific provisions on non discrimination, equality before the law, and integration of persons with disabilities, and also introduces concepts of social justice and solidarity between generations, while it is limited in addressing only EU institutions and does not expand powers to national situations within Member States, except in situations when they are implementing Union Law.⁴⁷ The CRPD has applicability in the Court of Justice of the European Union (ECJ) and in its

⁴³ FRA 2013 p. 13 and “*the issue of legal capacity and the rights of a disabled person to equality before the law is a field in large measure covered by EU law. The CRPD’s main objective is equal treatment and the prohibition of discrimination against the disabled. The area of non-discrimination and equality is a field in large measure covered by EU law – see, for example, Directive 2000/43/EC, Directive 2000/78/EC, Directive 2002/73/EC and Directive 97/80/EC.*” Michael Lynn, 2012, p. 19.

⁴⁴ As of 1 July 2014, 3 States in EU have yet to ratify the CRPD, Ireland, Finland and the Netherlands, the CRPD has 147 State parties, with 158 signatories. UN Treaty database, 2014

⁴⁵ High Court Judgment on Case *M.X. v Health Services Executive*, 23, 2012.

⁴⁶ The Irish Human Rights Commission IHRC had acted as *amicus curiae* (friend of the court) and welcomed the reference to CRPD and assisted decision making in the judgment in the case of *M.X. v HSE*, a case regarding non-consensual medical treatment and the required determination by a psychiatrist that the patient lacks capacity to consent to treatment.

⁴⁷ The Charter of Fundamental Rights of the European Union, Article 21, sites disability as one of the grounds on which discrimination must be prohibited. Article 26 includes the Union’s recognition of “*rights of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community*”.

interpretation of the articles relating to disability and discrimination in the Charter.⁴⁸ The Lisbon treaty of 2009 also saw the adoption of provisions for accession of the EU to the European Convention of Human Rights, allowing for future possibilities in converging of rights including right of persons with disabilities and judicial processes of the Court of Justice of European Union (ECJ) and the European Court of Human Rights (ECtHR).

Promotion of Member State's legislative reform on legal capacity to attain conformity with the CRPD is included in the EU Disability Strategy 2010-2020 and the European Union Agency of Fundamental Rights has conducted comprehensive research which indicates how far European States have yet to go in their legislative reform to become compliant with article 12.⁴⁹

3.5.2 Council of Europe

The Council of Europe's Commissioner for Human Rights, Thomas Hammarberg, was vocal on the level of discrimination against people with disabilities within European States during his term of office, from 2006 to 2012, with particular reference to the historical perception that they do not have the capacity to participate in legal and political decision-making procedures.⁵⁰

3.5.3 European Convention on Human Rights ECHR

The European Convention on Human Rights does not have a specific Article or reference to legal capacity, however case law has evolved where deprivation of legal capacity has been ruled as a violation of the right to respect of private life (Article 8) and has been linked to other rights within the ECHR related to access to justice and

⁴⁸ Clifford, Jarlath, 2011, p. 19.

⁴⁹ FRA, 2013, p. 13.

⁵⁰ Council of Europe Commissioner for Human Rights, 2012.

liberty. In the Grand Chamber judgment on *Stanev v. Bulgaria*, the CRPD was specifically referenced in the findings, where the applicant's inability to access court to challenge his detention and seek restoration of his legal capacity were found to be breaches of Articles 5 and 6 of the ECHR.⁵¹

The ECtHR has not fully incorporated the CRPD paradigm shift in relation to legal capacity to date in its findings, as they continue to justify some limitations of legal capacity based on level of mental capacity.⁵²

3.5.4 Council of Europe Recommendations on legal capacity – Council of Europe, Committee of Ministers Recommendation R(99)4

The language of the guideline recommendations (not legally binding) is indicative of its time of drafting, 15th of September 1999, with its intentions to provide guidance on “the legal protection of incapable Adults,” while it was progressive in challenging the existing harsh systems of plenary guardianship in European States to be more flexible to differing degrees of incapacity and to respect individuals wishes and feelings. The recommendations address areas such as the removal of legal capacity should not automatically deprive people of the right to vote or the right to consent to medical treatment (in line with findings of the ECtHR). The recommendations call for principles of necessity, proportionality and flexibility, while allowing for a restriction of legal capacity where there is a need, from a protection perspective. The guidelines call on States to review their national legislation in support of a range of regimes running in parallel, but which can in some circumstances limit the right to legal capacity, which conflicts with the CRPD Article 12 requirement to ensure substituted decision-making regimes are replaced with supported decision-making regimes. The continued use of the Council of Europe recommendations, is found in some national legislation in Europe, such as the Act 25/2010 Civil Code of Catalonia, Spain where the recommendations are cited in the establishment of a new assistance regime, while continuing existing systems

⁵¹ ECtHR Grand Chamber finding on *Stanev v Bulgaria*.

⁵² Council of Europe Commissioner for Human Rights Issue Paper CommDH/IssuePaper 2012, 2.

of full and partial guardianship in parallel.⁵³

The shift towards full recognition of the respect of will and preferences of person with disability replacing the protection based “best interest” approach to achieve full compliance with the CRPD has yet to be made within the Council of Europe institutions.

4. Implementation of legislation to enact CRPD Article 12 at national level with guidance from General Comment no 1 (2014)

4.1 Overview of European States progress in implementing Article 12

A number of reports have been produced with comprehensive information on European States progress in the implementation of the CRPD Article 12 within national legislative processes, with the overall finding that no European State has achieved full compliance with all aspects of Article 12 to date, with varying elements of limitation of legal capacity remaining all systems.⁵⁴

Examples of practices in some States in Europe indicate some systems currently in place that have abolished full plenary guardianship and introduced supported decision-making within them, for example the personal ombudsmen support model introduced in 1995 in Sweden, and the Betreuer model introduced in 2009 in Germany. Both countries have removed full guardianship but permit partial guardianship in certain circumstances, in Sweden the systems of tutor (“god man”) and trustee (“forvaltare”) are in place, the trustee can make decision in the best interest of the person, in financial

⁵³ Act 21/2010 p11 “*In line with the guidelines of Recommendation R (99) 4, of the Committee of Ministers of the Council of Europe, of 28 February 1999, and with the existing precedents in various neighbouring legal systems, it was considered that this model of protection, parallel to guardianship or curatorship, could be more appropriate. Moreover, this trend also inspires the Convention on the Rights of Persons with Disabilities.*”

⁵⁴ FRA, 2013, and MDAC report, 2013.

and personal matters. In Germany, limitation on legal capacity can be temporarily put in place by the court in some circumstances, often related to financial matters.⁵⁵

Some legislative reform, in attempting to modernise guardianship laws, have introduced legal capacity support systems alongside the traditional substituted decision-making guardianship regimes, such as the introduction of the Amministratore di sostegno (support manager) in 2004, even before the ratification of the Convention in Italy, along with the system of total judicial incapacity (interdizione) and system of partial incapacity (inabilitazione).⁵⁶ Legal reform introduced in the Mental Capacity Act of 2005 in England and Wales, while encouraging the use of an individual's social network or independent mental capacity advocates in supporting decision-making, the Act contains the determination of the person's capacity based on professionals' assessment of their functional mental capacity, while also sanctioning informal capacity assessments by third parties and operates on the basis of perceived best interest instead of the expressed will and preferences of the individual, all elements considered to be in violation of article 12 of the CRPD.⁵⁷

Reforms have been introduced in some countries, where full plenary guardianship has been abolished but partial guardianship introduced to replace it, without the option of supported decision-making assistance, such as new legal capacity legislation in Latvia, introduced in November 2012.⁵⁸ Russia adopted amendments to the Civil Code related to legal capacity in December 2012, which will introduce partial guardianship in 2015.⁵⁹

Legislative reforms are underway in some European countries, with the Czech Republic the first to enact a new Civil Code inspired by the CRPD and Article 12, to introduce supported decision-making to replace the previous full guardianship system that had

⁵⁵ Boundy, Marcia, Fleischner, 2013, p. 8.

⁵⁶ Cendon, Paolo, "Un altro diritto per i soggetti deboli, l'amministrazione di sostegno e la vita di tutti i giorni", en *L'amministrazione di sostegno. Una nuova forma di protezione dei soggetti deboli*, (G. Ferrando), Milano, 2005.

⁵⁷ Centre for Disability Law and Policy, Submission to the House of Lords Select Committee on the Mental Capacity Act, 2013

⁵⁸ Mental Disability Advocacy Centre MDAC, 2013, p. 61.

⁵⁹ MDAC, 2013, p. 73.

operated there. The new Civil Code was enacted in 2010 and came into force January 2014. Analysts have critiqued the new law in that it retains the possibility of time-limited restriction of legal capacity as a last resort, which limits its full compliance with the CRPD⁶⁰, but it is yet to be tested as to how much this element will be used, and how the CRPD inspired systems of supported decision-making, advance directives and financial and daily life planning documents contained within the legislation will be effective in the lives of persons with intellectual and psycho-social disabilities.

Since the CRPD came into force in 2008, some countries have attempted legislative reforms such as those which have taken place in Hungary, where a new Civil Code was adopted in 2009 to abolish plenary guardianship and introduce supported decision making but this Civil Code did not come into force and another new Civil Code adopted in 2013 maintains plenary guardianship, calling it “full limitation of legal capacity”⁶¹. Spain has made a number of attempts to introduce reforms to Spanish Legal Capacity provisions but has yet to do so, while in 2011, Catalonia introduced a new Civil Code with a new assistance regime to operate along side continued guardianship and partial guardianship regimes.⁶² New draft legislation Acts are at various stages of development in some European countries, Bulgaria, Ireland, Croatia,⁶³ with varying element of supported decision-making within them which when final drafting is concluded, will need final analysis as to level of conformity with CRPD Article 12.

4.2 Case example of Spain

Spain ratified the CRPD which came into force in 2008 and places mandatory requirement on Spain to address systems of a discriminatory nature such as deprivation of legal capacity of persons with disabilities. The Spanish Committee of Representatives of Persons with disabilities, CERMI, has been appointed as the independent civil society body to monitor implementation of the CRPD in Spain, with

⁶⁰ MDAC, 2013, p. 49.

⁶¹ MDAC, 2013 p. 55.

⁶² MDAC 2013, p. 79 and Act 25/2010, of the second book of the Civil Code of Catalonia.

⁶³ FRA 2013, p. 28.

the national focal point for the CRPD coordinated by the Directorate-General for the Coordination of Sectoral Policies on Disability, involving the Ministry of Foreign Affairs and Cooperation and the Ministry of Health, Social Services and Equality.⁶⁴ Distribution of competencies between the authorities in the autonomous regions and central ministries are coordinated through the Directorate-General with general directors for disability policies in each region. The National Disabilities Council was established by Royal Decree in 2004 and became the appointed coordination mechanism by Royal Decree in 2007 to protect, promote and monitor compliance with the CRPD, with consulting mechanisms including representatives of persons with disabilities and representatives from all the ministries.⁶⁵

The promotion of the CRPD has included its availability in easy to read format, audio format, Spanish and Catalan sign language, and all the official languages: Spanish, Galician, Basque and Catalan.⁶⁶

4.2.1 Legislative reform on Legal Capacity in Spain

Legislative reforms have taken place in Spain since the CRPD came into force, adding to existing laws on equal opportunity, non-discrimination and accessibility for persons with disabilities.⁶⁷ These reforms do not however address legal capacity. The Spanish Civil Code and the Civil Procedure Act (*Ley de Enjuiciamiento civil*)⁶⁸ regulates

⁶⁴ EU Disability High Level Group Draft Third Report on Implementation of the UN Convention on the Rights of Persons with Disabilities, 2010, p. 83.

⁶⁵ Royal Decree 1865/2004 saw the creation of the National Disabilities Council in 2004 in Spain, Royal Decree 1468/2007 extended functions of the National Council on Disabilities to include CRPD promotion and monitoring of compliance. Information sourced from EU Disability High Level Group Draft Third Report, 2010, pp. 83-85.

⁶⁶ Formats available at website http://www.convenciondiscapacidad.es/ConvencionEspana_new.html (last accessed 3 July 2014).

⁶⁷ Spain has published three legal reforms, since the enforcement of the UN CRPD: Ley 26/2011, de 1 de agosto, de adaptación normativa a la Convención Internacional sobre los Derechos de las Personas con Discapacidad.

Real Decreto 1276/2011, de 16 de septiembre, de adaptación normativa a la Convención Internacional sobre los Derechos de las Personas con Discapacidad.

Real Decreto-Legislativo 1/2013, de 29 de noviembre, por el que se aprueba el Texto Refundido de la Ley General de Derechos de las Personas con Discapacidad y de su inclusión social.

⁶⁸ Ley de Enjuiciamiento Civil (Civil Procedure Act).

procedures for incapacitation, guardianship and tutor systems for persons with disabilities in Spain. There have been a number attempts since 2009 to reform the procedures for legal incapacitation⁶⁹, while some autonomous regions have jurisdiction to amend their regional civil code, which has happened in the case of Catalonia, with the introduction of the “asistencia” assistance system in the civil code of Act 25/2010 of June 29th, which came into force in January 2011.

The Spanish Civil Code includes articles on incapacitation:

Article 199

“No one may be declared incapable save pursuant to a court judgment pursuant to the causes set forth in the Law”.

Article 200

“Persistent physical or mental illnesses or deficiencies which prevent a person from governing himself shall be causes for incapacitation”.

Article 201

“Minors may be incapacitated if a cause for incapacitation should apply to them and is reasonably expected to persist after they come of age”.

Detailed regulation of systems for incapacitated persons along with minors in the form of Guardianship, Conservatorship, Judicial Defender and de facto Carer are included in Articles 215 to 306 of the Civil Procedure Act.

CERMI have advocated that minor adjustments to the existing legislation will not be sufficient to remove the paternalistic systems which allow for substituted decision making on the grounds of disability and there is a need to replace them with robust

⁶⁹ Acts which promised the reform of procedures for legal incapacitation in 2009 and 2011 were Disposición final 1^a de la Ley 1/2009, de 25 de marzo, de reforma de la Ley de 8 de junio de 1957, sobre el Registro Civil, en materia de incapacitaciones, cargos tutelares y administradores de patrimonios protegidos, y de la Ley 41/2003, de 18 de noviembre, sobre protección patrimonial de las personas con discapacidad y de modificación del Código Civil, de la Ley de Enjuiciamiento Civil y de la normativa tributaria con esta finalidad; y Disposición adicional 7^a de la Ley 26/2011, de 1 de agosto, de adaptación normativa a la Convención Internacional sobre los Derechos de las Personas con Discapacidad.

supported decision making systems based on the CRPD Article 12.⁷⁰ It is recognized by those that have analysed the current legislation in Spain on legal capacity in terms of compliance with the CRPD, that removing the stigmatising language within the current civil code is just one of the many steps involved in the reform required.⁷¹

4.2.2. Civil Code of Catalonia – Act 25/2010 of 29 July

Introduced in January 2011, the Act 25/2010 of 29th July, the second book of civil code of Catalonia on persons and family, includes the introduction of a new system of assistance in the area of legal capacity, along with regulation of continued systems of guardianship and partial guardianship (curatorship). This legislation will be analysed in the next section.

4.3 Case example of Ireland

Ireland has signed the CRPD but has indicated that it needs to make changes to national legislation order to be compliant with the CRPD and to date, has not ratified it, while changes to legislation are progressing to replace the 1871 Lunacy Act. The Centre for Disability Law and Policy (CDLP) at the National University of Galway (NUIG) has been a driver for change in guardianship measures in Ireland and internationally, producing extensive academic and policy papers and submissions.⁷²

⁷⁰ CERMI's basic outline proposal for setting up a new procedure for providing support for decision making in accordance with the international convention on the rights of persons with disabilities, CERMI 2010 p. 2.

⁷¹ Bariffi, Francisco J., Professor of International Law at the University Carlos III Madrid, in 2009, recommended that it is not just simply replacing the name of tutelage or guardianship with 'support person' in the national legislation, complex systems will be required in the legal reform along with political action in aspects of education and in adequate financial resources, Futuex Documento para el debate. Configuración jurídica de un modelo de apoyos. Olivenza, 2010, p. 7.

Vivas Tesón, Inmaculada, Professor of Civil Law, University of Seville, identified ten guidelines which could be used in legislative reform in Spain, the first includes the importance of removing stigmatising language and creating a comprehensive framework for all situations that ensures the persons autonomy to manage their own private interest, in "Más allá de la capacidad de entender y querer. Un análisis de la figura italiana de la administración de apoyo y una propuesta de reforma del sistema tuitivo Español. Observatorio Estatal de la Discapacidad, Olivenza, 2012, p. 85.

⁷² See CDLP website for comprehensive list of papers and submissions on legal capacity: www.nuigalway.ie/cdlp/

The National Disability Strategy was introduced by the Irish Government in 2004 including three pieces of legislation; the Disability Act 2005, the Education for Persons with Special Educational Needs Act 2004; and the Citizen’s Information Act 2007. The Disability Act 2005 guides sectoral plans for six Governmental Departments on areas of employment, accessibility, integration within mainstream service provision and specific guidance on assessment of individual needs, but falls short in terms of rights of persons with disabilities with no right to seek judicial remedies relating to the provisions of the Act.⁷³ The Citizens Information Act 2007 included the introduction of a Personal Advocacy Service (PAS) for persons with disabilities with a range of statutory powers such as power to enter residential settings where people with intellectual disabilities live⁷⁴ and powers to assist people with the Assessment of Need process. Lack of prioritization of resources have prevented the establishment of this advocacy service to date.⁷⁵

4.3.1. Legislation on Legal Capacity in Ireland

The replacement of the 1871 Lunacy Act, which regulated a system of full guardianship, placing people in “wardship” of the court, is long over due and while some legislative reforms relating to mental health, involuntary detention and capacity of persons with mental health problems were introduced in the Mental Health Act 2001, this legislation is considered to be in violation of rights in terms of mechanisms for forced treatments and involuntary detention and in need of further reform.⁷⁶ A scheme

⁷³ ICCL, FLAC, IPRT, Joint Shadow Report to the Third Periodic Report of Ireland under the International Covenant on Civil and Political Rights, 2008, p. 17.

⁷⁴ 2011 figures report 4,000 people living in such settings in Ireland which up until recently, had no oversight mechanisms. January 2014, the body HIQA gained statutory power to commence regulating these settings, figures from Inclusion Ireland, 2013.

⁷⁵ A national advocacy service (NAS) was introduced but with less statutory powers, Inclusion Ireland and other organisations continue to call for establishment of range of advocacy services that can meet the required needs of people with disabilities in Ireland, including PAC statutory service, voluntary, self-advocacy, peer advocacy. Inclusion Ireland Report, 2013, p. 15.

⁷⁶ Oireachtas Library and Research Service The Mental Health Act 2001: Delivering on best practice? Spotlight report No. 5 2012.

of a bill was produced in 2008, Scheme Mental Capacity Bill 2008, but not enacted and while the delay in producing legislation is to be criticised, this time period has allowed for a better understanding of what CRPD Article 12 should look like when translated into national legislation, so that aspects such as determination of a person's best interest and legislation which gives no clear distinction between mental capacity and legal capacity will not be in the legislation finally enacted.⁷⁷

4.3.2 Assisted Decision-Making (Capacity) Bill 2013

The Assisted Decision-Making (Capacity) Bill 2013 was published in July 2013 and has gone through a number of stages of public consultation, debate in the Dail (Government) and re-drafting based on submissions, particularly submissions lead by CDLP, involving representative groups such as Inclusion Ireland, Age Action Ireland, Disability Federation Ireland and Amnesty Ireland. Introducing systems of "assisted decision-making agreements" to replace the current, 140 year old system of "ward of court", it will be analysed further in the following section.

4.4 Analysis of sample States' national legislation with regard to compliance with Article 12 and the General Comment

The two sample States' legislation relating to legal capacity and persons with disabilities are analysed here with reference to the text of the General Comment no 1 (2014) in relation to implementation of Article 12 and compliance with same. The reason for choosing these two sample cases are, the legislation is in proposed draft form in the case of Ireland, the Assisted Decision making (capacity) Bill 2013,⁷⁸ and it is avidly awaited not only in Ireland but internationally as an example of legislation that

⁷⁷ Scheme Mental Capacity Bill 2008, contained definition of capacity as (1)*Subject to this Head capacity means the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made, hereinafter referred to as "the capacity to make a decision". Head 2 – Definition of capacity.*

Scheme Mental Capacity bill 2008 contains guidelines on the determination of what is in a person's best interest. Head 3- Best Interest in Scheme.

⁷⁸ Assisted Decision-Making (Capacity) Bill 2013.

has potential to meet full compliance with the CRPD Article 12.⁷⁹ This is in particular with reference to abolishing all substituted decision-making in the form of guardianship and introducing range of supported decision-making models. A submission on the draft bill to the legislators in Ireland from the Centre of Disability Law and Policy (CDLP) together with a group of civil society organisation was made in November 2013 and the submission's amendments to the Bill will be referenced here, to indicate how the bill can be brought in line with Article 12.⁸⁰

The sample legislation in the second case, Act 25/2010, of the second book of the Civil Code of Catalonia, on persons and family, is an example of implementation of legislative reform, enacted in 2011, that introduces a model of assisted decision-making along side continued forms of substituted decision making.⁸¹

The specific themes to be addressed in this analysis are:

- Legal capacity to be holder of rights and to exercise rights
- The (absolute) shift from substituted decision-making to supported decision-making
- Denial or adjustment of legal capacity - on what grounds? (the question of mental capacity)
- Supports to exercise legal capacity
- Safeguards to ensure the respect of right

4.4.1 Legal capacity: to be holder of rights and to exercise rights

The text of the general comment provides clear confirmation that the words Legal Capacity in Article 12 can only be interpreted to mean both holder of rights and ability

⁷⁹ FRA, 2013 and MDAC, 2013.

⁸⁰ CDLP Submission to the Department of Justice and Equality, 2013.

⁸¹ Act 25/2010, of the second book of the Civil Code of Catalonia,

to exercise rights and that they cannot be separated.⁸² The General Comment may serve to influence the inclusion of a clear definition of legal capacity in national legislation as the test case for Ireland indicates below.

No definition of legal capacity is found in either sample legislative text from Ireland or Catalonia.

Act 21/2010 Civil code of Catalonia mentions natural capacity as the capacity to act and provides mechanisms for its restriction within the legislation.⁸³

Assisted Decision-Making (capacity) Bill 2013 refers to capacity as mental capacity.⁸⁴ CDPL submission advocates for inclusion of definition of legal capacity in the bill, as *both the capacity to hold rights and exercise them*, referring to the text of the draft General Comment at the time of publication.⁸⁵

⁸² The text of the General Comment no 1 (2014) paragraph 11 states “*Article 12, paragraph 2, recognizes that persons with disabilities enjoy legal capacity on an equal basis with others in all areas of life. **Legal capacity includes the capacity to be both a holder of rights and an actor under the law.** Legal capacity to be a holder of rights entitles the person to full protection of his or her rights by the legal system. Legal capacity to act under the law recognizes person as an agent with the power to engage in transactions and in general to create, modify or end legal relationships. The right to recognition as a legal agent is provided for in article 12, paragraph 5, of the Convention, which outlines the duty of State parties....*”.

Paragraph 12bis states “*Legal capacity is an inherent right accorded to all people including persons with disabilities. As noted, it consists of two strands. The first is the legal standing to have rights, to be recognized as a legal person before the law. This may include, for example, having a birth certificate, seek medical assistance, register to be on the electoral role, or applying for a passport. The second is the legal agency to act on those rights, and to have those actions recognized by the law. It is this component that is frequently denied or diminished for persons with disabilities. For example, laws may allow persons with disabilities to own property, but do not always respect the actions of people in terms of buying and selling property. Legal capacity means that all people, including persons with disabilities, have legal standing and legal agency simply by virtue of being human. Therefore, both these strands of legal capacity must be recognized for the right to legal capacity for persons with disabilities to be fulfilled; they cannot be separated.*”.

⁸³ Act 21/2010 “*.... emphasises natural capacity as a basic criterion for the acquisition of the capacity to act, in accordance with the provisions of the Civil Code*”.

“*...the natural capacity of the persons and the respect for their autonomy in personal and family life, without ignoring that the possibility of abuse calls for appropriate control mechanisms.*”

⁸⁴ Assisted Decision-Making (capacity) Bill 2013 “*Capacity*” means mental capacity and shall be construed in accordance with section 3.

⁸⁵ CDLP Submission to the Department of Justice and Equality, 2013.

4.4.2 The (absolute) shift from substituted decision-making to supported decision-making

Can the aspiration of change embedded in the CRPD occur if States continue to implement forms of substituted decision-making, even if augmented with systems of assisted or supported decision-making? An understanding of the terminology is crucial along with an understanding of the philosophical thinking behind the language.

Gerard Quinn questions the enlightenment's discovery of humans capability for "*autonomous, rational being*", which legitimised the necessity for legal institution of substituted decision-making for those without capacity, in the many historical and modern day forms.⁸⁶ A capacity to rationally apprehend consequences and measure them to arrive at rational decisions, independently, in the human autonomous form, he argues is not the reality for most people when making decisions, rather we are products of our culture, influenced by our preferences and involve others, family, friends, professionals, in our choices. The conclusion is that few of us make 'rational' decisions, we use support in our decision-making and that any measurement or assessment of rational capability or capacity for persons with disability in order to remove their right to legal capacity is discriminatory.

Michael Bach describes the CRPD shift in thinking on legal personhood as moving away from what he defines as "*the narrowly based "natural rights" and "natural laws" based on individuals reason and capacity*" as formulated from works of Aristotle to Kant to Rawls, towards a "social recognition" of moral rights of personhood: recognition of persons as *intending subjects*, communicating their "personhood" through the expression of will and preferences, and inter-subjective elements - space between person and others, capacity to be known, to have a "life story" of likes, wishes, personal attachments, needs, strengths, all elements that can be recognized as personhood.⁸⁷ In the case of an individual with significant disability, Bach emphasises

⁸⁶ Quinn, Gerard, 20 February 2010, p. 7.

⁸⁷ Bach, Michael, Presentation on Legal Capacity, 2009.

the recognition that trusted networks surrounding this person with significant disability gives to that individual.

Theories on social capital have been used to guide developments in legal capacity theory and practice, particularly when focusing on family and social networks supporting people with significant disability.⁸⁸ The argument for supported decision-making, along with the argument that people have the right to make the “wrong” decisions, the right to be the person making the decision, rather than someone else substituting for them, are at the center of the CRPD, but what of the “difficult” or “problem” cases? Is there a need to retain some form of substitution for people who may require it, those that might be at risk of injuring themselves or others, and those that do not have a method of communication that allows them to participate in the decision. If so, how do we protect the slippery slope that could allow discriminatory practices of denial of legal capacity to fall into place or continue to occur? If not, how are the difficult cases to be dealt with?

What insight does the General Comment offer? Firstly, it calls for all substitute decision-making regimes such as guardianship, conservatorship and mental health laws that permit forced treatments to be abolished.⁸⁹ Paragraph 9 calls for all practices that ‘*in purpose or effect*’ violate article 12 to be abolished to ensure full legal capacity is restored to persons with disabilities on an equal basis with others.

The General Comment goes on to clarify that to develop supported decision making regimes while maintaining substitute decision making regimes in parallel, is not sufficient to comply with Article 12.⁹⁰ Progressive realisation of the right is also

⁸⁸ Lashewicz, Bonnie; Mitchell, Jennifer; Salami, Eniola; Cheuk, Samantha; January 2014, p. 4.

⁸⁹ General Comment no 1 (2014) paragraph 7: *...substitute decision-making regimes such as guardianship, conservatorship and mental health laws that permit forced treatment. These practices must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others.*

⁹⁰ General Comment no 1 (2014) paragraph 24: *State parties’ obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. The development of supported*

clarified as not applicable to Article 12, a civil and political right to equal recognition before the law.⁹¹

Clarity on defining substitute decision-making is provided in paragraph 22 and the list of examples includes partial guardianship. Three common characteristics are listed; removal of legal capacity from the person; the appointment of substitute decision maker by someone other than the person and any decision made by a substitute decision maker based on what is believed to be in the “*best interest*” of the person, as opposed to being based on the person’s own will and preferences.⁹² The dominance of will and preferences within the supported decision-making system is required in order to replace the best interests concept, which is linked to the substituted decision maker(s) views potentially overriding that of the individual and the need to move away from the paternalistic, protective paradigm.

Eilonoir Flynn and Anna Arstein-Kerslake, who worked with the committee drafting the General Comment, advocate for a support model of legal capacity as a universal model, that can address all cases, including the hard cases.⁹³ They build their case on the shoulders of previous work, that of Gerard Quinn’s on personhood and legal capacity

decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.

⁹¹ General Comment no 1 (2014) paragraph 26: *The right to equality before the law has long been recognized as a civil and political right, with roots in the International Covenant on Civil and Political Rights. Civil and political rights attach at the moment of ratification and State parties are required to take steps to immediately realize these rights. As such, the rights provided for in article 12 apply at the moment of ratification and are subject to immediate realization. The state obligation to provide access to support for the exercise of legal capacity in Article 12(3) is a state obligation required for the fulfilment of the civil and political right to equal recognition before the law. Progressive realization (art. 4, para. 2) does not apply to article 12. Upon ratification, State parties must immediately begin to take steps towards the realization of the rights in article 12. These steps must be deliberate, well-planned, and include the consultation and meaningful participation of people with disabilities and their organizations.*

⁹² General Comment no 1 (2014) paragraph 22: *Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is just in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will or (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective “best interests” of the person concerned, as opposed to being based on the person’s own will and preferences.*

⁹³ Flynn, Eilonoir and Arstein-Kerslake, Anna, 2014, p. 98.

and the models of support presented by Bach and Kerzner.⁹⁴ They return to the guiding principle of arriving at the will and preferences of the person with each difficult case, using a continuum of flexible supports and that decision-making capabilities can almost always be augmented. They argue that this does not prevent a representative from making a decision for another person who is not in a position to communicate (for example; a person in a coma), but requires replacing best interest with a requirement to draw out the imagined will and preferences of the person. Only when it is not possible to conclude on will and preferences, should other considerations be taken into account. They do not elaborate on what ‘other considerations’ might constitute, but they advocate for the need to indicate that will and preferences have been sought as the essential start point. This approach to supported decision-making will be expanded further in section three.

The General comment uses the language “best interpretation” of will and preference as opposed to “imagined” for cases where it has not been possible to determine the will and preferences of the person, despite significant efforts being made.⁹⁵ It does not include, (perhaps intentionally) the mention of representative in making the decision *for* the person, based on the best interpretation of will and preferences (as Flynn and Arstein-Kerslake do in their article). The general comment does not elaborate beyond the requirement for best interpretation of will and preferences, that is, in terms of situations where even the best interpretation is not possible to ascertain and what requirements should be met to determine this.

For the case of a person who is at risk of self-injury in emergency situations, Flynn and Arstein-Kerslake call on common law duty of care, the defense of necessity and other laws covering intervention in emergency situations as opposed to relying on limitation

⁹⁴ Flynn, Eilonoir and Arstein-Kerslake, Anna, 2014, p. 82.

⁹⁵ *General Comment no 1 (2014) paragraph 18bis: Where, after significant efforts have been made, it is not practicable to determine the will and preference of an individual, ‘best interpretation of will and preference’ must replace ‘best interests’ determinations. This respects the rights, will and preferences of the individual, according to Article 12 (4). The ‘best interests’ principle is not a safeguard which complies with article 12 in relation to adults. The ‘will and preference’ paradigm must replace the ‘best interests’ paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.*

of legal capacity.⁹⁶ Guidance on this in the general comment is limited to the respect for individual autonomy and capacity of persons with disabilities at all times, including during crisis situations.⁹⁷

The sample legislation **Act 21/2010 Civil code of Catalonia** includes the implementation of a new regime of Assistance in parallel with continued regimes of guardianship and curatorship for persons with disabilities. By its nature of continued substituted decision-making in parallel with new supported system, it is in conflict with the principle of CRPD Article 12 and the general comment. The shift in thinking towards (but not there yet, in terms of compliance with) the CRPD is apparent, in the acknowledgement that *the implementation of a regime of guardianship may be disproportionate to the needs of some persons*.⁹⁸ The concept of proportionality here is influenced by and in line with the Recommendation No. R (99) 4 of the Committee of Ministers of the Council of Europe,⁹⁹ and the trend in other countries in Europe, where some modernization of guardianship systems has taken place, Italy and France for example.

Compliance with the COE Recommendations is one justification given for the introduction of the new assistance regime, along with the criteria of meeting the needs of persons who present with a “non-disabling decrease in physical or mental faculties”, removing the requirement to assess decision-making capacity and enabling assistance or support to be the more immediately available in this scheme of legal capacity assistance.

Aside from the fact that continued systems of full or partial denial of legal capacity is

⁹⁶ Flynn, Eilonoir and Arstein-Kerslake, Anna, 2014, p. 99.

⁹⁷ General Comment no 1, (2014) paragraph 16 “*At all times, including during crisis situations, the individual autonomy and capacity of persons with disabilities to make decisions must be respected.*”

⁹⁸ Act 21/2010, p. 11.

⁹⁹ Act 21/2010, p. 11 “*In line with the guidelines of Recommendation R (99) 4, of the Committee of Ministers of the Council of Europe, of 28 February 1999, and with the existing precedents in various neighbouring legal systems, it was considered that this model of protection, parallel to guardianship or curatorship, could be more appropriate. Moreover, this trend also inspires the Convention on the Rights of Persons with Disabilities.*”

not compliant with the CRPD, another issue with operating multiple systems in parallel, is the need for very clear guidelines on each of the systems to avoid practical problems in the administration of the systems, such as those experienced in the application of the Italian legal system, where a new supported regime was introduced in parallel with full and partial guardianship.¹⁰⁰ When a system of supported decision-making is introduced along with retained systems of substituted decision-making, the decision to apply one scheme over another is not clear. Uptake of the supported decision-making is considered to be less than intended or aspired for, while options of guardianship are available. When this is considered, the option of abolishing all systems of full plenary guardianship when introducing a new legal capacity system, such as that of the Betreuung system in Germany, allows for less confusion with system and removes the possibility of reverting to full guardianship.¹⁰¹

The **Assisted Decision-Making (Capacity) Bill** replaces the existing system of guardianship or “ward of court” with a range of systems based on supported decision-making: Assisted decision-making, Co-Decision-making, Representative decision-making. It also includes a section of legislation (part 7) covering informal decision-making in matters relating to personal welfare, that, on interpretation, justifies substitute decision-making to continue without safeguards.¹⁰²

This has been highlighted in the CDLP submission as important to address in the reform legislation, so that the final Act adopted does not have a provision within it that gives a form of legislative approval of informal substituted decision-making. Informal arrangements of decision-making are the day-to-day decision taken in life, occurring independently of any formal legal governance. For many people with disability, the informal decision-making arrangements they use work well, it is how families and communities operate, with or without the disability factor, with no need for legally binding contracts. However, research on legal capacity of persons with intellectual disabilities and persons with mental health problems, carried out by the European Union

¹⁰⁰ Vivas Tesón, Inmaculada, 2012, p 86, para 6.

¹⁰¹ Vivas Tesón, Inmaculada, 2012, p. 64 ss.

¹⁰² CDLP Submission to the Department of Justice and Equality, 2013, p. 18.

Fundamental Rights Agency (FRA), highlighted the fact that restrictions on decision making occurs frequently, irrespective of legal status, constraining life decisions about where to live, relationships, money, health. The FRA research points to reasons such as low expectations, paternalistic attitudes shared by professionals and parents, dependency and fear factors.¹⁰³ The numbers of people with disability in the formal “ward of court” system in Ireland is small,¹⁰⁴ indicating that most people with disabilities are not covered by capacity legislation and are living in the informal decision-making environment. Statutory measures have recently been introduced to regulate certain situations such as residential settings, in the form of the 2013 National Standards for Residential Services for Adults and Children with Disabilities.¹⁰⁵ The academic, civil society and disability representative groups in the CDPL submission call for an obligation on carers, family members and professionals to support persons with disabilities to create assisted decision-making agreements, rather than turning to informal substitute decision making.

4.4.3 Denial or adjustment of legal capacity - on what grounds? (the question of mental capacity)

Having ascertained that the general comment no 1 (2014) gives clear direction on the need to replace substituted decision-making with supported decision-making, and to avoid running both in parallel, the question of the criteria for introducing a supported decision-making regime for the individual requiring such regime remains. In order to make analysis of guidance on this in the general comment, the criteria included in the two sample legislative texts will be taken to illustrate what is presently included in national legislation. Academics and civil society groups have provided their thinking on the question of assessing capacity (for legal capacity). The distinction between mental

¹⁰³ FRA, 2013, pp. 49-51.

¹⁰⁴ Figures are published for each year, Irish Courts Service website, link to figures for 2012 at: <http://www.courts.ie/Courts.ie/Library3.nsf/66d7c83325e8568b80256ffe00466ca0/f3f5fb8247bbc825802575f20038272d?OpenDocument> (last accessed 6 June 2014).

¹⁰⁵ HIQA National standards for Residential Services for Adults and Children with disabilities 2013, p Under Regulation 09 (2) (a) *you are required to: Ensure that each resident, in accordance with his or her wishes, age and the nature of his or her disability, participates in and consents, with supports where necessary, to decisions about his or her care and support.*

capacity and legal capacity and how they inter-relate is important to establish and is one factor in how legislative implementation of Art 12 will continue to fail if this separation is not made clear. Recommendations from civil society/disability representative groups in the case of the Spanish Committee of Representatives of people with disabilities, CERMI and the CDLP submission documents on this, shine light on what is proposed as practice that could be applied in the process of establishment of supported decision-making regimes. The text of the general comment on this will then be presented in light of the national legislation findings.

In the case of the **Act 21/2010 Civil code of Catalonia**, the decision as to whether the new assistance regime can apply to a person who is considered to be to some degree incapable and in need of protection, appears to be based on the premise that a declaration of incapacity is not required. The Act outlines the principle that legal personality is attained at birth, (the conceived child included, provided s/he is born,) and is extinguished at death. Limitations on the capacity to act “must be interpreted restrictively” according to the Act¹⁰⁶.

The criteria for appointment of an assistant in the Act is based on a “non-disabling decrease in physical or mental powers.” A positive aspect to the Assistance Scheme is that it removes the requirement for the person to have a declaration of incapacity.¹⁰⁷ The reluctance of families to have a declaration of incapacity made about their family member is the official explanation given for the introduction of this system of assistance, thereby avoiding the negative connotations associated with the declaration of incapacity, which can impact negatively on the self esteem and the dignity of the person

¹⁰⁶ ACT 21/2010 ARTICLE 211-3. CAPACITY TO ACT

1. The capacity to act of the persons is based on their natural capacity, in accordance with the provisions of this Code.

2. Full capacity to act is reached upon attaining majority.

3. The limitations on the capacity to act must be interpreted restrictively, with regard to the natural capacity.

¹⁰⁷ “This Act maintains the traditional protection regimes related to incapacity, but it also regulates other regimes which operate or may eventually operate without a declaration of incapacity, as in many cases the disabled persons or their families prefer not to request it.” Act 21/2010 III Structure and Content, p. 7.

and affect the possibility of improvements in capabilities with rehabilitation.¹⁰⁸ The Act defines the need for guardianship on “incapable persons” required by court order and in the case of curatorship, incapable person for whom guardianship is considered not appropriate.

A mixed set of regimes are within the Act, allowing selection to be made based on nebulous criteria linked to status of capability/disability. The variety of possible situations that can and do arise for people in changing and evolving lives, leaves this law open to many questions of applicability. This is a symptom of the retention of guardianship schemes along with new assisted or supported regimes based on medical model criteria of selection or attainment of any given scheme. The continued use of the medical model to categorise level of disability within the legal civil code is even more blunt in the section of the Civil Code on Estate Protection where degrees of disability such as a mental disability of 33% or more or a physical or sensory disability of 65% or more are included when referring to potential beneficiaries of the estate protection scheme.¹⁰⁹

CERMI, the umbrella organisation for Disability Representative Groups in Spain, advocate for minimum intervention and a “supports focused” system to apply to the process.¹¹⁰ The shift is away from requiring criteria of proven incapacity (considered to be based on the medical model) to one of requiring information on the level of support or assistance which might be required in order to make decisions. CERMI suggest the people involved in the procedure might include the person claiming support (or for whom support is being claimed), the required legal, social and/or civil personnel and the multidisciplinary team. The multidisciplinary team’s suggested role is to “*appreciate the person’s situation and to make recommendations on suitable supports for the*

¹⁰⁸ De Barron Arniches, Paloma, 2013, p. 813.

¹⁰⁹ “Persons with a mental disability of 33 percent or more or with a physical or sensory disability of 65 percent or more may be beneficiaries of a regime of protected estate established under this chapter. So may persons who are dependent on grade II or III, in accordance with the applicable legislation” Act 21/2010 Chapter vii, Article 227-1, p. 67.

¹¹⁰ CERMI, 2010, p. 4.

person.”¹¹¹ If this were to take place, the narrow lens focused only on the abilities/disabilities of the person could be opened wide, to allow the person remain in the center of the frame but other people, background information, and alterations to the environment are all now included in the picture, all of which can be appreciated in the analysis of the image. There is no longer a requirement for analysis of the person, in terms of what within the nature of that person might impede their decision-making, but rather a determination to find what supports will enable them. This is what is at the essence of Article 12.

The **Assisted Decision-making (Capacity) Bill 2013** in its draft bill text includes a requirement to have assessed incapacity in order to qualify for assisted decision making procedures. The formula applied to functional assessment of capacity to make decisions has been applied here in the legislation, so that the onus is on the person to fail the test of capacity in order to qualify for support. The functional approach to assessment of capacity for decision-making is determined to be the least discriminatory of the range of approaches used in this area and has featured in more recent law reforms such as the Mental Capacity Act 2005 in England and Wales.¹¹²

The idea that status of disability applied as criteria to deny legal capacity has been understood by most legislators, academics, policy makers and disability representative organisations, as being a form of discrimination and ought to be eliminated from all legal capacity procedures. The literature on this topic describes three main approaches that are generally be used in procedures determining capacity; the status approach; the outcome approach and the functional approach.¹¹³ The functional approach, viewed by some as a progressive step from the disability status and outcome approaches when included in legislation on legal capacity,¹¹⁴ is generally presented as an assessment or judgment on the person’s ability to follow a number of steps in the process of making a

¹¹¹ CERMI 2010, p. 4.

¹¹² Booth Glen, Kristin, 2012, p. 93.

¹¹³ Eilionoir Flynn and Anna Arstein-Kerslake, 2012, p. 86.

¹¹⁴ National Disability Authority in Ireland submission on the Mental Capacity Scheme of Bill 2008, welcomed the adoption of the functional approach as a key element in modernising Ireland’s law on capacity.

decision. It is often applied in medical settings, used to determine a person's ability to consent to medical treatments or interventions.¹¹⁵ The text in the Assisted Decision-making (Capacity) Act includes the proviso that for the purpose of creating a decision-making agreement, a person's capacity will be construed functionally, the following criteria included:

“A person lacks the capacity to make a decision if he or she is unable—
(a) to understand the information relevant to the decision,
(b) to retain that information,
(c) to 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, assisted technology, or any other means) or, if the implementation of the decision 35 requires the act of a third party, to communicate by any means with that third party.”¹¹⁶

The argument against using what is termed as the functional approach to determining legal capacity is two fold, one it is another form of discrimination in that this test of “ability” to make decisions is not applied to all, and two, the criteria within this test are intertwined with criteria for assessment of mental capacity in decision-making scenarios and to the questionable notion of rational decision making abilities¹¹⁷ The first part of the argument, the discriminatory aspect of using this as a measure to judge whether a person's legal capacity should be altered, (be it within substituted or supported framework) is what is applied in the case of Ireland and the CPDL's submission to amend the new Assisted Decision-Making (Capacity) Bill before it is enacted. The submission is clear in its direction; *“this bill should not make support options contingent on a test of mental capacity”*. The Bill, while introducing a range of supported decision-making schemes, retains the discriminatory practice of basing these schemes on a required test of incapacity, mental capacity tied to legal capacity, as opposed to clear distinction between the two, with the absolute requirement that legal

¹¹⁵ Chalmer, Julie, 2008, p.18.

¹¹⁶ Assisted Decision-Making (Capacity) Bill, 2013, p. 14.

¹¹⁷ Quinn, Gerard, 2010, p. 6.

capacity cannot be denied or limited because of mental capacity. In order to give clarity to this issue, the CDLP submission calls for the definition of legal capacity to include the clarity that all natural persons have legal capacity and that no restrictions based on disability / mental capacity can apply.¹¹⁸

The experience of States submissions to the CRPD Committee in terms of the use of each of the approaches; status, outcome and functional, playing a role in the denial of legal capacity, has influenced the inclusion of clear instructions in the General Comment that none should be used to deny legal capacity as this practice can be viewed as discriminatory in each case.¹¹⁹

In part III of the General Comment, Obligations on States Parties, a list of key provisions that all supported decision-making regimes should have incorporated, includes, at the last point, the provision that they should not hinge on mental capacity assessments, and goes on to point out the requirement for the development of new, non-discriminatory indicators of support needs.¹²⁰

The debate on mental capacity and how it should be addressed in the General Comment

¹¹⁸ CDLP Submission to the Department of Justice and Equality, 2013, p. 12.

¹¹⁹ General Comment no 1 (2014) Paragraph 13. *“In most of the State party reports that the Committee has examined so far, the concepts of mental and legal capacity have been conflated so that where a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed. This is decided simply on the basis of the diagnosis of an impairment (status approach), or where a person makes a decision that is considered to have negative consequences (outcome approach), or where a person’s decision-making skills are considered to be deficient (functional approach). The functional approach attempts to assess mental capacity and deny legal capacity accordingly. (Often based on whether an individual can understand the nature and consequences of a decision and/or whether she/he can use or weigh the relevant information.) This functional approach is flawed for two key reasons. The first is that it is discriminatorily applied to people with disabilities. The second is that it presumes to be able to accurately assess the inner-workings of the human mind and to then deny a core human right – the right to equal recognition before the law – when an individual does not pass the assessment. In all these approaches, a person’s disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but rather requires that support be provided in the exercise of legal capacity.”*

¹²⁰ General Comment no 1 (2014) paragraph 25 (i) *The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.*

no 1 (2014) on Article 12 continued up to and during the discussion day on the final reading of the general comment in Geneva on the 8th March 2014.¹²¹ Inclusion of definitions of both legal and mental capacity is made in an attempt to illustrate the distinction between the concepts, the text in the General Comment:

*“Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors.”*¹²²

The fact that previous legal instruments did not include this distinction is mentioned, citing the examples of the UDHR (article 6), ICCPR (Article 16) and CEDAW (Article 15), and that the CRPD (Article 12) is now making it clear that discriminatory labels such as “unsoundness of mind” cannot be reasons for denial of legal capacity.¹²³ *Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.* This is how the General Comment establishes the clear distinction, allowing Legal Capacity to be free from the ties of discriminatory restriction or denial based on mental capacity.

The debate on mental capacity and its assessment, in terms of the CRPD and the rights of persons with disability (particularly within the realms of psychosocial mental health) will continue beyond the General Comment 1 (2014). An indication of this is in the additional text introduced to the final text of the General Comment (not in the draft

¹²¹ Author attended and witnessed General Comment discussion Day 8th April 2014. Recording available at <http://www.treatybodywebcast.org/category/webcast-archives/crpd/> Reading of Draft General Comment on article 12 8 April 2014. Last accessed 19 June 2014.

¹²² General Comment no 1 (2014) Paragraph 12.

¹²³ General Comment no 1 (2014) paragraph 12 *“In the past, legal instruments such as the UDHR (Article 6), the ICCPR (Article 16), and CEDAW (Article 15) did not specify the distinction between mental and legal capacity. The CRPD (Article 12) now makes it clear that ‘unsoundness of mind’ and other discriminatory labels are not legitimate reasons for the denial of legal capacity (legal standing and legal agency). Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.”*

version) where mental capacity is described as a controversial entity, the exact text of the general comment included here:

“The concept of mental capacity is highly controversial in and of itself. It is not, as it is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity.”

This could be interpreted in different ways, one of which could be to interpret it as a call for those involved in the practice of assessment of mental capacity to take a fresh look at this practice through the eyes of the CRPD. The debate will continue with advocate groups such as the World Network of Users and Survivors of Psychiatry (WNUSP) and other Disability Representative Organisations making representations.

At first impression, when analysing the importance of the now clearly distinguished differences between the concepts of Legal Capacity and Mental Capacity, it could be interpreted that mental capacity has now been removed from the equation of legal capacity. It has, in the text of the General Comment, in terms of a factor in discriminating against persons with disabilities and that it must not be used to deny legal capacity, both in terms of legal standing and legal agency. The Assisted Decision-Making (Capacity) Act 2013 is an example of legislation, where mental capacity in the form of the functional approach, crept back into the legislation, disguised as a criteria required for accessing supports in exercising legal capacity. What was considered a forward thinking, potentially trend setting piece of national legislation, striving for full compliance with the CRPD, will fall at one of its first major hurdles of compliance, if this is not addressed in the final text of the Act.

The concept of mental capacity has not been removed from the equation of legal capacity, on analysis of the General Comment, it has been repositioned for now, no longer applicable at the entry point, but still in existence both inside and outside the

door of the court. The fact that the implementation of article 12 demands that assessment of mental capacity is not required for legal capacity attainment, in and of itself, should result in an impact over time, in that it will force change in practices where currently, assessment of mental capacity is used in decisions about persons with disability for example, when considering their options for housing /accommodation.

The relationship between, on the one hand, the dominance of expression of will and preferences and on the other hand, the dominance of other factors within mental capacity assessment, (i.e. ability to understand, use/weigh information in decision-making process) is what will be played out in the repositioning within the legal context of the new systems of supported decision-making. A rhythm can be found between all these factors, as experiences of those who go about making decisions everyday testify. Within the CRPD inspired, re-defined, legal apparatus of universal supported decision-making, they have yet to stand the test of time and experience. Sheila Widleman¹²⁴ illustrates this dilemma with an example of what critics of the minimalistic conception of legal capacity may raise – can the person’s expression of will and preferences be considered as a capable choice if, despite supports, the person is unable to understand what is at stake? She pinpointed the question whether this might create a standard where there is some requirement to determine if the person grasps the likely consequences, bringing the question back to how and by whom consequences are judged and the interference of others in the autonomy of the person. These questions were at the heart of the debate during the negotiation of Article 12 and will continue, as supported decision-making models are being analysed and developed in light of the CRPD.

There may be indicators as to how these factors are dealt with in supported decision making arrangements outside the legal system, while continued denial of legal recognition of the person as a person, and therefor denial of opportunity of legal redress, can be considered an influencing factor that has and continues to contribute to

¹²⁴ Wildeman, Sheila, 2013, p. 60.

attitudes and expectations at play in situations where people with disability's decisions are under consideration.¹²⁵ This leads to the expectation that is held for the anticipated change in attitude as a result of addressing discrimination at the point of legal capacity, linked to the comparison with the historical deprivation of women's legal capacity and the consequences of this reform.¹²⁶

4.4.4. Supports to exercise Legal Capacity

Article 12(3) places an obligation on States to provide access to the supports which persons with disabilities may require in exercising their legal capacity.¹²⁷ Analysis of the General Comment no 1 (2014), the selected sample national legislative texts, and in the case of Spain, the State report and CRPD Committee's report in 2010, along with some other support or assisted decision-making models in current practice, results in a wide range of interpretations of what supports refers to in the context of Article 12(3).

The **Assisted decision-making (Capacity) Bill, 2013**, refers to supports in a number of manners:

The use of support is included in the functional assessment of capacity within the Bill.¹²⁸ The application of supports here, however is misdirected, if compliance with the CRPD and Article 12 is considered, as it is focused on eligibility criteria of identification of the persons capacity to succeed or not in make decisions, rather than focused on the person's exercising of the act of decision-making within the context of legal agency. The reference to "*all practical steps are taken to help him or her make a decision,*" refers to the wide scope the Bill has taken in terms of supports to be offered,

¹²⁵ FRA, 2010, p. 15.

¹²⁶ Gerard Quinn/ Theresia Degener eds, 2002, p. 14.

¹²⁷ CRPD Article 12(3): *States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.*

¹²⁸ Section 8 (Guiding principles) sets out the principles applying to all decisions and actions taken under the Bill in support or on behalf of a person lacking capacity..... It requires that a relevant person shall not be treated as unable to make his or her own decisions unless all practicable steps to help him or her make a decision have been taken without success (subsection (3)).

while the last line of this particular section, “...have been taken without success....” demonstrates the potential limitation of access persons with disabilities could actually have to the schemes on offer by creating the potential for the person to demonstrate ability to make a decision with supports which, if successful with these supports, the person is then not eligible for the decision making agreements and the safeguard mechanisms of the Act?

A further anomaly in the current draft of the Act is the fact that incapacity to make decisions (despite all practical steps taken to support the person), is a requirement for each of the schemes in the Act, the co-decision making scheme has a specific requirement that the person must have capacity to appoint the co-decision maker. This requirement does not mention support in terms of the capacity involved in making this appointment. These anomalies are addressed once the requirement *to fail a supported capacity assessment* in order to qualify for assisted decision-making arrangements is removed from the Act. The CDPL submission recommends that no qualifying assessment be applied, that the agreements be available to anyone. It includes reference to a basis of trust between the parties involved and an understanding of the nature of the agreement.¹²⁹

The final version of the Assisted Decision-Making (Capacity) Bill may redirect the “*all practical steps to be taken to help him or her make a decision*” to be applied within the assisted decision making agreements outlined in the Act. These Practical steps are then considered to be supports. The agreements themselves can be viewed as a type of support, as can the models of assistance, the persons providing the assistance and assistance “tools” used within any one of the given models.

¹²⁹ CDLP Submission to the Department of Justice and Equality, 2013, p. 12, “*Assisted decision-making agreements and co-decision-making agreements should be available to anyone to enter into, based on a relationship of trust between the parties and an understanding of the nature of the agreement, rather than a high level of mental capacity (including understanding the consequences of decisions) currently set out in section 3.*”

The Assistance Scheme in the **Act 21/2010 Civil code of Catalonia** is the only reference to support contained within the civil code, the scheme of appointing assistant is “the support”. The scheme allows for the person in question to request the appointment of an assistant and directs that the judicial authority must respect the choice of the person as to who may be appointed to perform the function of assistance.¹³⁰ There are also terms of termination of the scheme if the circumstances which motivated the appointment have changed¹³¹. The Act refers to assistant, singular, which would indicate that only one person can be appointed, unlike the German model which can accommodate a number of people for specific tasks required by the person. Ease of functioning of the system is one reason given for this in analysis of the Act and the guidance included on the assistant within the Act.¹³²

Considering the assistant or the assistance agreement as the “support” in national legislation without further clear guidelines, raises a number of concerns. In the case of this civil code, there is insufficient guidance to ensure that the assistant does not fall into the role of substituted decision maker and limited direction on the scope of their role. Within the scheme, the judicial authority is given power to decide on which aspects of the persons personal or property issues the assistant must protect. The assistant is given the task of ensuring the welfare of the assisted person, with respect for their will and preferences. This appears to be giving more weight to the welfare of the person than their will and preferences and could be interpreted as the assistant’s opinion on what the “welfare” of the person might be. It is close to the “best interest” position which the CRPD and the general comment have indicated needs to be replaced so that a shift from the paternalistic paradigm can be made.

¹³⁰ Act 21/2010 Article 226-1 Appointment of an Assistant The Judicial authority must respect the wishes of the person requiring assistance regarding the appointment or exclusion of any person to perform the function of assistance, p. 65.

¹³¹ ACT 21/201 Article 226-5 Termination of Assistance. Assistance terminates on the following grounds, a) Death or declaration of death or absence of the assisted person; b) Extinction of the circumstances which motivated assistance; c) Declaration of incapacity of the assisted person. In the case of b, the judicial authority, on application of a party, must specify the grounds for termination of assistance and must anul the appointment of the assistant.

¹³² De Barron Arniches, Paloma, 2013, p. 829.

The World Network of Users and Survivors of Psychiatry (WNUSP), in their submission to the CRPD Committee on the General Comment on Article 12, raised the importance of ensuring that *support* within national implementation of Article 12 refers not only to the schemes of supported decision making but that it also includes the supports, formal and informal, that promote the full legal capacity of the person, including measures of accessibility and (reasonable) accommodation.¹³³ WNSUP advocate for the redefining of focus when it comes to supports in that the emphasis should not be on whether the supports are tailored to the needs of the individual but whether the supports are tailored to the exercising of the individual's autonomy and will. The person is not to be considered the object of social supports within society, but rather the society has the obligation to support the mutual exercise of autonomy by each individual, a move from social objectivisation to social solidarity.¹³⁴

The section of the General Comment on normative content notes that Article 12(3) does not specify what form support should take, emphasising that it is a broad term and should be understood to mean both formal and informal support arrangements.¹³⁵ The use of the term State parties must provide "access" to supports, is interpreted to mean that States do not have to be the primary provider of supports but must ensure that support is available. While the concern exists that if States are not obliged to provide the supports, it gives potential for a lack of resource allocation by States to this, the argument presented by some DPOs is that there is a need to avoid State appointed supports to ensure that new schemes of disability service providers are not established to implement systems of continued over-regulation of persons with disabilities lives.¹³⁶ Some DPOs advocate for the strengthening of existing naturally forming networks of support and development of these within communities rather than State provided or professionally top heavy arrangements. WNUSP state "*not top professional but tap*

¹³³ WNUSP side event on legal capacity 8th March 2014, held prior to reading of draft general comment, Digital podcast available at <http://www.treatybodywebcast.org/category/webcast-archives/crpd/>.

¹³⁴ WNUSP side event on legal capacity, 8th March 2014.

¹³⁵ General Comment no 1 (2014) paragraph 15.

¹³⁶ Sociedad y Discapacidad, Peru in their submission on the draft General Comment state "*This emphasis is needed to ensure that supports do not become a regime that over-regulates the lives of persons with disabilities through a new army of service providers*" Sosis Peru, 2014, p 2.

professional”, meaning that professionals can be tapped into but not profession lead top down approach.¹³⁷

The importance of not being overly prescriptive on the aspect of support, what it should entail, how it should be configured etc., was emphasised at the general discussion day of the reading of the General Comment. Theresa Degener, CRPD committee member and head of the committee working on the General Comment (which took place over a 5 year period) spoke of the need for systems to evolve over time, for room for flexibility and diversity and stressed the need to research and record the range of systems in use. The establishment of a database to enable the collection and collation of different schemes was suggested.

In the State’s obligations section, the General comment provides a list of key provisions that all supported decision-making regimes should incorporate in order to be in compliance with article 12, which are summarised here:

- availability to all, especially those with high needs
- based on will and preferences, not perceived best interests
- mode of communication, including non-conventional not to be a barrier
- legal recognition of support person(s) chosen by person, and state obligation to facilitate creation of support, particularly for those who are isolated, and mechanism to verify and challenge action of support person if perceived to be not acting on will and preferences of person
- access to support, at nominal or no cost, so financial resources are not a barrier
- support in decision-making not a justification to limit other fundamental rights, such as right to vote, right to civil partnership, right to consent, etc.
- person to have right to refuse support and terminate or change it at any time
- safeguards must be set up to ensure respect for person’s will and preferences

¹³⁷ WNUSP side event on legal capacity, 2014.

- provision of support not to hinge on mental capacity assessment, new, non-discriminatory indicators of support needs are required.¹³⁸

The definition of supports should not be limited to that of supported decision-making regimes but should also include range of supports which could be used within these schemes or for some people, they do not require a support regime as such, but a form of support or adjustment that enables them and others to engage in the process; sign language, accessibility options such as physical assess, or information in an alternative format or use of alternative communication system. In the general comment this relationship between ‘supports’ and that which is termed ‘reasonable accommodation’ is covered in the section on relationship with other provisions of the Convention. Article 5 of the CRPD is about equality and non-discrimination and includes a specific direction that reasonable accommodation is a right in the fulfilment of equality for persons with disability.

The general comment attempts to give clarity, as there is potential for confusion between the terms support, reasonable accommodation and accessibility. The General Comment states that while reasonable accommodation is separate and complementary to support for legal capacity, where support over-rides any limitation or proportionality imposed by reasonable accommodation, it is an absolute obligation to provide access to support in exercising legal capacity. This neutralises the undue burden limitation inherent in reasonable accommodation, in situations where support is required for the person to achieve legal capacity. Any form of accommodation linked to the person’s achievement of legal capacity can be included as a form of support in this sense.

How this is translated into national legislation is worth investigating when looking at supports for legal capacity. Are the national policies and legislation guiding reasonable accommodation sufficient in the context of enabling exercise of legal capacity or should specific guidance be included in legislation on legal capacity to ensure clarity on all aspects of support and not limited to the operation of new statutory schemes of

¹³⁸ General Comment no 1 (2014) paragraph 25.

assisted decision-making. When developing or enhancing existing natural or informal supported decision-making arrangements within communities, this absolute State obligation to provide access to supports can potentially be called upon to ensure these groups are resourced to create opportunities to be effective in their role.

4.4.5 Safeguards to ensure the respect of rights

When Article 12(4) on safeguards is interpreted, safeguards could be considered a way to legitimize substitute decision-making, which Gerard Quinn described as creating the potential for Article 12(4) to “swallow the paradigm shift” contained within Article 12.¹³⁹ The interpretation of safeguards as systems of regulating the actions of guardians in their substitute decision-making role is described in the State Report of Spain in 2011 to the CRPD.¹⁴⁰ The General Comment no 1 (2014) gives direction that safeguards apply to systems of support in the exercise of legal capacity, with the primary purpose of ensuring the respect of the rights, will and preference of the person.¹⁴¹

¹³⁹ Quinn, Gerard, 2010, p. 16.

¹⁴⁰ State Report 2011, para 55. *The safeguards and measures concerning the exercise of legal capacity mentioned in paragraph 4 of this article are enshrined in Spanish legislation in the following term Para 56. Respect for the rights, will and preferences of the individual is fundamentally reflected in article 200 of the Civil Code, which requires guardians to perform their task in a manner in line with the personalities of their wards and respectful of their physical and psychological integrity. Para 57 The requirement of absence of conflicts of interest is mentioned in article 244(4), which states that the existence of major conflicts of interest with the incapacitated person is a disqualification for guardianship, while article 247 provides for removal of guardianship where this disqualifying factor arises or the guardian is guilty of misconduct in the performance of his task through failure to discharge the duties pertaining thereto, either through manifest incompetence or when serious and continuing problems of coexistence arise.*

Both provisions also apply to curators and legal defenders. Article 299 provides for the appointment of a legal defender to represent and safeguard the interests of the disabled person when a conflict of interest arises between that person and his/her legal representatives or curator. Finally, article 221 prohibits any person discharging a guardianship function from representing the ward when by so doing he or she will intervene in a personal capacity or on behalf of a third person and there is a conflict of interest.

¹⁴¹ General Comment no 1 (2014) Para 18: Article 12, paragraph 4, outlines the safeguards that must be present in a system of support in the exercise of legal capacity. Article 12, paragraph 4, must be read in conjunction with the rest of article 12 and the whole Convention. It requires State parties to create appropriate and effective safeguards for the exercise of legal capacity. The primary purpose of these

In terms of the development of supported decision making regimes, the form that safeguards will take in regulating the systems of supports, ensuring the will and preferences of the person are respected and in addressing situations of conflicts of interest will evolve along with the systems themselves, still considered to be in evolution stages.¹⁴² Can the same safeguards apply in informal systems of supported decision making, the need for which was highlighted by the CDLP submission on the Assisted Decision-Making (Capacity) Bill 2013, where the need is raised for safeguards and for “*the informal supporter to be under an obligation to minimise conflict of interest?*”¹⁴³

The conflict of interest concern is present in both systems, supported and substituted decision-making, with the argument that by having safeguards to ensure the persons’ expression of will and preference is supported, should ensure the person’s own wishes are heard as opposed to the situation of substituted regimes, which does not guarantee the person can play a role in the decision making, and can give greater power to others involved in the decision. The safeguards in the supported decision-making scenario, need to regulate how that support is delivered, by whom it is delivered and ensure the individual is central to the process at all times. The General Comment no 1 (2014) speaks of “undue influence” that all people can be at risk of experiencing and in situations where a person is using supports to make decision, they can be more exposed to this risk which needs safeguarding. This undue influence is illustrated as something that might be possible to witness in aggressive, fearful, threatening, deceitful or manipulative interactions between support person and individual concerned.¹⁴⁴ However, this may not always be possible to identify and how this subjective judgment can be translated into safeguards in a piece of legislation is not clear. How this is

safeguards must be to ensure the respect of 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.

¹⁴² Quinn, Gerard, 2010, p. 17.

¹⁴³ CDLP Submission to the Department of Justice and Equality, 2013, p. 18.

¹⁴⁴ General Comment no 1 (2014) Para 18ter*Undue influence is characterized where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation. Safeguards for the exercise legal capacity must include protection against undue influence – however the protection must also respect the rights, will and preferences of the person, including the right to take risks and make mistakes.*

translated into national legislation can be guided by those systems of supported decision-making already in place and will evolve more as more States introduce these systems in place of substituted ones. The right to take risks and to make mistakes is included in the safeguards section of the General Comment.¹⁴⁵ Another guiding reminder included in the General Comment is that these systems should not over-regulate the lives of persons with disabilities.¹⁴⁶

The **Act 21/2010 Civil code of Catalonia** has been criticised for its silence on the statutory guidance on the appointment of the assistant, using only the generic term “person” and not providing further guidance on aspects such as potential for conflict of interest or need for professional if complex tasks are required of the assistant.¹⁴⁷

The **Assisted Decision-Making (Capacity) Bill 2013** contains some guidelines on regulating the systems of assisted, co-decision and representative decision-making. Some safeguards refer to the assessment of capacity, recommended by the CPDL submission to be removed from the legislation (such as aspects relating to review of decision of the court on capacity of person using medical and professional reports in relation to assessed capacity). There are safeguard relating to restrictions on the duties of the co-decision maker or decision-making representative, in areas such as exercising powers in relation to settlement of property, refusing consent to carry out life sustaining treatment and necessity to act in order to prevent harm to related person or to another.¹⁴⁸ The guidelines on safeguards in the current draft text blend those that comply with CRPD Article 12, with safeguards that do not comply, such as introducing the concept that the person acting as decision-making representative can, with the

¹⁴⁵ General Comment no 1 (2014) para 18ter

¹⁴⁶ General Comment no 1 (2014) Para 25*Furthermore, systems of supported decision-making should not over-regulate the lives of persons with disabilities.*

¹⁴⁷ De Barron Arniches, Paloma, 2013, p. 829.

¹⁴⁸ Assisted Decision-Making (Capacity) Bill, 2013, Chapter 5, Decision Making Representative, Chapter 4 Co-decision maker.

courts approval, “do an act that is intended to restrain the person, if they reasonably believe that the person lacks capacity.”¹⁴⁹

The submission from CDLP on the Assisted Decision-Making (Capacity) Bill lists suggested duties and obligations of co-decision makers and decision-making Representative, the list provided for decision-making representative is included here:

Decision-making representatives should be under the following duties:

(a) to build a relationship with the relevant person over time in order to fully understand the relevant person’s will and preferences, recognizing that this may be a long-term process

(b) to ascertain the will and preferences of the relevant person on a matter the subject of a relevant decision, using all forms of communication, including, where relevant, total communication, augmented or alternative communication, and non-verbal communication or gestures)

(c) to consult those who know the relevant person well, including friends, family members, and others, in order to formulate the best interpretation of the relevant person’s will and preferences

(d) to assist the relevant person to explore options for each decision to be made, including giving the person the opportunity to try different options before making a final decision

(e) to support the person to connect with and build a network of naturally-occurring community supports, with a view to transitioning out of representative decision-making back to less intrusive options like the decision-making assistance agreement

(f) to assist, where possible, the appointer to communicate his or her will and

¹⁴⁹ Assisted Decision-Making (Capacity) Bill, 2013 Chapter 5, p. 42.

(5) A decision-making representative for a relevant person shall 15 not do an act that is intended to restrain the relevant person unless—

(a) the relevant person lacks capacity in relation to the matter in question or the decision-making representative reasonably believes that the relevant person lacks such capacity,

(b) the decision-making representative reasonably believes 20 that it is necessary to do the act in order to prevent harm to the relevant person or to another person, and

(c) the act is a proportionate response to the likelihood of the harm referred to in paragraph (b) and to the seriousness of such harm.

preferences to third parties,

(g) to make concerted efforts to advise the relevant person by explaining relevant information and considerations relating to a relevant decision in a manner the relevant person can understand,

(h) to assist the appointer to obtain any information or personal records (in this section referred to as “relevant information”) that the relevant person is entitled to and that is or are required in relation to a relevant decision,

(i) to assist the appointer to make and express a relevant decision,

(j) to make the decision based on his or her best interpretation of the relevant person’s will and preferences as communicated and to endeavor to ensure that the relevant decisions are implemented,

(k) to explain to the relevant person, his or her duties as a representative in a manner the relevant person can understand

(l) to investigate and pursue any opportunities for the relevant person to develop natural and community supports, and to support the relevant person to make decision-making assistance agreements or co decision-making agreements with other supporters if applicable,

(m) to abide by the terms of the agreement and not to act beyond the scope of their powers or in breach of their duties

(n) to remain a support for the exercise of the relevant person’s legal capacity and not to act as a substitute decision-maker

The Bill should contain consequences for breach of duties.¹⁵⁰

5. Supports to enable persons with intellectual disabilities to exercise their right to decision-making

Having analysed the legislative aspects addressing the specific themes identified, this section will focus on the evidence available on the application of supported decision

¹⁵⁰ CDLP Submission to the Department of Justice and Equality, 2013, pp. 15-16.

making in exercising the right to make decisions, giving specific reference to the voices of people with intellectual disabilities who have had opportunity to access a supported decision-making system. Experience of the proposed legislation for Ireland has yet to be enabled, as the legislation continues its journey through steps of Governmental approval. The uptake of the new system of Assistance in Catalonia has been minimal to date¹⁵¹, thus not providing adequate information on its application in practice. The research that is becoming available on models of supported decision-making stems from further afield, with evidence coming from the model of Representative Agreements in British Columbia, Canada and new models of non-statutory supported decision-making being trialled in some regions of Australia.

5.1 Research on supported decision-making in practice

There is a scarcity of research on supported decision-making in terms of its application as a replacement to guardianship and outcomes for those who use it.¹⁵² The European Union Agency for Fundamental Rights (FRA) 2013 published research on the topic of legal capacity, included semi-structured interviews and focus groups with 105 people across nine countries in Europe to capture their experiences. Many of the accounts related to experiences of guardianship, choices about where to live and daily activities, and loss of control over finances. Some related their experience of assessment of mental capacity:

“A young psychologist came up to me in the hospital and asked me to do something. She brought a sheet of paper and a pencil and asked me to draw a picture of a farmhouse and a man and a woman on a rainy day on one side of the sheet. On the other side she asked me to draw an animal that has never existed [...]. So I drew a timber house and a man holding an umbrella. On the other side, well, I was supposed to

¹⁵¹ For example in the region of Tarragona, in Catalonia, there is only one appointment of Assistant (Asistente) out of the 600 positions of substituted decision-making (Tutelaes) at the most important Foundation of Guardianship (Fundacion Tutelar) in the area. The use of powers of attorney and Guardianship are considered contributory factors in the failure of the system of Assistance (Asistencia)

¹⁵² Kohn, Nina A, Blumenthal, Jeremy A, Campbell, Amy T., 2013, p. 1113.

draw an animal that does not exist. So I started to draw something with a cow's head, a woman's lips, horns, feathers [...], seven talons, and whatever else I could think of. And then she took it and looked at it. And I said, 'What do you think?' [...] 'Not bad' – she said, then she left, [she] did not say another word”.

(Man with mental health problems, 68, Latvia).¹⁵³

The accounts given in the Human Rights Agency report are clear indicators of the need to reform guardianship regimes and to include professionals and others in roles that have direct influence over the lives of people with disabilities in the reforms. Accounts of informal restrictions on decision-making are also included in the FRA research, indicating that irrespective of legal status, restrictions on choices and exercising of rights are present, within families and communities and amongst health and social care professionals.¹⁵⁴ The need for training to build up skills to recognise situations in which they could take decisions, was identified by members of a focus group on intellectual disabilities in Hungary.¹⁵⁵

A small section of the FRA report gives reference to the experiences of three participants that had access to a formal supported decision-making service in Sweden, through having a “contact person” who provided support in dealing with authorities and welfare agencies, with financial and housing affairs.¹⁵⁶ Informal access of support through family, professionals and some positive experiences of advocacy networks are given mention in the report and the need to investigate further how mechanisms of supported decision-making can be introduced to replace the guardianship mechanisms is indicated.

It is clear the legal systems need to be replaced with new systems, and a small number of research projects are becoming available on the outcomes of supported decision-

¹⁵³ FRA, 2013, p. 43.

¹⁵⁴ FRA, 2013 pp. 49 – 51.

¹⁵⁵ FRA, 2013, p. 49.

¹⁵⁶ FRA, 2013, p. 53.

making models in practice¹⁵⁷. These developments include reports on two projects on non-statutory supported decision-making used in Australia (one is an evaluation of the model used in a trial in South Australia by the Office of the Public Advocate, South Australia, and the other is a research project in Canberra, Australia, where the model developed in South Australia was used - Exploring Supported decision making for people with disability Aged and Carer Advocacy Service, (ADACAS)).

The Law reform Commission of Ontario, Canada, conducted research, described as an initial scoping of the issues involved, with inclusion of a small number of individuals with personal experience of using the supported decision-making system of Representative Agreements in British Columbia. This research was conducted as background research for Ontario, another province of Canada, as they consider changes to their legal capacity legislation.

The objectives of the analysis of the limited research available, is to identify if and how, the use of supported decision-making is increasing the participation and empowerment of people with disabilities in decision-making and if so, to identify elements of the supported decision-making processes that contribute to the success of this achievement and to establish the link with the General Comment on Legal Capacity. First, clarity on the definitions and terms used when discussing systems of supported decision-making is given.

5.2 Defining supported decision-making

Variations of definitions of supported decision-making exist, describing it as a process; “something that happens as a decision is being made”¹⁵⁸ and a means to an end; “supports that enable individuals to make decisions for themselves and expand their capacities to do so”¹⁵⁹; “mechanisms that provide for as much support as is necessary

¹⁵⁷ Gooding, Piers, 2013, p. 442.

¹⁵⁸ Quinn, Gerard, 2011, p. 18

¹⁵⁹ Council of Europe Commissioner for Human Rights. 2012, p. 7.

for people to exercise their right to decide”¹⁶⁰ Some definitions of supported decision-making explicitly tie the definition to the exercising of legal capacity “Supported decision-making, a process by which a third party helps an individual with intellectual or cognitive disabilities make legally enforceable decisions for him or herself.”¹⁶¹. This narrow definition, defining disability groups specifically and identifying the support with an individual third party, precludes the idea of a supported decision making agreement that might include provision that only on agreed occasions, call on a third party or parties, limits the wider concept that anyone can potentially have access to supported decision making (not only specific disability groups), and binds the system to decisions that are legally enforceable.

Clarity on the concepts and the link between supported decision-making and legal capacity is recognized as important when engaging with those who can bring about the changes in practices and attitudes that are recognized as required to realise the right to decide.¹⁶² Linking supported decision-making with legal capacity is important, when focusing on developing legal mechanisms and proposed new law reforms, and Browning et al suggest one way of conceptualizing this is by distinguishing between *supported decision-making in exercising legal capacity* from support *with* decision-making.¹⁶³ The argument made here is that support *with* decision-making is not always linked to achieved autonomy for the person. In some circumstances it can look more like a process of decisions being *accommodated*, but not particularly related to the autonomy for the persons involved. The example given to illustrate was an experiment where consent for a blood test was based on capability to make decisions, which in this case was altered from incapable to capable, on the basis of the provision of simple information, accessible in size and form¹⁶⁴.

¹⁶⁰ UN Enable: Implementing the Convention: Legal Capacity and Supported Decision-Making.

¹⁶¹ N. A. Kohn and J. A. Blumenthal, 2014, p. 40.

¹⁶² Browning, Michelle, Bigby, Christine & Douglas, Jacinta, 2014, p. 34.

¹⁶³ Browning, Michelle, Bigby, Christine & Douglas, Jacinta, 2014, p. 41.

¹⁶⁴ Browning et al, cite a research project by Gunn, Wong, Clare and Holland where it was found that by providing simple information, the findings of the assessment changed from being assessed as incapable to being capable of making the decision, in this instance, consenting to have a blood test or not. Gunn, M. J., Wong, J. G., Clare, I. C. H. & Holland, A. J. (1999). Decision-making capacity. *Medical Law Review*, 7, 269–306. In Browning, Michelle, Bigby Christine, & Douglas Jacinta, *Supported Decision Making*

Aspects to consider if limiting the definition of supported decision-making to that which leads to exercising legal capacity are: one, the potential for missed opportunity to influence and be influenced by others outside the legal settings in this change process, others such as those who make decisions regarding resources or policies, those involved in assessing capacity in spheres of health and education, and those that play vital roles in the lives of people with disabilities, circles of supportive friends and families. Two, the fact that non-statutory supported decision-making occurs in informal and formal arrangements, and systems being introduced in legal reforms need to recognise the role informal processes play, particularly when considering future systems of legislation that can include them in the overall system of regulation and provision of safeguard¹⁶⁵ All considerations of supported decision-making definitions or conceptualisations need to include the opinions of people with disabilities and their representative groups.

What Inclusion International have found in their global research published in 2014, is that changes in legal mechanisms will not achieve the right to decide for people with disabilities without recognition of this right in all aspects of life, by families, communities and societies.¹⁶⁶ The global research addresses all aspects of decision-making for people with intellectual disabilities, cross-referencing denial of the right to decide in health, financial and property and personal life matters, with implications of Article 12 for governments, communities and families.¹⁶⁷ For example, the right to decide about getting married or having children is often denied by families, professionals or social service workers. The implication of article 12 is the recognition of entitlement, either directly or through supported decision-making mechanisms, to make decisions about whether to get married or have children. This could be seen as outside the scope of article 12 if a narrow focus on the legal mechanisms such as

(2014), p. 41.

The process of giving consent for persons with intellectual disabilities is not addressed in this thesis, Other laws govern this, laws which should be linked to legal capacity laws and the establishment of new legal systems for governing supported decision-making should be mindful of this issue in ensuring that the laws dovetail in a way to address this important area. This is addressed in the case of Spanish Law in Vivas Teson, Inmaculada, 2013, p. 1076.

¹⁶⁵ Gooding, Piers, 2014, p. 441.

¹⁶⁶ Inclusion International, 2014, p. 27.

¹⁶⁷ Inclusion International, 2014, Chapter 3 Implications of Article 12 across all areas of Life, pp. 31-48.

removing guardianship is taken, while the introduction of supported decision-making mechanisms should be flexible and accessible and should be concurrent with attitude changes within societies so as to result in an individual having access to support in relation to all aspects of their life. Many people with disability currently live with no official denial of legal capacity, but limited opportunity to make decisions, so the changes in legal systems could potentially have no impact on their lives, unless they have opportunity to exercise their right to decide, and if required, to access official legal mechanisms of support or informal, family and/or community based supports. Changes at grassroots of families, communities and local services through to legislative and government policies are required and building supports for decision making are needed at both ends of the spectrum.¹⁶⁸

It is relevant to address the definitions and terminologies used when referring to supports in the exercising of legal capacity and for the purposes of clarity here, they are categorised in three ways:

Approaches to supported decision-making in exercising legal capacity;

Supported decision-making systems, regimes, models, agreements,

Supports in decision-making;

Approaches to Supported decision-making in exercising legal capacity – broad theoretical frameworks defining the processes of supported decision-making in exercising right to legal capacity.

Supported decision-making systems, regimes, models, agreements – the specific processes used in the exercising of supported decision-making in formal legal capacity context and, bearing in mind the points made above, also included here are non-statutory supported decision-making models. Examples are the Personal Ombudsman in Sweden, German Betreuung system, Representative Agreements in British Columbia, Canada, and the non-statutory supported decision-making model used in South Australia.

Supports for decision-making – broad range of supports that can be used to support an

¹⁶⁸ Inclusion International, 2014, p. 62.

individual in decision-making, in all decision making contexts, including but not exclusive to contexts that give primacy to the autonomy of the person to express their will and preference.

Some examples are listed here,

Types of supporters – family member, advocate, peer supporter, network or circle of supporters

Advocacy

Accessibility, adaptations, assistive technology support

Communication support

Education, training, promotion

Information support

Opportunities to try before making decision

Development of decision readiness,

Communication methods,

The three broad categories are utilised so that information can be presented with clarity, while there is overlap across the three areas categorized and some differences in how the terms are used is evident in academic papers and articles, depending on the jurisdictions and the authors' approaches to the topic.

5.3 Approaches to Supported decision-making

The main concepts that serve to differentiate between the theoretical frameworks/approaches are; whether the inclusion of any form of substituted decision making is permitted, and the role that assessment of capacity plays within the approach.

Three main approaches and the main thinkers behind them are described here:

Stepped model approach (John Brayley) (also described as continuum approach)

Conceptual framework of decision-making supports and decision-making statuses (Bach and Kerzners) (universal approach)

Support model of legal capacity (Flynn and Arstein-Kerslake) (universal approach)

5.3.1 The stepped approach

The “**Stepped approach**” is a spectrum of regulations, described by John Brayley from the Office of Public Advocate, South Australia, which places supported decision-making in the middle of the spectrum, with independent legal decision-making at one end and substituted decision-making based on best interests at the other end¹⁶⁹. The approach taken is to acknowledge the range of models currently available or possible future models, in the legal jurisdiction in this case South Australia, including those models which support and those that substitute in the decision-making process. The spectrum of models, published by the Office of the Public Advocate, includes two models of supported decision-making, statutory and non-statutory. The development of a non-statutory model of supported decision-making in South Australia has enabled evidence of the experiences of people accessing it to be gathered to inform research in this area.¹⁷⁰ For the trails of supported decision-making agreements, statutory recognition was not needed and did not impede their establishment. One important reason for having statutory recognition of supported decision-making, which John Brayley has raised in the context of South Australia, is to counteract the culture of risk management in use within some service organisations, where guardianship orders enable transfer of risk, overriding recognition of decisionmaking rights.¹⁷¹

The stepped approach, described as a continuum approach to legal capacity, includes the use of assessment of the person’s ability to make decisions, while it is not necessary in all of the models contained within the spectrum. The presentation of models used in legal capacity using the stepped approach in Australia is influenced by the fact that a distinction has been made between the capacity to have rights and the capacity to exercise rights, through the registration of an interpretive declaration/reservation on Article 12¹⁷² The continuum approach is said to recognize that a person’s ability to act

¹⁶⁹ Brayley, John, Developing a Model of Practice for Supported Decision-Making June 2011.

¹⁷⁰ Office of the Public Advocate November 2012, Evaluation of the Supported Decision Making Project, and Brayley, John, Supported decision making: A Case for Change, presentation at Conference Supported Decision-Making, 2013.

¹⁷¹ Brayley, John, Supported Decision Making: A Case for Change, 2013, p. 7.

¹⁷² Browning et al, make the point that the reservation on Article 12 which Australia has taken, allows for

legally can fluctuate over time depending on personal and environmental factors and is reflected in the systems available to accommodate this.¹⁷³

5.3.2 Conceptual Framework of decision-making supports and decision-making statuses

Bach and Kerzner developed a **conceptual framework of decision-making supports and decision-making statuses**, which they link with the CRPD recognition of States' obligations to provide people with disabilities with support in exercising legal capacity.¹⁷⁴ The first category or status is defined as “Legally Independent Decision-Making Status” based on the idea that the person understands and appreciates the consequences of a decision, regardless of whether it is considered a wise or unwise decision by others, and the person can communicate this decision to another person. Supports in this status category might be easy to read information, use of brail or technologies or sign language. The second category is the “Supported Decision-making status, where the person is in need of support to express his or her will or intention in the process of decision-making. The Representative Agreement Act of British Columbia, Canada is one example of this type of support system¹⁷⁵.

The third category is the “Facilitated Decision Making Status” to be used as the last resort, for those with significant difficulties in communicating their will and preference, with no possibility of family or a network who know the communication methods of the person. The facilitator is engaged to maximize the persons legal capacity based on the knowledge they have of the person and best interest principles can apply where no

the possibility of a person to be declared incompetent, based on some form of mental capacity assessment. Browning, M, Bigby, C, & Douglas, J, Supported decision-making, (2014) P 40. The interpretive declaration/reservation taken by Australia, asserts that in its view the CRPD permits involuntary hospitalization and treatment in accordance with the country's mental health laws. Wildeman, Sheila. 2013, p. 57.

¹⁷³ Browning, M, Bigby, C, & Douglas, J, Supported Decision-making (2014), p. 40.

¹⁷⁴ M. Bach and L. Kerzner, “A New Paradigm for Protecting Autonomy and the Right to Legal Capacity,” The Ontario Law Commission, Canada, 2010.

¹⁷⁵ Devi, Nandini, 2013, p. 796.

knowledge of will and preference is available.¹⁷⁶

The conceptual framework developed by Bach and Kerzner includes the concept that the knowledge available about a person, their life story, can be attached to their human agency, or their capacity to be known and to be intentional, and can be introduced onto the sphere of legal capacity.¹⁷⁷ Michael Bach presents a narrative about a woman with a physical and intellectual disability, an artist and a dancer, who communicates in ways that her family and close network can understand.¹⁷⁸ He intertwines this narrative into the world of legal agreements which she and her personal network can enter into, within the supported decision-making status framework. Such legal agreements may be open to question as to whether they are the individual's will and preference or their personal network's interpretations, but the process can be considered as an inclusive process and reflective of our interdependency as people. Recognition of interdependency was given emphasis in the findings of the global research report, published by Inclusion International on the right to decide, "Independent but not Alone", which included the recognition of interdependency as one of the recommendations of the report, along with empowerment, self-advocacy and strengthening a collective voice.¹⁷⁹ In the scenario of the woman described by Bach, she has the advantage of having a supportive family and network available to her to give her supported decision-making status. In situations where this is not available, facilitated decision-making status is the default option within this framework, which introduces the provision of best interest and substituted decision-

¹⁷⁶ Devi, Nandini, 2013, p. 796.

¹⁷⁷ Bach, Michael, Presentation 2012.

¹⁷⁸ Bach, Michael, Presentation, 2012.

¹⁷⁹ Inclusion International makes the following recommendations and conclusions in advancing the right to decide:

- Invest in empowerment, self-advocacy and strengthening a collective voice
- Recognize our interdependence
- Families have a critical role to play in building the social connections necessary for supported decision making
- Family based organizations must play a leadership role as agents of change in community
- The right to decide cannot be achieved without community inclusion
- The right to decide is about more than the removal of guardianship and substitute decision making
- Legal reform must go hand in hand with strategies for building community supports and supports for decision making. Inclusion International (2014) p xiii.

making where the persons will and preferences are not understood.¹⁸⁰

This approach, described as a universal approach to legal capacity in line with the CRPD, while it includes a last resort of substituted decision-making, has opened the minds and eyes of those that operate within the context of the legal capacity sphere, to the possibilities that exist for people with disability to make decisions, show their intentions and claim their right to legal personality. The necessity to define legal capacity on levels of assessed mental capacity has been reduced or redefined within this model, which instead introduces criteria of “capabilities to function” or “capabilities for decision-making” as a combination of an individual’s decision making abilities along with their access to decision making supports and accommodations.¹⁸¹

5.3.3 Support model of legal capacity

Eilionoir Flynn and Anna Arstein-Kerslake propose a **support model of legal capacity** which is based on the universal right to legal capacity with no limitations based on conceptions of capabilities¹⁸². The model is built on the work of Bach and Kerzner, which they further develop, by eliminating all forms of capability assessment linked to legal capacity including functional assessments. They acknowledge Bach and Kerzner’s advances in expanding concepts of functional assessment, linking them to accessing supports rather than altering legal capacity, however, they remove all potential for assessment to be linked to status within the model of supported decision-making and instead the focus is on the provision of enabling conditions to ensure the person’s will and preferences can be expressed and acknowledged.¹⁸³

They give solutions to some of the perceived hard cases in theoretical terms, some of which have yet to be fully tested in a national scenario where legislation, policies and

¹⁸⁰ Bach, Michael and Kerzner, Laura, 2010, p. 93.

¹⁸¹ Gooding, Peirs, 2014, 143 or Bach and Kerzner, 2010, p. 21.

¹⁸² Flynn, Eilionoir, and Arstein-Kerslake, Anna, 2014, p. 81.

¹⁸³ Flynn, Eilionoir, and Arstein-Kerslake, Anna, 2014, p. 89.

cultural attitudes can come together to support this.¹⁸⁴ To give an example, a person in an emergency situation where they are engaged in self-harm should not be left unprotected with this shift from best interest to respecting the individual's will and preference. Their suggested interventions to assist the person in stopping the self-harm include interacting with the individual in a caring manner, creating a safe and comfortable environment, with the intended goal of arriving at the point where the person may be able to express their will and preference. The dynamics at play on interpretation of this scenario are; that best interests may still guide the persons intervening, the interests of others may also play a role in some circumstances, while opportunity for the individual involved to be supported to arrive at a point where they stop self-harm and they express their wishes is given precedence. Flynn and Arstein-Kerslake determine that difficult cases to resolve based on best interest will continue to be difficult to resolve with approaches giving priority to will and preference.¹⁸⁵ This determination may be a useful starting point, when engaging dialogue with health professionals on changes in legal capacity and more importantly, the voice of those with direct experiences of emergency situations should be heard. A Citizen's Jury on Legal Capacity is a mandatory read for those interested in hearing those voices, as it involved a panel of 12 women and 7 men, 16 of whom had direct experience of mental health services, while 3 had worked in the area.¹⁸⁶

5.4 Supported decision-making models

The representative agreement in British Columbia, Canada and the non-statutory supported decision making model in South Australia have recently been examined in published reports which give insights into the applications of these models and the outcomes for those accessing the models.¹⁸⁷ Analysis of the findings can be made in

¹⁸⁴ Series, Lucy, Arstein-Kerslake, Gooding, Piers, Flynn, Elionoir, 2014, p. 15.

¹⁸⁵ Series, Lucy, Arstein-Kerslake, Gooding, Piers, Flynn, Elionoir, 2014, p. 16.

¹⁸⁶ Amnesty International Ireland, A citizens' Jury on Legal Capacity Law, 2012.

¹⁸⁷ Reference to reports here include two reports on research on the model of non-statutory Supported Decision making, South Australia, One is an evaluation of the model used in a trial in South Australia - Evaluation of the Supported Decision Making Project, Office of the Public Advocate, South Australia, November 2012, and the other is a research project in Canberra, Australia, where the model developed in South Australia was used - Spectrum of Support, A report on a project Exploring Supported decision

light of the General Comment no 1 (2014), using the same themes as applied in section four.

5.4.1 Model of Representative Agreement

Based on presumption of capacity, entered into freely by an individual along with their representative, the Agreement allows for the authorisation of the representative, usually family member or friend, to “help the adult make decisions” or to “make decisions on behalf of the adult.”¹⁸⁸ It is a private contract, which only requires appearance before a court if a representative applies to the court for guidance or the Public Guardian and Trustee Office follows up on an objection submitted by a party.

The agreement includes the naming of a monitor who undertakes to provide oversight and can report to the Public Guardian and Trustee office, if they have concerns such as a belief that a representative is acting inappropriately. Capability is presumed, and factors to be considered if a test to demonstrate the contrary is called upon, include; whether the person can demonstrate choices and preferences, express feelings of approval or disapproval of others; demonstrate awareness that the representative is involved in decision making process or, whether the adult has a relationship with the representative that is characterised by trust.¹⁸⁹

Areas about which decisions may be supported included in the Act are; personal care; where and with whom a person might live; financial affairs such as payment of bills,

making for people with disability in the Act, ACT Disability, Aged and Carer Advocacy Service, (ADACAS) Advocacy, September 2013.

Understanding the lived experiences of supported decision-making in Canada, Legal Capacity, Decision making and Guardianship, was Commissioned by the Law Commission of Ontario. 2014.

¹⁸⁸ Representation Agreement Act RSBC 1996, Purpose of the Act, Presumption of capability 3 (1).

¹⁸⁹ *Until the contrary is demonstrated, every adult is presumed to be capable of*

(a) making, changing or revoking a representation agreement, and

(b) making decisions about personal care, health care and legal matters and about the adult’s financial affairs, business and assets.

(2) An adults way of communicating with others is not grounds for deciding that he or she is incapable of understanding anything referred to in subsection (1)

Representation Agreement Act British Columbia, RSBC 1996 Chapter 405.

receipt and deposit of income; making investments; and /or health related matters.¹⁹⁰

5.4.2 Model of Non-Statutory Supported Decision-Making

This model was developed by the Office of the Public Advocate in South Australia, as an alternative to substitute making, in the context of the stepped approach.¹⁹¹ In practice, this means that people, both with and without a statutory guardian, could enter into the non-statutory supported decision-making agreement process with a view to limiting the required use of the guardian, or in time, remove an appointed guardian. The Agreement template used in the evaluated trial in South Australia specified a range of decision related areas the supporter can help the individual with, including “where I live, who I spend time with, what I do (work/study/activities), my health” and did not cover decisions about finances or assets.¹⁹² The agreement, entered into freely, with presumed capacity, included an agreed supporter and a monitor, whose role was to monitor and report to the project coordinator as an element of the safeguards in place for the trial.¹⁹³ Another element of oversight was the regular meeting and guidance that the project committee offered, the membership of which included people with disability, academics, advocate, a legal practitioner and staff from the office of Public Advocate.¹⁹⁴

Two projects on non-statutory supported decision-making used in Australia are analysed here. One is the Office of the Public Advocate, (OPA) South Australia, and the other is a research project in Canberra, Australia, where the same model developed in South Australia was used. This second project was conducted by Act, Disability, Aged and Carer Advocacy Service, (ADACAS)

¹⁹⁰ RSBC 1996, Standard Provisions 7, p. 5.

¹⁹¹ Office of Public Advocate, South Australia, Developing a Model of Practice for Supported Decision Making, Background Information to assist the facilitation of agreements, 2011.

¹⁹² Office of the Public Advocate, (OPA) Evaluation of the Supported Decision Making Project, 2012, Appendix 3 Supported Decision Making agreement, pp. 64-65.

¹⁹³ OPA, Evaluation of the Supported Decision Making Project, 2012, p. 64.

¹⁹⁴ OPA, Evaluation of the Supported Decision Making Project, 2012, p. 7.

5.5 Analysis of models with regard to compliance with Article 12 and the general comment and outcomes for participants

5.5.1 Legal capacity: to be holder of rights and to exercise rights

Representative agreement British Columbia: Depending on how the agreement is set up, any or all the decision-making areas related to health, personal care, finances, etc., mentioned in the Act can be included in the agreement.¹⁹⁵ Refusal of life-supporting care or treatment cannot be included.¹⁹⁶

In practice, an individual with a representative agreement can be denied their ability to exercise rights, despite having the agreement, when others such as bank managers or health workers do not respect or understand the nature of the agreement¹⁹⁷. Their ability to act fails, falling somewhere between the cracks of the representative agreement and a guardianship order. In one example, a 23 year old woman, who worked part-time and whose parents were her named, joint supportive decision- makers, was denied the possibility of opening a savings plan in her name on the basis of her supported decision-making agreement, which had limitations on her financial matters, but which she and her supporters did not perceive to extend to the opening of a savings account.¹⁹⁸ She was left with the option of requiring a full guardianship order, labeling her incapable and denying her legal capacity, to be in a position where she could open a savings account in her name.¹⁹⁹

Non-Statutory Supported Decision Making Agreements trailed in Australia demonstrated for one participant the possibility of achieving all identified goals, during the time of partaking in the supported decision-making project, including moving from a nursing home to supported accommodation, acquiring a pet, volunteering at local

¹⁹⁵ RSBC 1996 Chapter 405 Standard Provisions 7 (1) (2), p. 5, 6.

¹⁹⁶ RSBC 1996 Chapter 405 Standard Provisions 7 (2.1), p. 6.

¹⁹⁷ Law Commission of Ontario, Understanding the lived experiences of supported decision-making in Canada, 2014, pp. 73-74.

¹⁹⁸ Law Commission of Ontario, 2014, pp. 48-49.

¹⁹⁹ Law Commission of Ontario, 2014, pp. 48-49.

public hospital gift shop and voluntary work with homeless men, reacquainting with friends and family and obtaining a refund for a contested inaccurate phone account²⁰⁰. The result of a scheduled review after 6 months of the project was the revoking of his guardianship order.²⁰¹

Another participant's description of barriers to her being able to act, in this case due to the need for a family member to be available to assist with personal care in order for her to attend a local center, demonstrate that the decision to act, regardless of legal or non-legal agreements, can be denied due to barriers, over and above what people without a disability might face.²⁰² In terms of analysis based on legal capacity to act, the non-statutory model gives no guarantees; while some participants achieved outcomes in relation to their living arrangements, work arrangements, and reported their sense of empowerment, others were restricted in participating in the project because of a guardian's ability to overrule and deny them the right to participate.²⁰³ The projects demonstrate positive potential for community based support system, with an underlying rights based approach, but without the backing of a legal system which enables over protective guardianship arrangements to be challenged, the system does not allow all those that may benefit from its approach from accessing it.

5.5.2 The (absolute) shift from substituted decision-making to supported decision-making

Both models, the representative agreement and the non-statutory model of decision making, are within jurisdictions which also include substituted decision making within the legal framework. This can impact on uptake of the supported decision making scheme, as noted in the case of the representative agreement in British Columbia, despite the fact that it is in place for over 20 years now.

²⁰⁰ OPA Evaluation of the Supported Decision Making Project, 2012, p. 17.

²⁰¹ OPA Evaluation of the Supported Decision Making Project, 2012, p.19.

²⁰² OPA Evaluation of the Supported Decision Making Project, 2012 p. 22.

²⁰³ ADACAS, Spectrum of Support, 2013, p. 47.

Within the **model of representative agreements in British Columbia**, potential for reverting into functioning as almost full plenary guardianship, (substituted decision-making) was raised as a concern by those familiar with the system.²⁰⁴ This is allowed for in the way the system has been set up, where the representative is required to consult with the person involved and act according to their wishes, however, the caveat “*to the extent reasonable*” is included in the legislation guiding the agreement. This aspect along with the fact that the entitlement “*to make decisions on behalf of the person*” along with helping the person to make decisions is included within the agreement, leaves it open to question as to whether it can be interpreted as a statutory model that is truly consistent with supported decision making, when interpreted with reference to the General Comment no 1 (2014).

The **non-statutory model of supported decision-making** demonstrated some impact on changing opinions on reliance on substituted decision-making, through highlighting possibilities and challenging existing guardianship arrangements.²⁰⁵ The projects also highlighted the restraint that a guardian’s authority has within services where care workers perceived it as limiting their ability to support choice.²⁰⁶ It demonstrated the capacity this non-statutory model has to challenge and alter guardianship for individuals while frustrating others who were unable to avail of its possibilities, while guardianship remains in the system.

5.5.3 Denial or adjustment of legal capacity - on what grounds? (the question of mental capacity)

The **Representative Agreement in British Columbia** does not have any required assessment of capacity. To enter into the contract, the legislation states a presumption of capacity is in place, unless the contrary is demonstrated. Criteria given for testing of incapacity, should it be called into question, include determining that the person has

²⁰⁴ Law Commission of Ontario, 2014, p. 50.

²⁰⁵ OPA, Evaluation of the Supported Decision Making Project, 2012, pp. 17-27 and ADACAS Spectrum of Support, 2013, p. 47.

²⁰⁶ ADACAS Spectrum of Support, 2013, p. 47.

awareness that making representation agreement will affect them.²⁰⁷ The lack of requirement to have assessment of capacity in order to access the system, on its own, is not sufficient to enable its uptake, while it is in competition with guardianship, with some evidence from British Columbia, where Representative Agreements have been in place for 20 years now, that supported decision-making is not widely understood, seen as imprecise and awkward to take instructions from, by some in the legal, financial and health practice fields, pushing people towards guardianship orders as they are perceived as easier to operate with²⁰⁸. The cost involved is also reported as a barrier, at a time when resources in the services sectors supporting people with disabilities are constrained.²⁰⁹ This validates the concern that new and liberating legal systems adopted will not be effective without resources within services and communities to enable people to realise their choices and decisions in life.²¹⁰

The access criteria for the projects using **non-statutory supported decision making** model did not entail any formal assessment of decision-making capacity, while the projects could set specific criteria for eligibility, which for one project included; not being at the center of significant conflict within family and friends; not assessed as having experienced abuse or neglect; not having mental illness as a primary diagnosis or degenerative dementia.²¹¹

²⁰⁷ *In deciding whether an adult is incapable of making a representation agreement consisting of one or more of the standard provisions authorized by section 7, or of changing or revoking any of those provisions, all relevant factors must be considered, for example:*

(a) *whether the adult communicates a desire to have a representative make, help make, or stop making decisions;*

(b) *whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;*

(c) *whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult;*

(d) *whether the adult has a relationship with the representative that is characterized by trust.* Representation Agreement Act British Columbia, RSBC 1996 Chapter 405 Test of incapability for standard provisions. 8 (1), p. 5.

²⁰⁸ Law Commission of Ontario, 2014, p. 54.

²⁰⁹ Law Commission of Ontario, 2014, p. 54.

²¹⁰ Carney, T. Guardianship, citizenship, & theorizing substitute-decision making law. In Doron, I & Soden, A (Eds.), *Beyond elder law: new directions in law and ageing*, 2012, pp. 1–17.

²¹¹ OPA, *Evaluation of the Supported Decision Making Project*, 2012, p. 15.

The ADACAS project included a phase of supporting or developing decision readiness for the participants, which was flexible to the individual participants in terms of input and time, considering factors such as their experiences and expectations, as well as those around them, their social connectedness as well as independence.²¹² Capacity to understand concepts such as anticipated consequences or imagined options for the future were not requirements in order to be able to participate in the project, to receive support in decision-making, which for one participant, involved transition from school to future options of supported employment or specific education programme. The supported decision-making model enabled her to move from a position where it was considered that she did not understand choices offered to her, to her having the opportunity to visit and try out both centers and to be able to express her preference for one.²¹³ The project demonstrates the possibilities advanced through use of support with no attention placed on assessment of capacity, instead with a focus on providing the level of support needed.

5.5.4 Supports to exercise legal capacity

Analysis of the models to identify what types of supports are referred to, was carried out, while it is acknowledged that all supports used may not be indicated in the research reports, as none mentioned this as a specific measure they undertook to document in the research. Analysis of which supports are most effective in supporting decision-making is beyond the confines of this thesis, yet worthy of further research.

British Columbia Representative Agreement²¹⁴

Information

- Forms – downloadable, easy to access, easy to read

²¹² ADACAS Spectrum of Support, 2013, p. 20.

²¹³ ADACAS Spectrum of Support, 2013, pp. 44-47.

²¹⁴ All supports listed here, unless specified otherwise, are referred to in the report: Understanding the lived experiences of supported decision-making in Canada, Legal Capacity, Decision making and Guardianship, 2014.

- Leaflets about Representative Agreement tailored to specific audiences
- Flexible options to pick and choose supports

Education / awareness

- Designated staff engaged in community outreach, awareness
- Target potential third parties – lawyers, health professionals, financial sector
 - To alleviate concerns, support autonomy
 - To be vigilant and act appropriately if concerned re abuse
- Education support, ongoing, from practical help filling out forms to explaining terms

Supporters

- Family members, friends, people from local community network
- Two or three representatives, more popular than just one
- Use of “two out of three” consensus in decision-making
 - To relieve stress from representatives along with protect interest of supported decision maker.
- Circle of supporters – larger network of people who support with decision-making behind scene, with only one or two named in the Agreement
- Flexible over time, as older family members die, siblings, aunts, nephews come on board
- Organisations provide support through advice, meetings – Public and private organisations, Advocacy Groups, caregivers networks, Law Societies,

Accessibility

- The need for support assistance resulting from barriers to inclusion people with disability face.

Communication *(not sourced from British Columbia Representative Agreement research by Law Commission of Ontario, rather from background research on Legal Capacity, Decision-making and Guardian project, also conducted by the Law*

*Commission of Ontario, Canada.)*²¹⁵

- Within family/caregiver context, use of external decision facilitator to critique established patterns of communication, potential obstructions to expressions of interest of person with disability.
- Alternative communication methods, and methods to enhance communication, through use of technology, consult journals on supporting communication,
- Awareness of time pressures and stresses, take time out, use un-rushed pace
- Attending to silences, as part of communication process
- Extra time for responses
- Techniques used in interviews – critically examining interactions in communication that impact on person with disability having voice.

Model of non-statutory Supported Decision-Making²¹⁶

Information / Resources

Online web based tools such as “support my decision” website

Easy to read materials

Decision Making Practice Manual

Education / awareness

Training programmes for individuals, families and care workers

Community based education programmes

²¹⁵ No specific references were made to communication support used in Representative Agreement, in the report “Understanding the lived experiences of supported decision-making in Canada, Legal Capacity, Decision making and Guardianship.”

Results from another study carried out by Law Commission of Ontario on “Understanding and addressing voices of adults with disabilities within their family caregiving contexts: Implications for capacity, Decision-making and Guardianship”. January 2014 are included in this section.

²¹⁶ All supports listed here are referred to in the reports, Office of the Public Advocate, Evaluation of the Supported Decision Making Project, 2012 and ADACAS, Spectrum of Support, 2013.

Supporters

- Family members, friends, (volunteer and professional supporters investigated but more research indicated as to how to establish these supporters)
- Project coordinator or monitor on occasion stepped in to be supporter
- Mostly one supporter, in some cases, two
- Flexible, supporter can change with circumstances or relationship changes
- Volunteer supporters, professional supporter roles
- Advocate also in place, considered a support in addition to decision supporter

Processes of support – dynamic processes

- Phased stages of project: Building awareness
 Decision Readiness
 Decision Support
 Becoming a decision maker
 Fulfilling decision
- Flexible to each individual as to how much support, how long to move through each stage, not all need to access all elements/stages, decision-maker is in control
- Developing confidence to articulate decisions, use of negotiation skills
- Review processes, Use of a Diary (decision diary, or decision support diary)
- Learning and practicing decision-making.
- Taking control, identifying others as supports,
- Identifying arrangements where others help with finance managing as support
- Use of harm minimization strategy – a way of thinking about outcomes of decision
- Using “pros and cons” strategy – to measure options or consequences of decision
- Other related skills, budgeting, saving skills in relation to finances

Communication

- Write things down

- Learn to use strategies – “I’ll call you back” to buy time to make decision
- Technologies – Ipad, voice recognition software – system where voice is registered and produced in text, screen reading software – system where text is read out aloud.
- Communication around making choices – supporting with visual objects, introducing opportunities for real choices to be made, revisit choice to confirm, opportunity to try both options before making choice, revisit and confirm (as described for transition from school to next option)

References to developments in methods of communication used by people with intellectual disabilities, appearing in journals of law, can be seen as an attempt at cross referencing of information from professional groups working, whether deliberately or unintentionally, towards a common goal of enabling and supporting decision-making by people with intellectual disability²¹⁷

Speech and Language therapy research has shown that the communication skills of people with severe intellectual disabilities span a wide spectrum and warn against linking communication abilities with categories of mild, moderate and severe intellectual disabilities²¹⁸. The diverse abilities of individuals to use gestures, eye gazing or eye pointing, touch, movement, switches, computers or speech devices in a communicative manner with others are many, as are the approaches taken by others in communicating with those who have difficulty with speech, sight, hearing or other difficulties. It is this relationship dynamic of interdependency that needs greater recognition across all members of society. Barriers to communication for those with severe intellectual and physical disabilities, who have access to communication systems such as switches, voice output devices or other communication systems, can simply be

²¹⁷ Devi, Nandini, 2013, P 801 where she refers to developments in communication methods, citing article; M. Schepis, D. Reid, and M. Behrman, “Acquisition and Functional Use of Voice Output Communication by Persons with Profound Multiple Disabilities,” Behavioral Modification 20, no. 4 (1996), pp. 451-468.

²¹⁸ Schalick III, Walton O, Westbrook, Cecelia and Young, Brittany, Communication with Individuals with Intellectual Disabilities and Psychiatric Disabilities, 2012, pp. 6-7.

the lack of knowledge or expectation of the person with whom they are communicating and can be addressed with education and training.²¹⁹

5.5.5 Safeguards to ensure the respect of rights

The **Representative Agreement** directs that the supportive-decision-maker, (representative) can be appointed at 19 years of age or older, and excludes the appointment of an individual or employee who provides health or personal care services for compensation to the person.²²⁰ Concerns raised by those familiar with the agreement arrangements are that in some cases the person for whom the Representative agreement has been undertaken, may be perceived as having little understanding of the processes, while this has not lead to any known negative effect, supported by the fact that, overall, the representatives are highly engaged in the lives of those they support.

No reported difference in concerns regarding abuse of the system were evident, between supported and substituted decision-making, with the supported decision-making provisions providing opportunity to support and promote dignity, accessibility and personhood.²²¹ The use of monitors was generally reported to be positive, considered as a further level of support to the process, while a lack of clarity on the specific functioning and role of the monitor was also reported.²²² The General Comment direction that safeguards apply to systems of support in the exercise of legal capacity, with the primary purpose of ensuring the respect of the rights, will and preference of the person. The reported concern that the system of Representative Agreement can slip into defacto substituted decision-making mode, indicates the

²¹⁹ *The need for training in skills to use the device functionally was also highlighted, such as learning to ask questions and how to introduce a communication partner to the device. This may overcome potential barriers relating to communication partner negative responses.* In Baxter, S., Enderby, P., Evans, P. and Judge, S. Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: a systematic review and qualitative synthesis, 2012, p. 123.

²²⁰ RSBC 1996 Chapter 405 (section 5(1)(a)).

²²¹ Law Commission of Ontario, 2014, p. 50.

²²² Law Commission of Ontario, 2014, p. 78.

challenges involved in implementing safeguards that can in practice ensure this is taken place, while recognising the diversity of supports involved.

While the **model of supported decision-making** piloted in the two project reports from Australia, is non-statutory in nature, safeguards to ensure the participants will and preference were recognised and respected were incorporated into the mechanisms which included; education and training for all involved: the focus on building relationship with supporters; the role of a monitor to facilitate the agreement, provide oversight and coaching when required; a complaints procedure; flexibility to adapt to diversity of issues related to individuals, family circumstances, community organisations that people were in contact with, and flexibility to change supporter person could play over time. In particular, the advocacy role that the project coordinator could take on, particularly for those who did not have family or friends to take on supporter role.

No evidence of abuse, undue control or exploitation was found in the external evaluation report of the OPA project and none reported in the ATACAS report. The presence of a project coordinator, committee and planned timeframe of the projects may be factors to consider in terms of resources involved. Processes of gradually reducing the interventions for those in established supported decision-making agreements, without a feeling of abandonment, need to be explored, so that others can access the system and its benefits can be extended. Safeguards provided by a legal system should, in practice, not be required to be proactive or overly regulatory, instead ensuring that the law supports the new systems that are active at a community level.

5.6 Influence on health professionals working with people with intellectual disabilities – the case of Occupational Therapy

The CRPD, in particular article 12 and the General comment no 1 (2014) raises questions for health professionals working with people with intellectual disabilities as to

whether practices can be refocused in contexts where support to enable capacity is what is required, rather than determining incapacity. While acknowledging the changed model of understanding of health and disability which combines medical and social elements, in the form of the International Classification of Function, the ICF has been criticised, in some respects because of a continued prioritization of a model focused on evaluation of impairment and in other respects, because it potentially enables a new, overly invasive surveillance of the attitudes and activities of people with disabilities, both respects influenced by the concerns of power relations dynamics.²²³

Health professionals working with those with intellectual disabilities interface with the current applications of legal capacity practices in their jurisdictions and can be called upon to provide professional assessments.²²⁴ The CRPD General comment has given clear direction that use of mental capacity or functional capacity assessment should not be used to curtail legal capacity and the challenge has been given in the general comment to instead re-focus on ways to identify indicators for supports.²²⁵

Evidence of the influence that legal capacity legislation can have on practices of assessment is evident in some health practices. The English Mental Health Act's overt influence on Speech and Language Therapists practices can be identified in the Royal College of Speech and Language Therapy manual on communication standards where a person with intellectual disabilities can potentially be subject to a capacity assessment for every significant decision to be made. In situations where capacity is deemed to be lacking, a full multidisciplinary and inter-agency 'best interest' assessment is to be completed.²²⁶

²²³ Wildeman, Sheila, 2013, p. 51.

²²⁴ Darzins, Peteris, 2010, This article describes an assessment tool which is presented as a tool to measure capacity for decision making, in medical and legal settings, with a declared conflict of interest by the author as the developer and beneficial owner of the assessment.

²²⁵ General Comment no 1 (2014) para 25 (i) *The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.*

²²⁶ RCSLT Five good communication standards. Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings, 2013, p. 12.

At minimum, health professionals can question the legitimacy of carrying out an assessment by first identifying if the intended use is to deny the individual's right to legal capacity, taking each individual situation into consideration. Professional bodies ethics standards and profession statements such as the World Federations of Occupational Therapists (WFOT) Statement on Human Rights²²⁷, need to be more than words on paper, and should influence day to day practices of professional groups working with people with intellectual disability, in the spirit of the guidance of the CRPD.

How assessment criteria are devised and implemented by those health professionals working with people with intellectual disabilities changes over time with developments and influences on practices and the theoretical approaches behind them. Research on the use of some standardized assessments indicates that when used in clinical settings the findings do not always correspond to the lived experiences of people with disabilities.²²⁸ Aspects of an individual's abilities and impairments to their participation are indicators to identify, as one part of the process of establishing supports, ie., to establish effective strategies, rehabilitation interventions, adaptations to the environment, advocacy, amongst other actions, and this forms a part of existing practice of Occupational Therapy and has done for many years.

Occupational Therapy as a profession is at its early stages of developing an approach to practice that brings justice within its framework, "Occupational Justice"²²⁹ Occupational therapy, a profession which promotes health through person-centred enhancement of abilities, through adaptation of the environment and support, continues to evolve as a profession. The practice of Occupational Justice is based on an *emphasis of rights, responsibilities and liberties that enable the individual to experience health*

²²⁷ WFOT Statement on Human Rights, 2006

²²⁸ Schalick III, Walton O, Westbrook, Cecelia and Young, Brittany, Communication with Individuals with Intellectual Disabilities and Psychiatric Disabilities, 2012, p. 9.

²²⁹ Durocher, Evelyne Gibson, Barbara, E & Rappolt, Susan, Occupational Justice: A Conceptual Review, 2013, p. 1.

*and quality of life through engagement in occupations.*²³⁰ It supports diversity and participation in communities through access to rights and resources, linking this to health and quality of life. The approach grew out of a need to bring to the public's attention the injustices that occur when participation to occupations are restricted, marginalized or barred and the need to give the profession a new language and new set of beliefs, ideas and values when addressing these injustices, placing responsibilities on occupational therapist to address inequities and injustices through social transformation.²³¹

While in its infancy stages of development in practice, the theoretical approach has been used when looking at areas such as the use of assistive technology in people with disabilities lives, including its use to exercise choices and achieve empowerment.²³²

Research and practices in approaches which health professions are developing, can potentially play a role in influencing the development and practice of supported decision-making and vis-versa. The use of assistive technologies, communication support devices, strategies to support and enhance decision-making, problem solving, life planning, advocacy, are all tools that can come together with practices, both formal and informal, of supported decision making, to achieve the fulfillment of autonomy and right to make decisions. The collaboration of occupational therapists with disability representative groups along with other advocates, in building supported decision-making models, could be considered, one more tool to add to the tool box towards rights achievement.

²³⁰ Wolf, L, Ripat, J, Davis, E. Becker, P, MacSwiggan, J, Applying an occupational justice framework. 2010, p. 15.

²³¹ Townsend, Elizabeth, Marval, Rebecca, Can Professionals actually enable occupational justice? 2013, pp. 215-228; Galheigo, Maria Sandra, What needs to be done? Occupational Therapy responsibilities and challenges regarding human rights. 2011, p, 60,

²³² Arthanat, S, Doughlas, S, Favreau, M, Exploring Occupational Justice in Consumer Perspectives on Assistive Technology, p. 309.

6. Conclusions

The conclusions presented here tie together the findings from the thematic analysis, determined by the CRPD Article 12 and the General Comment no 1 (2014) on sample legislative reforms and models of supported decision-making, while consulting with academic papers and the views of representative disability organisations working towards the right to exercise legal capacity.

The conclusions are provided as a set of statements which can serve diverse purposes, depending on the aims of the reader. Some may want reassurances about this change, others may want practical suggestions as to how to proceed, charged with bringing about this change from legal or service provision perspectives, involving the drafting of new legislative texts or operational policies. The conclusions may serve as inspiration for some to delve further into research, ideally research that is transformative in nature, involving people with disability. Finally, they may serve as broad inspiration: that we as people are the solution and that each of us can play a role in supporting others.

1. Legal capacity is about fully respecting the “person before the law”, their dignity, their choices and their rights and denying legal capacity on the grounds of disability is discriminatory.
2. Supported decision-making in practice can enable people with disability to exercise their right to make decisions about their lives.
3. Systems of guardianship or substituted decision-making deny people with disabilities their right to exercise their legal capacity. Even when not directly applied to a person with disability, they can indirectly restrict their rights, by creating the expectation that people with disabilities should have other people decide for them. Legal reform is required, to eradicate substituted decision-making and establish supported decision-making.

4. New ways of measuring non-discriminatory indicators for supports are called for to replace existing assessments of mental or functional capacity that restrict or deny the right to legal capacity for people with disabilities.

5. Professions that have influence in the power dynamics that exist in legal and medical care settings can further develop their practices and can assist in the development of evolving systems of supported decision-making in collaboration with people with disability representative groups and other advocate groups.

6. Decision-making is not purely based on rational thinking, just as no human being is purely rational. Our interdependency is more often at play when decisions are made. The interplay of what is “in the best interest of a person” and “a persons will and preference” is yet to be fully tested in new systems of legal capacity. The challenge to addressing this dilemma can be added to the difficulties experienced when addressing this for those that have full legal capacity when it comes to the hard decisions of life.

7. Creative and alternative methods of decision-making and communication can result in empowerment for people with disability, with clear, flexible and the least invasive regulatory system possible to provide safeguards.

8. People with significant intellectual disabilities can be supported to express their will and preferences through many forms of communication and interpretation of their life stories, their interests and the inter-relations that they foster with family and friends.

9. Changes in attitudes and expectations throughout communities, through the use of education and awareness, is as important a goal in achieving the right to legal capacity for persons with disabilities as the legal reform that is required.

10. Support can be something that each and everyone can offer, some families and communities blend it into their day to day lives so that each individual members is valued and respected and in turn, gives their support to others, without reciprocity or consumerism. Where networks of support are not available to people, community based initiatives as close to that person's life as possible are desirable, with piloted models showing potential for how they might operate.

11. Just as the onus is not on people with disabilities to prove or disprove others perceptions of their capacity, they should not be required to wait for others to correct the misjudged prescriptions of how legal systems should work. This is only one right that people with disability should not be denied, other rights to employment, access to housing, health, education, family, relationships, privacy and dignity go hand in hand with eliminating discrimination and respecting diversity and the CRPD gives good indicators as to how this might be achieved.

We may find it's a better world if we all choose to make these changes in laws and in how we perceive disability.

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International Covenant on Civil and Political Rights (1966) (Entered into force 1976)

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Universal Declaration of Human Rights (1948).

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Convention on the Rights of Persons with Disabilities, CRPD (2006) (entered into force 2008) with optional protocol (OP-CRPD)

African Union (AU)

Organisation of American States (OAS)

European Instruments

European Union:

Charter of Fundamental Rights of the European Union 2012, 2012/c 326/2

EU ratification of the CRPD through Council Decision formally adopted on 26th November, 2009, 2010/48/EC

Lisbon Treaty amending the Treaty on European Union and the Treaty establishing the European Community, 13 December 2007, 2007/C 306/01

EU Directives

Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin Official Journal L 180, 19/07/2000 P. 0022 – 0026

Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation Official Journal L 303 , 02/12/2000 P. 0016 – 0022

Directive 2002/73/EC of the European Parliament and of the Council of 23 September 2002 amending Council Directive 76/207/EEC on the implementation of the principle of equal treatment for men and women as regards access to employment, vocational training and promotion, and working conditions L 269/15

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Council of Europe:

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Council of Europe Committee of Ministers Recommendation No R(99)4 on Principles concerning the legal protection of incapable adults, adopted on 23 February 1999.

National Legislation

Ireland

Lunacy Act 1871

Citizens Information Act 2007

Disability Act 2005

Education for Persons with Special Education Needs Act 2004

Mental Health Act 2001

Scheme Mental Capacity Bill 2008

Assisted Decision Making (Capacity) Bill 2013

Spain

Ley de Enjuiciamiento Civil, Spanish Civil Code and the Civil Procedure Act

Ley 1/2009, de 25 de marzo, de reforma de la Ley de 8 de junio de 1957

Ley 41/2003, de 18 de noviembre,

Ley 26/2011, de 1 de agosto,

Royal Decree 1865/2004 (creation of the National Disabilities Council in 2004 in Spain)

Royal Decree 1468/2007 (extended functions of the National Council on Disabilities to include CRPD promotion and monitoring of compliance)

Catalonia

Act 25/2010 of 29th July, the second book of civil code of Catalonia on persons and family

Canada, British Columbia

Representation Agreement Act British Columbia, RSBC 1996 Chapter 405

Cases

M.X. v Health Services Executive, 23 November 2012, High Court Judgment, available at

<http://courts.ie/Judgments.nsf/09859e7a3f34669680256ef3004a27de/eb54fa0ba9d7014a80257ac3004b1698?OpenDocument> (last accessed 03 June 2014).

Stanev v Bulgaria, ECtHR Grand Chamber finding, at <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-108690> (last accessed 1 July 2014)

ANNEX I Article 12 CRPD

ANNEX II General Comment no 1 (2014)

Article 12 of the Convention on the Rights of Persons with disabilities states as follows:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
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.
5. 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.



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Article 12: Equal recognition before the law

I. Introduction

1. Equality before the law is a basic general principle of human rights protection and is indispensable for the exercise of other human rights. The Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights specifically guarantee the right to equality before the law. Article 12 of the Convention on the Rights of Persons with Disabilities further describes the content of this civil right and focuses on the areas in which people with disabilities have traditionally been denied the right. Article 12 does not set out additional rights for people with disabilities; it simply describes the specific elements that State parties are required to take into account to ensure the right to equality before the law for people with disabilities, on an equal basis with others.

2. Given the importance of this article, the Committee facilitated interactive fora for discussions on legal capacity. From the very useful exchange on the provisions of article 12 by experts, State parties, disabled persons' organizations, non-governmental organizations, treaty monitoring bodies, national human rights institutions and United Nations agencies, the Committee found it imperative to provide further guidance in a general comment.

3. Based on the initial reports of the different State parties that it has reviewed so far, the Committee observes that there is a general misunderstanding of the exact scope of the obligations of State parties under article 12 of the Convention. Indeed, there has been a general failure to understand that the human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on

supported decision-making. The aim of the present general comment is to explore the general obligations deriving from the different components of article 12.

4. The present general comment reflects an interpretation of article 12 which is premised on the general principles of the Convention, as outlined in article 3, namely, respect for inherent dignity, individual autonomy — including the freedom to make one’s own choices —, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women; and respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

5. The Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities each specify that the right to equal recognition before the law is operative “everywhere.” In other words, there are no circumstances permissible under international human rights law in which a person may be deprived of the right to recognition as a person before the law, or in which this right may be limited. This is reinforced by article 4, paragraph 2, of the International Covenant on Civil and Political Rights, which states that no derogation from this right is permissible even in times of public emergency. Although an equivalent prohibition on derogation from the right to equal recognition before the law is not specified in the Convention on the Rights of Persons with Disabilities, the provision in the International Covenant covers such protection by virtue of article 4, paragraph 4, of the Convention, which states that the provisions of the Convention on the Rights of Persons with Disabilities do not derogate from existing international law.

6. The right to equality before the law is also reflected in other core international and regional human rights treaties. Article 15 of the Convention on the Elimination of All Forms of Discrimination against Women guarantees women’s equality before the law and requires the recognition of women’s legal capacity on an equal basis with men, including with regard to concluding contracts, administering property and exercising their rights in the justice system. Article 3 of the African Charter on Human and Peoples’ Rights provides for the right of every person to be equal before the law and to enjoy equal protection of the law. Article 3 of the American Convention on Human Rights enshrines the right to juridical personality and the right of every person to recognition as a person before the law.

7. State parties must holistically examine all areas of law to ensure that the right of persons with disabilities to legal capacity is not restricted on an unequal basis with others. Historically, persons with disabilities have been denied their right to legal capacity in many areas in a discriminatory manner under substitute decision-making regimes such as guardianship, conservatorship and mental health laws that permit forced treatment. These practices must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others.

8. Article 12 of the Convention affirms that all persons with disabilities have full legal capacity. Legal capacity has been prejudicially denied to many groups throughout history, including women (particularly upon marriage) and

ethnic minorities. However, persons with disabilities remain the group whose legal capacity is most commonly denied in legal systems worldwide. The right to equal recognition before the law implies that legal capacity is a universal attribute inherent in all persons by virtue of their humanity and must be upheld for persons with disabilities on an equal basis with others. Legal capacity is indispensable for the exercise of civil, political, economic, social and cultural rights. It acquires a special significance for persons with disabilities when they have to make fundamental decisions regarding their health, education and work. (The denial of legal capacity to persons with disabilities has, in many cases, led to the deprivation of many fundamental rights, including the right to vote, the right to marry and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty.)

9. All persons with disabilities, including those with physical, mental, intellectual or sensory impairments, can be affected by denial of legal capacity and substitute decision-making. However, persons with cognitive or psychosocial disabilities have been, and still are, disproportionately affected by substitute decision-making regimes and denial of legal capacity. The Committee reaffirms that a person's status as a person with a disability or the existence of an impairment (including a physical or sensory impairment) must never be grounds for denying legal capacity or any of the rights provided for in article 12. All practices that in purpose or effect violate article 12 must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others.

9bis. This General Comment is focused primarily on the normative content of Article 12 and the State obligations that emerge. The Committee will continue to do work in this area and provide further in-depth description of the rights and obligations in Article 12 with its future concluding observations, general comments, and other work

II. Normative content of article 12

Article 12, paragraph 1

10. Article 12, paragraph 1, reaffirms the right of persons with disabilities to be recognized as persons before the law. This guarantees that every human being is respected as a person possessing legal personality, which is a prerequisite for the recognition of a person's legal capacity.

Article 12, paragraph 2

11. Article 12, paragraph 2, recognizes that persons with disabilities enjoy legal capacity on an equal basis with others in all areas of life. Legal capacity includes the capacity to be both a holder of rights and an actor under the law. Legal capacity to be a holder of rights entitles the person to full protection of his or her rights by the legal system. Legal capacity to act under the law recognizes person as an agent with the power to engage in transactions and in general to create, modify or end legal relationships. The right to recognition as a legal agent is provided for in article 12, paragraph 5, of the Convention, which outlines the duty of State parties to "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”.

12. Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors. In the past, legal instruments such as the UDHR (Article 6), the ICCPR (Article 16), and CEDAW (Article 15) did not specify the distinction between mental and legal capacity. The CRPD (Article 12) now makes it clear that ‘unsoundness of mind’ and other discriminatory labels are not legitimate reasons for the denial of legal capacity (legal standing and legal agency). Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.

12bis. Legal capacity is an inherent right accorded to all people including persons with disabilities. As noted, it consists of two strands. The first is the legal standing to have rights, to be recognized as a legal person before the law. This may include, for example, having a birth certificate, seek medical assistance, register to be on the electoral role, or applying for a passport. The second is the legal agency to act on those rights, and to have those actions recognized by the law. It is this component that is frequently denied or diminished for persons with disabilities. For example, laws may allow persons with disabilities to own property, but do not always respect the actions of people in terms of buying and selling property. Legal capacity means that all people, including persons with disabilities, have legal standing and legal agency simply by virtue of being human. Therefore, both these strands of legal capacity must be recognized for the right to legal capacity for persons with disabilities to be fulfilled; they cannot be separated.

The concept of mental capacity is highly controversial in and of itself. It is not, as it is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity.

13. In most of the State party reports that the Committee has examined so far, the concepts of mental and legal capacity have been conflated so that where a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed. This is decided simply on the basis of the diagnosis of an impairment (status approach), or where a person makes a decision that is considered to have negative consequences (outcome approach), or where a person’s decision-making skills are considered to be deficient (functional approach). The functional approach attempts to assess mental capacity and deny legal capacity accordingly. (Often based on whether an individual can understand the nature and consequences of a decision and/or whether she/he can use or weigh the relevant information.) This functional approach is flawed for two key

reasons. The first is that it is discriminatorily applied to people with disabilities. The second is that it presumes to be able to accurately assess the inner-workings of the human mind and to then deny a core human right – the right to equal recognition before the law – when an individual does not pass the assessment. In all these approaches, a person’s disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but rather requires that support be provided in the exercise of legal capacity.

Article 12, paragraph 3

14. Article 12, paragraph 3, recognizes that state parties have an obligation to provide access to support in the exercise of their legal capacity. State parties must refrain from denying persons with disabilities their legal capacity, and instead must provide persons with disabilities access to the support that may be necessary to enable them to make decisions that have legal effect.

15. Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making. Article 12, paragraph 3, does not specify what form the support should take. “Support” is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may 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, advocacy (including self-advocacy support), or assistance with communication. Support to persons with disabilities in the exercise of their legal capacity might include measures relating to universal design and accessibility, —such as requiring private and public actors such as banks and financial institutions to provide understandable information or the provision of professional sign language interpretation —, 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. Support can also constitute the development and recognition of diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will and preferences. For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others. All persons with disabilities have the right to engage in advance planning and should be given the opportunity to do so on an equal basis with others. A choice of various forms of advance planning mechanisms can be provided by State parties to accommodate various preferences, but all options should be non-discriminatory. Support should be provided to the individual where desired to complete an advance planning process. The point at which an advance directive enters into force (and ceases to have effect) should be decided by the person in the text of the directive and should not be based on an assessment that the person lacks mental capacity.

16. The type and intensity of support to be provided will vary significantly from one person to another due to the diversity of persons with disabilities. This is in accordance with article 3 (d), which sets out “respect

for difference and acceptance of persons with disabilities as part of human diversity and humanity” as a general principle of the Convention. At all times, including during crisis situations, the individual autonomy and capacity of persons with disabilities to make decisions must be respected.

17. Some persons with disabilities only seek recognition of their right to legal capacity on an equal basis with others further to in Article 12, paragraph 2, and may not wish to exercise their right to support as provided for in article 12, paragraph 3.

Article 12, paragraph 4

18. Article 12, paragraph 4, outlines the safeguards that must be present in a system of support in the exercise of legal capacity. Article 12, paragraph 4, must be read in conjunction with the rest of article 12 and the whole Convention. It requires State parties to create appropriate and effective safeguards for the exercise of legal capacity. The primary purpose of these safeguards must be to ensure the respect of 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.

18bis Where, after significant efforts have been made, it is not practicable to determine the will and preference of an individual, ‘best interpretation of will and preference’ must replace ‘best interests’ determinations. This respects the rights, will and preferences of the individual, according to Article 12 (4). The ‘best interests’ principle is not a safeguard which complies with article 12 in relation to adults. The ‘will and preference’ paradigm must replace the ‘best interests’ paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.

18ter All people risk being subject to ‘undue influence’ yet this may be exacerbated for those who rely on the supports of others to make decisions. Undue influence is characterized where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation. Safeguards for the exercise legal capacity must include protection against undue influence – however the protection must also respect the rights, will and preferences of the person, including the right to take risks and make mistakes.

Article 12, paragraph 5

19. Article 12, paragraph 5, requires that State parties take measures — including legislative, administrative, judicial and other practical measures — to ensure the rights of persons with disabilities with respect to financial and economic affairs, on an equal basis with others. Access to finance and property has traditionally been denied to persons with disabilities based on the medical model of disability. This 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. In the same way as gender may not be used as the basis for discrimination in the areas of finance and property,²³³ neither may disability.

²³³

See Convention on the Elimination of All Forms of Discrimination against Women,

III. Obligations of State parties

20. State parties have an obligation to respect, protect and fulfil the right of persons with all disabilities to equal recognition before the law. In this regard, State parties should refrain from any action that deprives persons with disabilities of the right to equal recognition before the law. State parties should take action to prevent non-State actors and private persons from interfering in the ability of persons with disabilities to realize and enjoy their human rights, including the right to legal capacity. One of the aims of support in the exercise of legal capacity is to build the confidence and skills of persons with disabilities so that they can exercise their legal capacity with less support in the future if they so wish. State parties have an obligation to provide training for persons receiving support so that they can decide when less support is needed or when they no longer require support in the exercise of their legal capacity.

21. In order to fully recognize “universal legal capacity”, whereby all persons (regardless of disability or decision-making skills) inherently possess legal capacity, State parties must abolish denials of legal capacity that are discriminatory on the basis of disability in purpose or effect.²³⁴

22. In its concluding observations relating to article 12, the Committee on the Rights of Persons with Disabilities has repeatedly stated that the State parties concerned must “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”.

23. Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is just in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will or (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective “best interests” of the person concerned, as opposed to being based on the person’s own will and preferences.

24. State parties’ obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.

25. A supported decision-making regime comprises various support options which give primacy to a person’s will and preferences and respect human rights norms. It should provide protection for all rights, including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, etc.) and rights related to

art. 13 (b).²³⁴
art. 5.

See Convention on the Rights of Persons with Disabilities, art. 2, in conjunction with

freedom from abuse and ill-treatment (right to life, right to physical integrity, etc.). Furthermore, systems of supported decision-making should not over-regulate the lives of persons with disabilities. While supported decision-making regimes can take many forms, they should all incorporate certain key provisions to ensure compliance with article 12 of the Convention, including the following:

(a) Supported decision-making must be available to all. A person's level of support needs (especially where these are high) should not be a barrier to obtaining support in decision-making;

(b) All forms of support in the exercise of legal capacity (including more intensive forms of support) must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests;

(c) 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;

(d) Legal recognition of the support person(s) formally chosen by a person must be available and accessible, and the State has an obligation to facilitate the creation of support, particularly for people who are isolated and may not have access to naturally occurring supports in the community. This must include a mechanism for third parties to verify the identity of a support person as well as a mechanism for third parties to challenge the action of a support person if they believe that the support person is not acting based on the will and preference of the person concerned;

(e) In order to comply with the requirement set out in article 12, paragraph 3, of the Convention that State parties must take measures to "provide access" to the support required, State parties must ensure that support is available at nominal or no cost to persons with disabilities and that lack of financial resources is not a barrier to accessing support in the exercise of legal capacity;

(f) Support in decision-making must not be used as justification for limiting other fundamental rights of persons with disabilities, especially the right to vote, the right to marry (or establish a civil partnership) and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty;

(g) The person must have the right to refuse support and terminate or change the support relationship at any time;

(h) Safeguards must be set up for all processes relating to legal capacity and support in exercising legal capacity. The goal of safeguards is to ensure that the person's will and preferences are respected.

(i) The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.

26. The right to equality before the law has long been recognized as a civil and political right, with roots in the International Covenant on Civil and Political Rights. Civil and political rights attach at the moment of ratification and State parties are required to take steps to immediately realize these rights.

As such, the rights provided for in article 12 apply at the moment of ratification and are subject to immediate realization. The state obligation to provide access to support for the exercise of legal capacity in Article 12(3) is a state obligation required for the fulfilment of the civil and political right to equal recognition before the law. Progressive realization (art. 4, para. 2) does not apply to article 12. Upon ratification, State parties must immediately begin to take steps towards the realization of the rights in article 12. These steps must be deliberate, well-planned, and include the consultation and meaningful participation of people with disabilities and their organizations.

IV. Relationship with other provisions of the Convention

27. Recognition of legal capacity is inextricably linked to the enjoyment of many other human rights provided for in the Convention on the Rights of Persons with Disabilities, including, but not limited to, the right to access justice (art. 13), the right to be free from involuntary detention in a mental health facility and not to be forced to undergo mental health treatment (art. 14), the right to respect for one's physical and mental integrity (art. 17), the right to liberty of movement and nationality (art. 18), the right to choose where and with whom to live (art. 19), the right to freedom of expression (art. 21), the right to marry and found a family (art. 23), the right to consent to medical treatment (art. 25), and the right to vote and stand for election (art. 29). Without recognition of the person as a person before the law, the ability to assert, exercise and enforce these rights, and many other rights provided for in the Convention, is significantly compromised.

Article 5: Equality and non-discrimination

28. To achieve equal recognition before the law, legal capacity must not be denied discriminatorily. Article 5 of the Convention guarantees equality for all persons under and before the law and the right to equal protection of the law. It expressly prohibits all discrimination on the basis of disability. Discrimination on the basis of disability is defined in article 2 of the Convention as "any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms". Denial of legal capacity having the purpose or effect of interfering with the right of persons with disabilities to equal recognition before the law is a violation of articles 5 and 12 of the Convention. Indeed, a State has the ability to restrict the legal capacity of a person based on certain circumstances, such as bankruptcy or criminal conviction. However, the right to equal recognition before the law and freedom from discrimination requires that when the State denies legal capacity, it must be on the same basis for all persons. Denial of legal capacity must not be based on a personal trait such as gender, race, or disability, or have the purpose or effect of treating such persons differently.

29. Freedom from discrimination in the recognition of legal capacity restores autonomy and respects the human dignity of the person in accordance with the principles enshrined in article 3 (a) of the Convention. Freedom to make one's own choices most often requires legal capacity.

Independence and autonomy include the power to have one's decisions legally respected. The need for support and reasonable accommodation in making decisions shall not be used to question a person's legal capacity. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity (art. 3 (d)) is incompatible with granting legal capacity on an assimilationist basis.

30. Non-discrimination includes the right to reasonable accommodation in the exercise of legal capacity (art. 5, para. 3). Reasonable accommodation is defined in article 2 of the Convention as "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms". The right to reasonable accommodation in the exercise of legal capacity is separate from and complementary to the right to support in the exercise of legal capacity. State parties are required to make any modifications or adjustments to allow persons with disabilities to exercise their legal capacity, unless it is a disproportionate or undue burden. Such modifications or adjustments may include, but are not limited to, access to essential buildings such as courts, banks, social benefit offices, voting venues; accessible information regarding decisions which have legal effect; and personal assistance. The right to support in the exercise of legal capacity shall not be limited by the claim of disproportionate or undue burden. The State has an absolute obligation to provide access to support in the exercise of legal capacity.

Article 6: Women with disabilities

31. Article 15 of the Convention on the Elimination of All Forms of Discrimination against Women provides for women's legal capacity on an equal basis with men, thereby acknowledging that recognition of legal capacity is integral to equal recognition before the law: "State parties shall accord to women, in civil matters, a legal capacity identical to that of men and the same opportunities to exercise that capacity. In particular, they shall give women equal rights to conclude contracts and to administer property and shall treat them equally in all stages of procedure in courts and tribunals" (para. 2). This provision applies to all women, including women with disabilities. The Convention on the Rights of Persons with Disabilities recognizes that women with disabilities may be subject to multiple and intersectional forms of discrimination based on gender and disability. For example, women with disabilities are subjected to high rates of forced sterilization, and are often denied control of their reproductive health and decision-making, the assumption being that they are not capable of consenting to sex. Certain jurisdictions also have higher rates of imposing substitute decision-makers on women than on men. Therefore, it is particularly important to reaffirm that the legal capacity of women with disabilities should be recognized on an equal basis with others.

Article 7: Children with disabilities

32. While article 12 of the Convention protects equality before the law for all persons, regardless of age, article 7 of the Convention recognizes the

developing capacities of children and requires that “in all actions concerning children with disabilities, the best interests of the child [...] be a primary consideration” (para. 2) and that “their views [be] given due weight in accordance with their age and maturity” (para. 3). To comply with article 12, State parties must examine their laws to ensure that the will and preferences of children with disabilities are respected on an equal basis with other children.

Article 9: Accessibility

33. The rights provided for in article 12 are closely tied to the state obligations relating to accessibility (art. 9) because the right to equal recognition before the law is necessary to enable persons with disabilities to live independently and participate fully in all aspects of life. Article 9 demands the identification and elimination of barriers to facilities or services open or provided to the public.

Lack of accessibility of information and communication, and inaccessible services may constitute barriers to the realization of legal capacity for some persons with disabilities in practice. Therefore state parties must make all procedures for the exercise of legal capacities and all information and communication pertaining to it fully accessible. State parties must review their laws and practices to ensure that the right to legal capacity and accessibility are being realized.

Article 13: Access to justice

34. State parties have an obligation to ensure that persons with disabilities have access to justice on an equal basis with others. The recognition of the right to legal capacity is essential for access to justice in many respects. In order to seek enforcement of their rights and obligations on an equal basis with others, persons with disabilities must be recognized as persons before the law with equal standing in courts and tribunals. State parties must also ensure that persons with disabilities have access to legal representation on an equal basis with others. This has been identified as a problem in many jurisdictions and must be remedied — including by ensuring that persons who experience interference with their right to legal capacity have the opportunity to challenge such interference (on their own behalf or with legal representation) and to defend their rights in court. Persons with disabilities have often been excluded from key roles in the justice system as lawyers, judges, witnesses or members of a jury.

35. Police officers, social workers, and other first responders must be trained to recognize persons with disabilities as full persons before the law and to give the same weight to complaints and statements from persons with disabilities as they would give to non-disabled persons. This entails training and awareness-raising in these important professions. Persons with disabilities must also be granted legal capacity to testify on an equal basis with others. Article 12 of the Convention guarantees support in the exercise of legal capacity, including the capacity to testify in judicial, administrative and other legal proceedings. Such support could take various forms, including recognition of diverse communication methods, allowing video testimony in certain situations, procedural accommodation, the provision of

professional sign language interpretation and other assistive methods. The judiciary must also be trained and made aware of their obligation to respect the legal capacity of persons with disabilities, including legal agency and standing.

Articles 14 and 25: Liberty, security and consent

36. Respecting the right to legal capacity of persons with disabilities on an equal basis includes respecting the right of persons with disabilities to liberty and security of the person. The denial of the legal capacity of persons with disabilities and their detention in institutions against their will, either without their consent or with the consent of a substitute decision-maker, is an ongoing problem. This practice constitutes arbitrary deprivation of liberty and violates articles 12 and 14 of the Convention. State parties must refrain from such practices and establish a mechanism to review cases whereby persons with disabilities have been placed in a residential setting without their specific consent.

37. The right to enjoyment of the highest attainable standard of health (art. 25) includes the right to health care on the basis of free and informed consent. State parties have an obligation to require all health and medical professionals (including psychiatric professionals) to obtain the free and informed consent of persons with disabilities prior to any treatment. In conjunction with the right to legal capacity on an equal basis with others, State parties have an obligation not to permit substitute decision-makers to provide consent on behalf of persons with disabilities. All health and medical personnel should ensure appropriate consultation that directly engages the person with disabilities. They should also ensure, to the best of their ability, that assistants or support persons do not substitute or have undue influence over the decisions of persons with disabilities.

Articles 15, 16 and 17: Respect for personal integrity and freedom from torture, violence, exploitation and abuse

38. As has been stated in several concluding observations, forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement of the rights to personal integrity (art. 17), freedom from torture (art. 15), and freedom from violence, exploitation and abuse (art. 16). This practice denies the legal capacity of a person to choose medical treatment and is therefore a violation of article 12 of the Convention. State Parties must, instead, respect the legal capacity of persons with disabilities to make decisions at all times, including in crisis situations, ensure that accurate and accessible information is provided about service options and that non-medical approaches are made available, and provide access to independent support. State parties have an obligation to provide access to support for decisions regarding psychiatric and other medical treatment. Forced treatment is a particular problem for persons with psychosocial, intellectual and other cognitive disabilities. State parties must abolish policies and legislative provisions that allow or perpetrate forced treatment, as it is an ongoing violation found in mental health laws across the globe, despite empirical evidence indicating its lack of effectiveness and the views of people using mental health systems who have

experienced deep pain and trauma as a result of forced treatment. The Committee recommends that State parties ensure that decisions relating to a person's physical or mental integrity can only be taken with the free and informed consent of the person concerned.

Article 18: Nationality

39. Persons with disabilities have the right to a name and registration of their birth as part of the right to recognition everywhere as a person before the law (art. 18, para. 2). State parties must take the necessary measures to ensure that children with disabilities are registered at birth. This right is provided for in the Convention on the Rights of the Child (art. 7); however, children with disabilities are disproportionately likely not to be registered as compared with other children. This denies them citizenship, often also denies them access to health care and education, and can even lead to their death. Since there is no official record of their existence, their death may occur with relative impunity.

Article 19: Living independently and being included in the community

40. To fully realize the rights provided for in article 12, it is imperative that persons with disabilities have opportunities to develop and express their will and preferences, in order to exercise their legal capacity on an equal basis with others. This means that persons with disabilities must have the opportunity to live independently in the community and to make choices and to have control over their everyday lives, on an equal basis with others, as provided for in article 19.

41. Interpreting article 12, paragraph 3, in the light of the right to live in the community (art. 19) means that support in the exercise of legal capacity should be provided using a community-based approach. State parties must recognize that communities are assets and partners in the process of learning what types of support are needed in the exercise of legal capacity, including raising awareness about different support options. State parties must recognize the social networks and naturally occurring community supports (including friends, family and schools) of persons with disabilities as key to supported decision-making. This is consistent with the Convention's emphasis on the full inclusion and participation of persons with disabilities in the community.

42. The segregation of persons with disabilities in institutions continues to be a pervasive and insidious problem that violates a number of the rights guaranteed under the Convention. The problem is exacerbated by the widespread denial of legal capacity to persons with disabilities, which allows others to consent to their placement in institutional settings. The directors of institutions are also commonly vested with the legal capacity of the persons residing therein. This places all power and control over the person in the hands of the institution. In order to comply with the Convention and respect the human rights of persons with disabilities, deinstitutionalization must be achieved and legal capacity must be restored to all persons with disabilities, who must be able to choose where and with whom to live (art. 19). A

person's choice of where and with whom to live should not affect his or her right to access support in the exercise of his or her legal capacity.

Article 22: Privacy

43. Substitute decision-making regimes, in addition to being incompatible with article 12 of the Convention, also potentially violate the right to privacy of persons with disabilities, as substitute decision-makers usually gain access to a wide range of personal and other information regarding the person. In establishing supported decision-making systems, State parties must ensure that those providing support in the exercise of legal capacity fully respect the right to privacy of persons with disabilities.

Article 29: Political participation

44. Denial or restriction of legal capacity has been used to deny political participation, especially the right to vote, for certain persons with disabilities. In order to fully realize the equal recognition of legal capacity in all aspects of life, it is important to recognize the legal capacity of persons with disabilities in public and political life (art. 29). This means that a person's decision-making ability cannot be a justification for any exclusion of persons with disabilities from exercising their political rights, including the right to vote, the right to stand for election and the right to serve as a member of a jury.

45. State parties have an obligation to protect and promote the right of persons with disabilities to access the support of their choice in voting by secret ballot, and to participate in all elections and referenda without discrimination. The Committee further recommends that State parties guarantee the right of persons with disabilities to stand for elections, to effectively hold office and to perform all public functions at all levels of government, with reasonable accommodation and support, where desired, in the exercise of their legal capacity.

V. Implementation at the national level

46. In the light of the normative content and obligations outlined above, State parties should take the following steps to ensure the full implementation of article 12 of the Convention on the Rights of Persons with Disabilities:

(a) Recognize persons with disabilities as persons before the law, having legal personality and legal capacity in all aspects of life, on an equal basis with others. This requires the abolition of substitute decision-making regimes and mechanisms that deny legal capacity which discriminate in purpose or effect against persons with disabilities. It is recommended that State Parties create statutory language protecting the right to legal capacity on an equal basis for all;

(b) Establish, recognize and provide persons with disabilities with access to a broad range of supports in the exercise of their legal capacity. Safeguards for these supports must be premised on respect for the rights, will and preferences of persons with disabilities. The supports should meet the

criteria set out in paragraph 25 above on the obligations of State parties to comply with article 12, paragraph 3, of the Convention;

(c) Closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations, in the development and implementation of legislation, policies and other decision-making processes give effect to article 12.

47. The Committee encourages State parties to undertake or devote resources to the research and development of best practices respecting the right to equal recognition of the legal capacity of persons with disabilities and support in the exercise of legal capacity.

48. State Parties are encouraged to develop effective mechanisms to combat both formal and informal substitute decision-making. To this end, the Committee urges State parties to ensure that persons with disabilities have the opportunity to make meaningful choices in their lives and develop their personalities, to support the exercise of their legal capacity. This includes, but is not limited to: opportunities to build social networks; opportunities to work and earn a living on an equal basis with others; multiple choices for place of residence in the community; and inclusion in education at all levels.
