



CONTRACEPTION and CONSENT

A Comparative Analysis of the Legal Frameworks for Accessing Contraception

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Women With Disabilities ACT acknowledges and pays respect to the Ngunnawal peoples, the traditional custodians of the ACT Region on whose land our office is located. We pay our respects to their Elders past, present and emerging. We acknowledge their spiritual, social, historical and ongoing connection to these lands and the contribution they make to the life of the Australian Capital Territory.

strong women, strong voices

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Winner of the 2012 International Women's Day Award—Community Category

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About this research:

This research aims to improve women/girls with disabilities (cognitive, sensory, physical or dual disability) experiences in choosing a contraceptive device. The methodology followed adopts a human rights-based approach to provide a better understanding of contraception and consent issues concerning women with disabilities.

This research has been initiated by Women With Disabilities ACT (WWD ACT). WWD ACT is a systemic advocacy and peer support organisation for women and girls with disabilities in the ACT. WWD ACT follows a human rights philosophy, based on the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Elimination of Discrimination against Women (CEDAW). WWD ACT is a Disabled People's Organisation (DPO), governed by women with disabilities, and its proposals and recommendations to government are consistent with Article 4(3), and Article 29 of CRPD which outline the imperative for consultation. In the ACT, there are 32,600 women with a disability, who make up 52.5% of the population of people with disabilities, and 8.5% of the total population of the ACT (Australia Bureau of Statistics, Survey of Disability, Ageing and Carers Australia, 2015).

Many women with disabilities do not know about their reproductive rights. This arises from their limited access to sexual health education or information about reproduction, contraception, respectful relationships and sexuality. This is a barrier to them forming safe sexual relationships. Both young and adult women who have a learning disability which affects their decision-making, may be further compromised in exercising choice about contraception when third parties make decisions on their behalf. It is time to empower people with disabilities by granting them equal access to society and having control over any needed medical treatment.

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Dictionary

Agency is the right to act before the law

Girl is a female person under 18 except when highlighted differently.

Learning disabilities will be used to encompass any kind of mental, cognitive or psychosocial disability. WWDACT understands learning disability is a significant lifelong condition that entails a reduced ability to understand new or complex information or to learn new skills and a reduced ability to cope independently¹. These abilities are never abolished.

Legal Capacity is the right to have rights as a person before the law AND the right to act before the law to enforce those rights.

LARC means Long-Acting Reversible Contraceptive. They are contraceptive methods that do not depend on a person remembering to take or use them to be effective. LARCs usually include contraceptive implant, contraceptive injection, intrauterine device (IUD) and intrauterine system (IUS).

Sexual Health does not only include the absence of diseases. It is also *a state of physical, mental and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence*².

Supported Decision-Making is a series of relationships, practices, arrangements, and agreements designed to assist a person with disabilities to make and communicate to others decisions about his/her life³.

Substituted Decision-Making is when a third party is appointed, whether contractually or by court, to decide on behalf of a person.

Woman is a female person above 18 except when highlighted differently.

Women with disabilities encompasses women with learning disabilities and/or physical disabilities.

Abbreviations

ACAT	ACT Civil and Administrative Tribunal
ACSHR	Action Canada for Sexual Health and Rights
ACT	Australian Capital Territory
ACT HRA	<i>Human Rights Act 2004 (ACT)</i>
ACT HRC	ACT Human Rights Commission
ACT LRAC	ACT Law Reform Advisory Council
ADACAS	ACT Disability, Aged, Carer Advocacy Service
AGCDMA	<i>Adult Guardianship and Co-decision-making Act 2000 (Sk)</i>
AGTA 2008	<i>Adult Guardianship and Trusteeship Act 2008 (Ab)</i>
ALRF	Australian Law Reform Commission
AWIA 2000	<i>Adults with Incapacity Act 2000 (Scotland)</i>
CCRF	Canadian Charter of Rights and Freedoms
CEDAW	<i>Convention on the Elimination of Discrimination against Women 1979</i>
CRC	<i>Convention on the Rights of the Child 1989</i>
CRPD	<i>Convention on the Rights of Persons with Disabilities 2006</i>
DPO	Disabled People Organisation
FPAA	Family Planning Alliance Australia
GAA 2016	<i>Guardianship of Adults Act 2016 (NT)</i>
GAB 2014	<i>Guardianship and Administration Bill 2014 (Vic)</i>
HLSCR	House of Lords Select Committee Report 2014 (UK)
ICPD	International Conference on Population and Development
IFFP	International Planned Parenthood Federation
LARC	Long-Acting Reversible Contraceptive
LCO	Law Commission of Ontario
LD	Learning disabilities
MCA 2005	<i>Mental Capacity Act 2005 (England and Wales)</i>

MCA 2016	<i>Mental Capacity Act 2016</i> (Northern Ireland)
MHA 2003	<i>Mental Health (Care and Treatment) Act 2003</i> (Scotland)
NCAT	NSW Civil and Administrative Tribunal
NDIS	National Disability Insurance Scheme
NDIS Act	<i>National Disability Insurance Scheme Act 2013</i> (Cth)
NSW	New South Wales
NT	Northern territory
OPA	Office of the Public Advocate
RAA	<i>Representation Agreement Act 2001</i> (British Columbia)
RAA	<i>Representation Agreement Regulation 2001</i> (BC)
SA	South Australia
SDA	<i>Substitute Decisions Act 1992</i> (ON)
SDM	Supported Decision-Making
SHFPACT	Sexual Health and Family Planning ACT
STI	Sexually Transmitted Infection
UDHR	<i>Universal Declaration of Human Rights 1948</i>
UNECE	United Nations Economic Commission for Europe
UNFPA	United Nations Population Fund
VLRC	Victorian Law Reform Commission
WA	Western Australia

Abstract: Consent to contraception for women with disabilities

This study focuses on the achieving reproductive rights of women with disabilities. The intent is to identify the context of forced contraception and propose supported decision-making mechanisms adapted to all women with disabilities in the ACT. This paper compares different guardianship and decision-making legal frameworks in common law countries with regard to practical experiences of women with disabilities face when “choosing” a contraceptive. Consenting to contraception requires two prerequisites: the recognition of an individual as a full subject of law who enjoys full legal capacity and access to comprehensive sexual health education. This study argues that women with disabilities are sexual beings who require support in order to become self-advocates. Empowerment through information is the cornerstone to reach autonomy and limit abuse.

Acknowledgement

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WWDACT is indebted to the University of Canberra Institute of Governance and Policy Analysis which assisted with the development of the survey of doctors’ acuity in prescribing contraceptives.

Explanatory Note

This paper tackles the issue of consenting to contraception for women with disabilities. Therefore, due to the focus on consent, the major part of this piece deals with women with Learning Disability (LD). However, women with physical disabilities are considered as well in this research and some reference will be provided.

Further, because this research focuses on reaching an informed consent to contraception for a woman/girl with LD, emphasis is not provided on decision-making tools which require prior capacity. For instance, WWDACT does not deal with health direction as it is based on the person having capacity at the time of making a health direction⁴.

Furthermore, although Supported Decision Making (SDM) mechanisms have been more developed in relation to property management, WWDACT argues that they can be applied in the context of health care too. Moreover, this paper interrogates the decision-making issue through the lens of contraception and therefore does not provide expertise on the institutionalisation of people with psychosocial disabilities or property management, even if some reference to these issues will be made.

Besides, the fact SDM has been further developed in relation to property management rather than health care reveals that states might be reluctant in developing SDM and maintain legal capacity to every individual because they want to regulate and control mental diseases with psychiatric consequences. In fact, challenging the right to withdraw legal capacity to someone interferes with state prerogative to institutionalize people by force due to their psychiatric diagnosis⁵. Hence, forced institutionalization of people represents another topic which deserves further research and which is not tackled in this paper.

In addition, as this paper advocates to accessing sexual health education for all, it contends that programs should encompass both people with and without disabilities. However, this paper does not provide a thorough expertise on inclusive education as a human right for people with disabilities⁶. That is why further research should be undertaken in order to provide practical solutions to achieve an effective implementation of this human right and thus comply with international requirements.

Finally, this paper will be interspersed with special focus on the Australian Capital Territory (ACT)'s experience as this piece aims to participate in the reform movement engaged in developing decision-making mechanisms. WWDACT insists that the ability to learn and finally make decisions is reduced and not abolished by LD. Therefore, WWDACT promotes, in accordance with International Conventions, namely the *Convention on the Rights of Persons with Disabilities 2006* (CRPD), an SDM model in order to achieve United Nations (UN) goals Australia has ratified.

Executive Summary

This paper provides a comprehensive picture of current considerations dealing with decision-making and guardianship as it is the necessary step in achieving reproductive rights for women with disabilities. Therefore, this paper ends with recommendations adapted to the situation in the ACT in order to comply with international commitments, predominantly *Convention on the Elimination of Discrimination against Women 1979 (CEDAW)*, *Convention on the Rights of Persons with Disabilities 2006 (CRPD)* and the *Convention on the Rights of the Child 1989 (CRC)*.

The issue of contraception and consent for women with disabilities touches on various complexities in the social structure of human society. Contraception deals with the reproductive rights of women which are recognised as human rights by the CEDAW. Consent deals with the capacity to make decisions for him/herself which is closely entwined with full legal capacity recognised for an individual before the law. The latter is a corner stone of the CRPD. Moreover, behind contraception and consent, relies the question of sexuality. Yet, the sexuality of people with disabilities is polluted by social taboo and ignorance.

Therefore, this paper focuses on the current situations that women/girls with disabilities are facing when it comes to accessing contraception. It raises issues related to decision-making for women/girls with learning disabilities (LD) as well as access to information for women with physical and/or LD. In fact, too many studies evidence the lack of sexual health education provided to women with disabilities. Further, this project is informed by a social paradigm of respect and consideration for women/girls with disabilities as important actors in our society.

Further, the ACT Women's Plan 2016-26 is indeed focusing on better including women with disabilities within society and this paper sheds light on current issues regarding contraception and consent for women with disabilities. A specific focus is made for women with LD because the issue of consent is inevitably linked to the question of legal capacity and the right to decide for his/her own self. Therefore, this paper interrogates the burning issue of decision-making mechanisms and the inherent right of assuming legal capacity.

This research first focuses on the different legislations regulating consent to medical procedures for women with LD in Australia as well as in Canada, the United Kingdom (UK) and Ireland. Canada and the UK have been chosen because they have very similar political and legal structures with Australia. Further, Canada has an ongoing Law Reform Commission inquiry into guardianship and decision-making issues. Finally, Ireland was chosen because it has the most advanced and progressive legislation dealing with guardianship and decision-making. WWDACT argues that supported decision-making (SDM) must be implemented in order to truly include the woman/girl with LD in her own life decisions.

A second part of this paper addresses access to contraception for women in general, including women with and without disabilities. This task has been compromised by the blurriness of regulations dealing with medical procedure, and lack of clarity as to whether it encompasses contraception. In fact, the word contraception barely appears in legal texts – whether in Australia or elsewhere. This omission might be understood by the fact that people with disabilities,

especially women, are commonly considered as asexual beings. Therefore, the legal terminology hinders the assessment of how women/girls with disabilities could be granted contraception.

Finally, this project focuses on sexual health education and inclusion of women/girls with disabilities in those programs. In fact, WWDACT contends that without raising awareness of sexuality to the primary actors of this study, reaching their consent is a pie in the sky.

Introduction

The question of access to contraception and reaching consent for women/girls with disabilities encounters numerous hurdles. The first large-scale study dealing with experiences of women with disabilities in obtaining gynaecologic care was only published in 2017. In fact, this topic leads scholars to look at intersectional discrimination and social taboo. On the one hand, one is dealing with women, on the other hand, disability enters the discussion and finally, sexuality is at stake too⁸. Therefore, very few studies have been undertaken and the topic lacks documentation⁹. Even overseas, the most comprehensive piece on this topic published in 2015 by Open University in the United Kingdom (UK)¹⁰ only sampled 19 women with learning disabilities (LD).

Hence, in order to investigate the “contraception and consent” issue, Women With Disabilities ACT (WWDACT) focuses on decision-making process and guardianship laws which regulate these mechanisms. It appears that Australia, like most of the other countries worldwide, has an entrenched substituted decision-making process. Such process means that a third party, usually a guardian, is entitled to decide on behalf of the represented person who is denied an autonomous status before the law. Consequently, this system does not ensure access to information to the represented person and therefore, the informed consent of this person cannot be reached. Linked to contraception, the absence of informed consent of women with disabilities before being granted a contraceptive infringes their reproductive rights - guaranteed by the *Convention on the Elimination of Discrimination against Women 1979* (CEDAW). This project provides guidelines to improve women/girls with disabilities’ rights to control their sexuality. Hence, WWDACT proposes to rethink the legal status of people with LD in order to grant them equal recognition before the law – ensured by the *Convention on the Rights of Persons with Disabilities 2006* (CRPD). It is only by ensuring this autonomy before the law that informed consent of women with LD will be reached before granting them any contraceptive.

This paper will therefore first focus on guardianship laws and decision-making mechanisms (I). It will present the two main paradigms of substituted and supported decision-making (SDM) and their implementations in Western Common Law countries. Then, reproductive rights of women with disabilities will be tackled in order to argue that access to contraceptive knowledge is essential for empowering them (II).

I) Consent to medical procedure for people with learning disabilities

This part will provide an overview of the current guardianship legal systems in Australia, Canada, the UK and Ireland. Before developing the relevance of SDM (B), WWDACT presents the widely spread mechanism of substituted decision-making which is deeply mired in paternalism and denial of human rights (A). Finally, a special focus on the ACT will be provided (C).

A) Substituted decision-making paradigm

In this part, a definition of substituted decision-making will be provided (1) before proposing an analysis of the UK, Canada and Australia's implementations of this mechanism (2).

1) Definition of the substituted decision-making model

*All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood*¹¹. The *Universal Declaration of Human Rights 1948* (UDHR) starts with this powerful declaration. The UDHR has been drafted in the aftermath of the Second World War witnessing atrocities of the holocaust negating the very humanity of different human beings because of their differentness¹². Article 1 of the UDHR recalls therefore the need for recognition of equality between human beings, recognising their own reasons and conscious. However, our societies continue to categorise human beings and dispatch them into different boxes resulting in marginalisation of some groups.

All human beings, when they reach the age of majority turn into the adult category. Once adult, individuals embrace their full legal capacity. That is to say that they enjoy rights and that they can act before the law in order to enforce these rights if they are infringed. However, legal capacity can be rebutted if a person is assessed with mental incapacity. Yet, upon which basis can society categorise someone, a human being, as "incapable" and strip their legal capacity from them? This is at odds with the UDHR, concerning all human beings but also at odds with the CRPD, which brings a specific focus on people with disabilities.

In fact, when a person is declared as having a mental incapacity, states assert that withdrawing their legal capacity ensures them protection. A guardian will be appointed and decide on behalf of and *in the best interest* of the protected person. Therefore, the substituted decision-making process has been the widely established solution in most Western states to deal with people with LD. However, the *best interest* wording should not mislead our understanding of what this "protection" entails. In fact, this solution denies a part of humanity to people with LD because it prevents people declared with mental incapacity from enjoying their autonomy before the law.

Scholars have identified two major models to tackle disability and legal status deriving from it. On the one hand, there is the medical model, currently implemented worldwide and which considers that a person with disability is a person with deficits that need to be corrected in order to fit the "able bodied" norm¹³. On the other hand, there is the social model¹⁴ which is more consistent with a human rights-based approach since it argues that it is society which creates barriers to people with disabilities. The misfit paradigm¹⁵ is therefore shifted and this opens the door to a more human and social approach.¹⁶

As perfectly stated by Dr Anna Arstein-Kerslake:

The way most legal decision-making structures currently operate, the burden is on the individual with cognitive disability to prove that she or he can independently engage in decision-making. This is a reflection of the medical model of disability. The social model would instead require the legal

*system to ensure that appropriate social and other supports were in place to allow an individual with cognitive disability to engage in decision-making, either independently or with assistance from others. This is also the essence of what Article 12 of the CRPD requires and it should be the goal of any law, policy, or practice related to support for legal or other decision-making*¹⁷.

The omnipotence and omnipresence of substituted decision-making regimes demonstrate that states missed using a human rights approach toward enabling people with disabilities to give consent. Many texts focus on the *best interest* test. Yet, as the human rights lawyer Nicholas Caivano explains, even though substituted decision-makers must decide in the person's best interests, he/she is not required to effectively obtain the consent of the person¹⁸. In fact, most of the statutes provide that the best interest should be sought *as far as possible with* the person represented. The note *as far as possible with* adds a strong limitation to reaching an actual informed consent. Hence, when the best interest is considered, the person with LD's consent is not really sought. At best, the person represented will be told what has been decided on her/his behalf.

Further, in order to appoint a substituted decision-maker, current legislations use mental capacity tests which are mostly binary. Thus, there is no gradation in the definition of mental incapacity which carries the denial of legal capacity. That is to say that either full legal capacity or no legal capacity at all is established. This is called a status based approach. This status based approach breaches Article 12 of the CRPD and denies basic human rights to people with disabilities. Moreover, there are as many definitions of mental capacity as there are jurisdictions¹⁹. This reveals that this understanding of mental capacity is imbedded within social behaviours and therefore is subjective – *in fine* discriminatory²⁰. Currently, at the international level, there is only the Republic of Ireland which offers different degrees of incapacity according to which different kinds of support are proposed²¹. This latter approach is said to be functional.

2) Current implementations of substituted decision-making in the UK, Canada and Australia

Substituted decision-making has been translated into guardianship regulations which provide different kinds of substituted decision-makers. For instance, usually courts appoint guardians or managers²². The first one decides on behalf of a person for personal matters whereas the latter decides on property matters. Then, public advocates can also be appointed by the court to act as a guardian or a manager when no trusted relative is available to assume this role. Finally, contractual substituted decision-making mechanisms exist, for example with appointment of powers of attorney and with advanced health directives. The first one offers the possibility to any person to choose a trustworthy relative to decide on his/her behalf for matters limitedly described in the letter of attorney. Advanced health directives describe a person's wishes for future medical treatment if this person loses his/her capacity to decide.

For the purpose of this research, WWDACT will focus on guardians' prerogatives and managers' ones when relevant – predominantly in the context of decision-making mechanisms. Hence,

powers of attorney, advanced health directives and public advocate's roles will not be studied due to the fact that our research focuses on consenting to contraception.

In order to provide a complete understanding of the different trends in the different countries studied, a presentation of the different implementation and reforms going on in the UK, Canada and Australia will be undertaken here.

i. The United Kingdom

There are four countries in the UK and three different jurisdictions concerning regulations of guardianship and decision-making. England and Wales, share a single jurisdiction, separate to those of Scotland and Northern Ireland.

In England and Wales, the relevant Act dealing with consent to medical procedure for people with mental incapacity is the *Mental Capacity Act 2005* (MCA 2005). In Scotland, they are the *Mental Health (Care and Treatment) Act 2003* (MHA 2003) and the *Adults with Incapacity Act 2000* (AWIA 2000). Northern Ireland, for its part, did not have any regulation governing this matter²³ before the enactment of the *Mental Capacity Act 2016* (MCA 2016) on the 9th of May 2016. Hence common law had been applying in Northern Ireland and did not provide enough safeguard to ensure the human rights of people with disabilities.

Every British Act enshrines "capacity" as the criteria to justify or require a guardianship regime or a psychiatric treatment. Further, both the new MCA 2016 and the MCA 2005 use the best interest test²⁴ in order to decide on behalf of the represented person. However, Scottish laws give primacy to the *will and preferences* of the individual. This is consistent with the CRPD since the best interest criteria does not allow inclusion of the individual's consideration in the way that consideration of wishes and preferences would.

Nonetheless, MCA 2016 embraces a functional approach to capacity and not a status based approach like other Acts. That is to say that it defines the "lack of capacity" in relation to a specific matter, not as a whole²⁵. Hence, such a proposal is a progression which approaches CRPD recommendations²⁶.

MCA 2005 states five core principles which promote a SDM paradigm. Nonetheless, the road to hell being paved with good intentions, scholars²⁷ have highlighted that the MCA 2005 has not been correctly implemented²⁸ and continues to breach people with disabilities' right to participate in decisions concerning themselves.

The House of Lords Select Committee Report 2014 (HLSCR) bemoans the fact that there is a lack of understanding of the MCA 2005's principles. This is particularly true for health and social care professionals²⁹. The report notes that there is a continuing prevalence of paternalistic substituted decision-making rather than the intended SDM. Finally, it warns that the attitudes of professionals remain based on a caring and protective approach rather than on an enabling and empowering culture³⁰.

In fact, MCA 2005's principles recall that there is a presumption of capacity; that substitute decision-making should be taken as the last resort; that making unwise decisions is never a ground for denying capacity; that in the case of a decision made on behalf of an individual deemed incapable, his/her best interests should be considered; finally, that the person's rights and freedom of action should not be unreasonably restricted.³¹ However, as Dr Lucy Series highlights, empirical research suggest that assessors find it very difficult to distinguish between "incapacitous" and "unwise" decisions³². Further, she continues noting that other researchers advocate for more transparency in assessing mental capacity³³. In this regard, MCA 2016 seems to offer some safeguards³⁴. For instance, it provides that the "capacity assessment" needs to be reasoned. Hence, the person carrying out the assessment should provide evidence and proofs as to why the person has been assessed as lacking capacity in the matter at stake and why the alternative supports failed to be sufficient³⁵. Thus, if capacity is being assessed in order to strip, or not, legal capacity off someone, there are at least some arguments that would be able to be challenged.

However, it is worth noting that the MCA 2016 has not been implemented yet due to the necessity for extra implementation statutes. Thus, even though it offers safeguards and recognises that capacity can fluctuate according to the decision to be taken, there is no assurance that the Act will be correctly implemented. In fact, as indeed Harper and colleagues noticed, the MCA 2005 had similar ambitions in its text but is not implemented³⁶. Moreover, if the MCA 2016 is progressive for Northern Ireland, it still does not fulfil international commitment enshrined in the CRPD.

Moreover, the HLSCR notes that under the MCA 2005, capacity assessment is carried out by professionals who are not closely involved with the person alleged with incapacity which impairs communication³⁷. Yet, studies on mental capacity and support highlight that relationships can foster autonomy when an appropriate support is provided³⁸. Hence, one of the shortcomings of the MCA 2005 – which is true for all the statutes studied - is due to the fact that "cold professionals" are assessing mental incapacity. On the contrary, people trusted by the person with mental disabilities should be involved for a better outcome and more accurate approach to decision-making capacity.

Furthermore, the MCA 2016's definition of the "best interest" provides that it should be established *so far as practicable with the person involved in the matter*³⁹. Thus, even though the system remains embedded in a substituted scheme, the new Act seems to try to recognise the person represented as an actor, a subject, of the decision too⁴⁰. Nonetheless, this model echoes the Scottish system which envisages support in a substituted decision-making model. Scottish MHA 2003 and AWIA 2000 both establish a substituted decision-making process where the guardian has to seek the wishes and preferences of the person. This is an intermediate system between substitution and support. Indeed, the represented person is supposed to be involved in the decision-making process *in fine* done by the guardian. Hence, if Scottish Acts were quite progressive when enacted in 2000 and 2003, they have not been updated and remain embedded in a substituted decision-making framework⁴¹. In fact, the Mental Welfare Commission of Scotland (MWCS) admits that SDM mostly happens within the context of substituted decision-making which does not allow the person represented to fully enjoy his/her human rights⁴². Further, MWCS points out that a full SDM process, outside of any substituted decision-making regime, happens only

informally⁴³.

This situation is open to criticism since it creates a pseudo support and falls short of CRPD's intent. However, the UK is not the only state approaching support within a substituted decision-making regime. In fact, the Australian *NDIS Act 2013* provides that decision-making should be *supported as much as possible*⁴⁴ and that a supporter nominee⁴⁵ should help the person with a disability to make a decision and not take over her/him⁴⁶. At first, it is a positive evolution to see that the SDM framework is promoted under the *NDIS Act*⁴⁷. However, as underlined by the Australian Law Reform Commission 2014 (ALRC), those nominees are something between substituted and supported decision making⁴⁸. Consequently, scholars like Professor Terry Carney⁴⁹ and Dr Fleur Beaupert alert us to the risk that nominees forget their duty to support and became another actor or paternalistic representative deciding on behalf of the person in the matter⁵⁰.

In fact, this risk has been demonstrated in the Scottish situation as well as the English and Welsh MCA 2005 (mis)implementation. If indeed the wording of the MCA 2005 promotes a SDM idea, it remains short changed by the continuation of substituted decision-making as a lawful option. Maybe the United Nations Committee on the Rights of Persons with Disabilities report on the UK expected to be carried out in 2017 will provide more specific actions for progress in the field.

ii. Canada

Canada is more complex since it has ten provinces⁵¹ and three territories⁵² with very heteroclitic laws, and even distinct legal cultures. According to a 2012 census, almost 14% of Canadians were reported as having a disability. This number includes elderly people⁵³. Further, like in Australia, Canadians with disabilities face multiple barriers to accessing labour market or being present in public spaces. Moreover, people with disabilities are more at risk of poverty compared to their non-disabled counterparts. Finally, as underlined by researchers in 2009, the Canadian approach to disability follows a medical model and disregards the social approach⁵⁴.

Further, Canada is interesting because it shares legal characteristics with Australia. The main difference relies on the *Canadian Charter of Rights and Freedoms 1982* (CCRF)⁵⁵. The Charter has constitutional value that binds federal and provinces and territories' courts to its fundamental principles. This is an important difference since it allows judges to interpret statutes in the light of human rights. In Australia, ACT and Victoria's courts can do so as well but it is not possible at the federal level. Nonetheless, Canadian legislations dealing with decision-making processes for people with LD will vary from one province/territory to another. The situation will be the same concerning contraception.

Most of Canadian guardianship and decision-making regulations are imbedded in substituted decision-making regimes too. Such a situations breaches Article 12 of the CRPD but does not breach Canadian federal law because Canada has made a reservation⁵⁶ of application on this Article 12⁵⁷. This reservation, similar to the one made by Australia⁵⁸, provides that substituted decision-making can remain as a last resort option. However, if six⁵⁹ of the thirteen provinces and territories do not provide any SDM process, five⁶⁰ of them provide mixed regimes and two of them provides SDM schemes.

Even though both Quebec and British Columbia are providing SDM regimes, the Quebec one should not be fully recognised as a real SDM model. Indeed, Quebec has a particularity in Canada because its civil matters are regulated under *the Civil Code of Quebec 1991*, which is entrenched in the civil law tradition inherited from the French colonisation. Therefore, when it comes to disability and representation⁶¹, civil law principles apply and they are slightly different from common law principle with regard to property management. For instance, under civil law, *a fortiori* Quebec law, an individual can be considered capable to manage his/her daily spending but classified as incapable of making decisions in important questions of property management. Therefore, the guardianship and decision-making rationale remains paternalistic and leaves little space for an effective SDM process.

The *Civil Code of Quebec* offers three “protective” measures for people who are declared lacking mental capacity⁶²: curatorship⁶³, a tutorship⁶⁴ and an adviser to persons of full age⁶⁵. The two first are substituted decision-makers while the latter shall assist the adult in his/her decisions concerning property⁶⁶. Advisers never decide on behalf of the supported person and are here to help a person with mild incapacity to take decision concerning the management of his/her property.

Each one of these options depends on the level of mental incapacity assessed of the person. The assessment of mental incapacity is carried out by both a doctor and a social worker⁶⁷ who will establish the need for assistance or representation of a person. The presence of a social worker is welcomed since it adds a social approach which balances the medical rationale behind the capacity test as criticized by the HLSCR.

On the other hand, British Columbia can be highlighted as a model for an SDM mechanism. However, if indeed, it proposes an SDM framework closer to the CRPD requirement through the *Representation Agreement Act 2001* (RAA)⁶⁸, in contrast, the Law Commission of Ontario (LCO) underlines that the RAA is a door to both support as well as abuse⁶⁹. In fact, a representation agreement can act as a power of attorney and therefore lead to a substituted decision-making. That is why the lawyer community in Canada are wary about the limit of representation agreements as they can easily be misused⁷⁰.

Nonetheless, the RAA mechanisms are worth noting since they can be used in relation to health matters and *a fortiori* contraception. The RAA envisages a contractual approach to support for decision-making and not a judiciary one⁷¹. This alleviates some burden for people who would need to enter quickly into this kind of contract. Further, a person who is deemed incapable of making a contract or managing his/her personal or property matters will still be eligible to make the representative agreement⁷². The Act presumes that every adult is capable and that *an adult's way of communicating with others is not grounds for deciding that he or she is incapable of understanding anything referred to (...) making, changing or revoking a representation agreement, and making decisions about personal care, health care (...)*⁷³. However, RAA also asserts that incapacity can be proven. This constitutes its biggest flaw in the field.

A representation agreement offers the possibility for an adult to choose a representative to help him/her or decide on her/his behalf⁷⁴. Further, for the representation agreement to be valid, the adult must choose a monitor who would control the representative's actions. Consequently, RAA sets up safeguards protecting the person with disabilities from abuses. Moreover, both representatives and monitors shall fulfil duties established by the Act, including seeking the inclusion of the person in the matter⁷⁵.

Finally, for assessing the capability of an adult to enter into a representative agreement, trust between the representative and the adult is taken into account⁷⁶. This limits abuse and is a progressive point which widens the possibility of including people with disabilities within their own decisions. Therefore, British Columbia represents the most progressive Canadian jurisdiction in the field of decision-making.

Concerning other jurisdictions, namely Alberta, Saskatchewan, Manitoba⁷⁷ and Yukon, guardianship regulations propose mixed regimes of decision-making even if substituted decision-making remains and is overused. This confirms the UK experience which proposed support within a substitution rationale. This exposes a patent oxymoron. However, it is worth looking at what SDM options look like in these provinces and territories.

In Alberta, on the one hand, the *Adult Guardianship and Trusteeship Act 2008* (AGTA)⁷⁸ provides possibilities for SDM. It proposes two alternatives to the predominantly used substituted decision-making process. It offers a supported as well as a co-decision-making process⁷⁹.

The SDM procedure requires an SDM authorization. This consists of appointing a trustworthy person for the person with a mild disability to assist her/him in her/him personal matters such as health⁸⁰. However, AGTA's provisions for supported and co-decision-making do not apply to property decisions. The co-decision-making process would target people with more serious mental impairment but who do not "need" a guardian to decide without them⁸¹.

Further, when no supporter has been appointed, and the person in question appears to lack mental capacity, medical practitioners may choose a relative to decide on behalf of the person. The designated person has power for one specific question of health care only and does not have the right to decide for sterilisation or other major treatments⁸². This model remains a substituted way of making a decision. However, it can be challenged by any close friend, relative or legal representative⁸³ which provides a safeguard against undue influences.

In Saskatchewan, the *Adult Guardianship and Co-decision-making Act 2000* (AGCDMA) is very ambiguous. On the one hand, it does provide a co-decision-making possibility for adults with disabilities. On the other hand, AGCDMA's capacity test is very restrictive and states that capacity includes the ability to take into account the reasonably foreseeable consequences of making or not making a decision⁸⁴. Moreover, the Act outlines that personal co-decision makers appointed by the court share, with the adult in the matter, the authority to make decisions in the specific fields listed in the court order⁸⁵. Hence, the co-decision maker can easily take over the supported person. However, AGCDMA asserts some important principles regarding the different ways an adult with LD can express him/herself⁸⁶. This is also highlighted in Yukon's *Decision Making, Support and*

*Protection to Adults Act 2003*⁸⁷. This regulation underlines the fact that a person's way of communicating with others is not, by itself, a ground for deciding that they are incapable of understanding anything referred to health care⁸⁸. Further, it provides that the care provider must communicate in an appropriate manner and may allow a relative to assist the patient so that he/she can understand what is at stake⁸⁹. However, without proper safeguards, this goodwill falls into deaf ears.

Guardianship and decision-making mechanisms for people with LD deal with the very foundations of societal thinking in the sense that these mechanisms reveal how humans categorise "otherness" and rationalise how certain groups are treated. That is why it is hard to reform them. However, this is happening now and most Western countries are currently engaging in law reform commissions. In Canada, Ontario demonstrates this current climate of reform. The current Ontarian legal framework on guardianship and consent to medical procedure is a classical substituted decision-making regime⁹⁰. Meanwhile, Ontario's court judgements are pushing for promoting people with disabilities' rights and autonomy⁹¹.

The Ontarian Office of the Public Guardian and Trustee's Guidelines for Conducting Assessments of Capacity states that mental capacity under the *Substitute Decisions Act 1992* (SDA)⁹² is the ability to understand information relevant to making a decision and appreciate the reasonably foreseeable consequences of a decision or lack of decision⁹³. Therefore, this definition, like the one noted in the Saskatchewan law⁹⁴, offers a narrow interpretation of mental capacity and denies the social approach to capacity promoted by the CRPD.

Further, it corroborates what was underlined by N. Caivano: *the legal tests used to determine decision-making capacity vary by jurisdiction, but they often focus on a person's cognitive abilities. This approach is consistent with the medical model of disability, which emphasizes ways to "cure" people with disabilities so that they can conform to normative modes of functioning*⁹⁵. In his article *Conceptualizing Capacity: Interpreting Canada's Qualified Ratification of Article 12 of the UN Disability Rights Convention*, N. Caivano explains that many of capacity tests in Canada focus on two main factors: a person's ability to comprehend the information at hand and a person's ability to appreciate the reasonably foreseeable consequences of his or her decision⁹⁶. This view does not allow taking into account the complexity of LD. Indeed, some decisions might be complex when other can be easy to make for a person with LD – as well as for any other abled person. An "abled person" might require help from a specialist for legal aid or accountancy for instance. Therefore, these criteria for assessing capacity to make decisions are too narrow.

For example, in *Calvert (Litigation Guardian of) v. Calvert* (1997), a woman in an early stage of Alzheimer's disease was first denied capacity to request a divorce. Finally, the Ontario Court of Appeal found that she had the capacity to decide to leave her husband. The Court determined that decisions related to marriage, separation and divorce required a low level of capacity. It distinguished these types of decisions from those related to instructing counsel, which it said required a higher level of capacity that included being able to understand financial and legal issues. In the Court's view, instructing counsel was on a "significantly higher" level on the "competency hierarchy."⁹⁷ The Court decided that, *"While Mrs. Calvert may have lacked the capacity to instruct*

counsel, that did not mean that she could not make the basic personal decision to separate and divorce”⁹⁸. This case reveals the subjectivity of assessing mental capacity of a person with LD. One can imagine that with an appropriate support, the applicant would have been able to instruct a counsel.

However, in 2012, Ontario established a Law Commission (LCO) to engage in reforms which will be more comprehensive of LD. The LCO proposes that Ontario’s government works on alternatives to a substituted decision-making process when it is possible. Further, the LCO issued its final report in March 2017⁹⁹ and acknowledges that a binary mental capacity test prevents people with disabilities from being part of their own lives. Priorities identified by the LCO include reducing unnecessary and inappropriate intervention of a guardian¹⁰⁰, as well as limiting discretion for evaluating capacity¹⁰¹.

This last recommendation echoes criticisms made by the HLSCR in 2014. Furthermore, the McGill Centre for Human Rights and Legal Pluralism has provided a complete overview of the current legislations in Ontario addressing issues of legal capacity, decision-making and guardianship¹⁰². It underlines that the SDA is not consistent with Article 12 of the CRPD because it does not consider situations where a person’s decision-making capacity fluctuates on a day-to-day and decision-by-decision basis due to the nature of the specific disability or medical condition.¹⁰³ It is worth noting that the functional approach has been integrated within recent Acts in the matters such as the *Assisted Decision-Making (Capacity) Act* 2015 in the Republic of Ireland or the MCA 2016 in Northern Ireland. Finally, SDA creates a risk of exploitation, abuse and neglect for people under guardianship. Section 40(1) of the Act allows a guardian to take “compensation” from the person with disabilities on a monthly, quarterly or annual basis while no proper safeguards have been implemented.¹⁰⁴

Accordingly, the LCO acknowledged the short-comings of the current legal framework and proposes to strengthen safeguards against abuse. For this purpose, it recommends that a monitor should be appointed to control guardians and limit abuse of power¹⁰⁵. This recommendation echoes the British Columbian RAA system.

The main obstacle faced by people with LD relies on the reservation that states make on Article 12 of the CRPD. Indeed, the UK, Canada and Australia formulated a reservation of interpretation of Article 12 of the CRPD. If Australia and Canada did it in order to justify the conservation of old regulations enforcing substituted decision-making¹⁰⁶, the UK’s reservation appears less restrictive regarding the CRPD’s goals. One of the essential ideas of the CRPD is to totally abolish the substituted decision-making process and not to maintain it as a last resort. This risks normalising the substitution model and traps people with disabilities in the societal fringe. However, most of the states reviewed remain reluctant to pass SDM regulations to empower people with disabilities¹⁰⁷. N. Caivano underlines that the UK and Canada – *a fortiori* Australia - have substantially contradicting statement in this regard. He highlights that the UK considers changes in the future while Canada reserves the right not to suppress substituted decision-making¹⁰⁸. This criticism applies to Australia which has also made a reservation similar to the Canadian one.

Canadian Disabled People Organisations (DPO) urge Canada to withdraw this reservation in order to move forward and foster political and legal changes¹⁰⁹. Therefore, civil society organisations have successfully raised awareness on disabilities and the need for better inclusion and care¹¹⁰. Furthermore, as it has been underlined by many scholars, the CRPD, like all international conventions, has to be implemented by signatory states themselves. This leads to a “fox guarding the henhouse” situation. Therefore, it has been noticed that there is a lack of appropriate legislation ensuring human rights of people with LD¹¹¹. However, some cases from the Supreme Court of Canada reveal the need to adopt new legislation. Judges have been keener on recognising the human rights of people with disabilities. Nonetheless, these changes should not rely on judges alone and should rather be enshrined into the law too.

For instance, N. Caivano highlights cases from the Supreme Court of Canada which underline the power of a human rights charter with constitutional value. For instance, in 1988, the Canadian Supreme Court recognised that Section 7 of the CCRF protecting the right to life, liberty, and security of the person, guarantees personal autonomy with respect to decisions “*intimately affecting [one’s] private [life]*”¹¹². Section 7 of the CCRF echoes Section 18 of the ACT *Human Rights Act 2004* (ACT HRA) and can be used to promote autonomy before the law of people with LD. In fact, ensuring legal capacity will foster and guarantee autonomy of people with disabilities before the law. Hence, in 2003, the Supreme Court of Canada stated that “[u]nwarranted findings of incapacity severely infringe upon a person’s right to self-determination”¹¹³. Finally, in 1999, the same Canadian superior judiciary body asserted that the equality guarantee “*is concerned with the realization of personal autonomy and self-determination. Human dignity means that an individual or group feels self-respect and self-worth*”¹¹⁴.

However, Canadian laws are far from being homogeneous. The country is going through a lot of changes in this regard. Hence, if some Canadian jurisdictions provide SDM mechanisms, substituted decision-making regimes remain overused. Current evolutions in Canadian legislations witness such progress. Moreover, it is interesting to note that Courts in Canada have been far more progressive than governments on recognising people with disabilities’ mental capacity. For instance, as early as 1982, the Ontario County Court admitted that a man with cerebral palsy who was not able to speak was “mentally competent”¹¹⁵. The man in question had learned how to communicate through pictures and symbols and this was recognised by justices in their decision. Moreover, 15 years later, the Ontario Supreme Court went even further with Justice Quinn who asserted that “*mental capacity exists if the appellant is able to carry out her decisions with the help of others*”¹¹⁶. Thus, a further 20 years on again, it is time to enact new laws.

iii. Australia

All the different legislations on decision-making in Australian states and territories are based on substitution rather than support. Nonetheless, the idea of a more inclusive procedure is not totally absent since some regulations consider the wishes of the represented person¹¹⁷ - when possible -. Further, the new Victorian’s *Guardianship and Administration Bill 2014* (GAB 2014) even proposes formal SDM regimes¹¹⁸. At the same time however, these legislations do not provide any remedy to ensure the participation of the person deemed “incapable” to be involved in his/her decision-

making process. Most of the statutes establish who is responsible for and can decide on behalf of a person who has been assessed with mental incapacity¹¹⁹. This highlights a common issue with overseas laws already reviewed which use mental incapacity as a ground for withdrawing legal capacity. Consequently, even though a guardian usually has to consent considering the best interest of the represented person, the actual consent of this person appears to be left aside. Further, some laws provide that information should be given to the individual *or* the guardian – and not to the individual *and*¹²⁰ the guardian. In such situations, how far is the person with LD included in the decision-making process concerning him/her?

In this paper, guardianship regulations have been studied in relation to accessing a chosen contraception. However, most of the regulations, except for the ACT and the Northern Territory (NT), are very blurry on this subject. This will be debated in the second part of this paper focusing on contraception. Consequently, WWDACT has focused on guardianship and decision-making regulations concerning consent to health care.

First of all, it is worth noting that in six states and territories, namely the ACT, Victoria, Northern Territory (NT), Western Australia (WA), Tasmania and Queensland, decision-making processes for women and girls with LD are regulated by different rules before and after 18 years of age. In South Australia (SA), girls with LD fall into the procedure for adults when they turn 16¹²¹. In New South Wales (NSW), statutes provide a specific procedure for girls under 16 and for women, after 18. However, there is no statute concerning the decision-making process to grant a contraceptive to young women with LD between 16 and 18 years old¹²².

In every state and territory legislation, except in NSW, girls can be granted a contraceptive with the sole consent of their parents or the person representing them¹²³. Parents decide based on their parental responsibility toward their child and should act in the best interest of the child and provide him/her with appropriate care¹²⁴. For minors, there is no mention of the parents' requirement to ascertain the wishes and preferences of the child concerned.

However, in NSW, when the girl is under 16, an order from the NSW Civil and Administrative Court (NCAT) is required before granting a contraceptive. According to NCAT guidelines, the Court considers the medical views as well as arguments from close people surrounding the girl. Further, it is only “when possible” that NCAT tries to seek the girls' views¹²⁵. This possibility left to the Court might lead to disregard for the person in the matter since it is not mandatory to include the person's views and that there is no safeguard.

Further, in six states and territories, namely NT, SA, Queensland, Tasmania, WA¹²⁶ and Victoria, guardians are vested with the right to consent on behalf of the woman/girl they represent for contraceptives without having to go to court. However, the situation is different in two other states and territories. Further, it is worth highlighting that in the NT, guardians used to have to seek a court order before being able to consent to a contraceptive on behalf of the woman. Nonetheless, the new *Guardianship of Adults Act 2016*¹²⁷ (GAA 2016) has repealed this duty and now allows a guardian to consent to granting contraceptives to the woman represented without seeking a court order¹²⁸. Thus, the ACT remains the sole Australian jurisdiction to require guardians to seek a court

order to be able to grant a contraceptive on behalf of a woman – but not on behalf of a girl. Such situation is very burdensome and more details will be provided in the coming sections of this paper.

In the NT, Queensland, Tasmania, WA and Victoria, laws require guardians to look for the person's best interest before consenting to any medical treatment¹²⁹. However, all academic studies on the matter denounce the inconsistency of the “best interest” test with the respect to the human rights contained in the CRPD¹³⁰. In fact, the major issue these regulations are facing is the lack of safeguards to ensure the inclusion of the represented person. Further, due to the negation of legal capacity, no remedy appears effective to ensure the participation of the person represented. Furthermore, certain statutes describe the guardian’s duties as comparable to that of parents toward their children¹³¹. This reveals the paternalistic mindset of guardianship laws in Australia.

Moreover, the Queensland *Guardianship and Administration Act 2000* sounds very restrictive concerning adults with LD assessed as having impaired capacity. Even though it underlines that “*an adult with impaired capacity has a right to the greatest possible degree of autonomy in decision-making*”¹³², the Act clearly states that they should be subject to restrictive rights when it comes to make decisions¹³³.

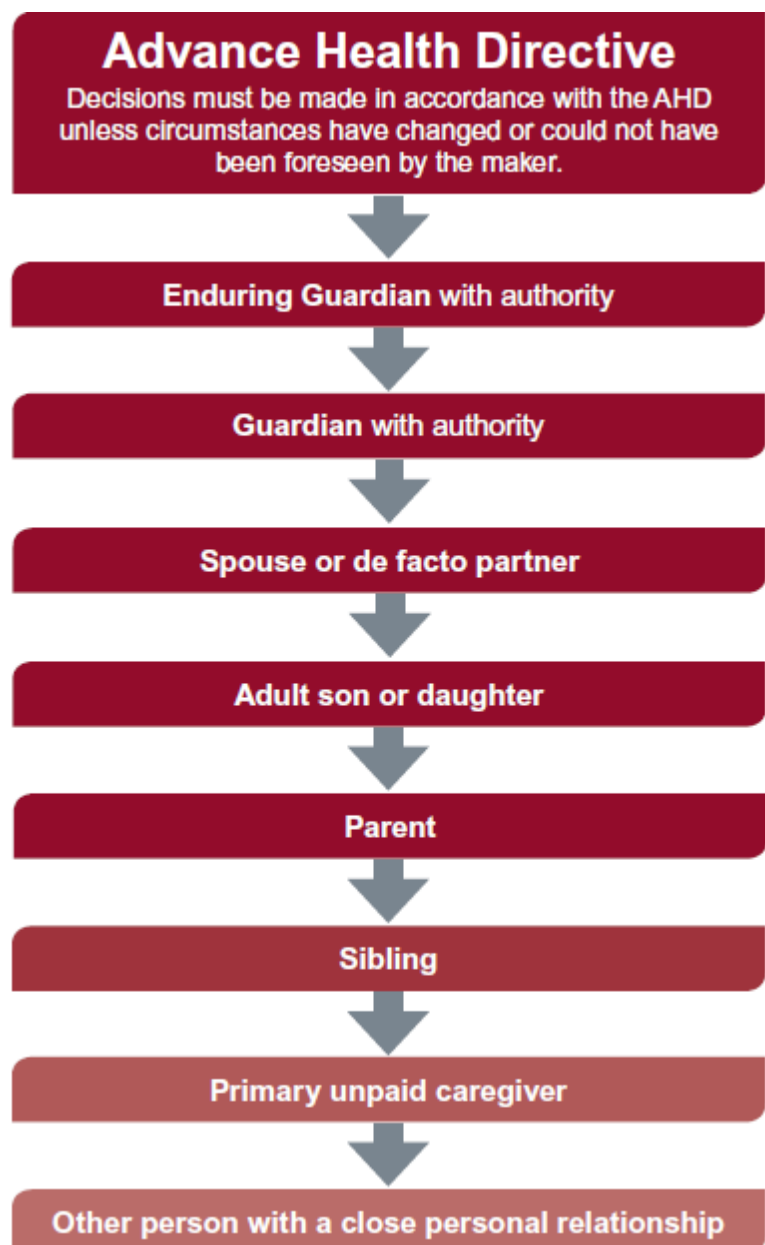
Nonetheless, in SA, it is worth noting that the law does not require the guardian to act in the best interest of the person represented. Rather, it requires consideration to be given to what would, according to the guardian, be the wishes of the person in the matter if he/she were not mentally incapacitated¹³⁴. This phrasing might give more chances for including the represented person even though the system remains imbedded in a substituted decision-making rationale.

Further, the NT legislation has recently changed, the *Adult Guardianship Act 1988* has been repealed and legal mechanisms for adults’ decision-making whose capacity is impaired is now governed by the GAA 2016. There are two major changes relevant to this research. First, and this will be discussed further in the second part of this study, the term contraception disappears which makes it fall within the wide category of “health care actions”. Secondly, the new Act governs the guardian’s authority to consent for health care actions and repeals the court order requirement¹³⁵. However, if capacity is recognised as fluctuating, the best interest test remains enshrined in the Act.

Finally, the WA Department of Health’s description of the hierarchy of decision-maker for treatment for a person lacking mental capacity ¹³⁶ illustrates perfectly the exclusion of the person deemed incapable within his/her own decisions:

WA Department of Health: Hierarchy of decision-makers for treatment

Where an AHD does not exist or does not cover the treatment decision required, the health professional must obtain a decision for non-urgent treatment from the first person in the hierarchy who is 18 years of age or older has full legal capacity and is willing and available to make a decision.



The absence of the patient in the process is striking. However, and this will be highlighted below, Victoria and SA are going through some changes which represent an important step toward better inclusion and respect of people with LD¹³⁷.

Accordingly, regimes implemented in Australia remain as substituted decision-making processes which exclude the person in question from being part of him/her own decision. Further, if some regulations try to offer a place for the person's wishes and preferences, there is a lack of safeguard in all legislation to ensure the participation of the person with LD in decisions concerning his/her health. This situation has been acknowledged in the UK too. The MCA 2005, while stating the progressive principle for including the "incapable" within his/her decisions, practices have proven otherwise. It appears therefore that the quality of inclusion of the person with LD into her own decision-making process for granting contraception remains largely attributable to the professional dealing with the case.

Finally, it is worth highlighting that as DPOs in Canada urge their country to withdraw its reservation to Article 12 of the CRPD, DPOs in Australia are also advocating for such withdrawal¹³⁸. Indeed, WWDACT joins this call for removing this reservation which degrades the CRPD spirit. Moreover, Australian reservation on Article 12 of the CRPD allowing national regulations to maintain substituted decision-making as a last resort breaches the *Vienna Convention on the Law of Treaties 1969*¹³⁹. One of the key and controversial elements of this Convention is contained in its Article 19 regarding reservations. In fact, Article 19 (c) of the Convention prohibits reservations which are incompatible with the object and purpose of the treaty to which they relate¹⁴⁰. This echoes the criticism made with regards to whom the duty to implement international law relies: states, primary subjects of international law¹⁴¹. Notwithstanding this, international law and the human rights deriving from it should not be limited due to incongruous reservations which contradict the essence of a treaty. The CRPD promotes equal status before the law for people with disabilities and requires states to take appropriate measures to achieve this goal. This reservation should not be used by states and territories in Australia to limit their scope of action in promoting supported decision making. The key to an effective inclusion and full respect of what Australia had committed to by ratifying the CRPD relies on this very support mechanism rather than simple substitution in the best interest of a person.

B) Supported Decision-Making paradigm

This part provides a definition of SDM consistent with the CRPD (1). Then, the Irish new *Capacity Act 2015* will be studied in order to grasp the possibilities of implementation of such a system (2). Finally, this part provides an overview of the current reform movement happening in Australia (3).

1) Supported Decision-Making consistent with the CRPD

As Steven J. Hoffman, Lathika Sritharan and Ali Tejpar explain it, the CRPD consists of a 25-paragraph preamble and 50 articles that address the obligations of state parties, enumerate the rights of persons with disabilities, and outline the implementation and monitoring processes of the Convention¹⁴². The preamble provides that disability should be understood as an evolving concept. There is only one country which fully translated this evolutive concept into a law: the Republic of Ireland. The *Assisted Decision-Making (Capacity) Act 2015* envisages different levels of mental capacity (disability) for different situations and clearly states this evolutive characteristic¹⁴³. In Australia, Canada or in the UK, no legislation is currently as progressive as the Irish one.

Further, Article 12 of the CRPD represents the most pertinent section of the Convention with regard to decision-making. It is about attributing legal capacity to people with disabilities. This is essential because one of the most burning issues when dealing with people with LD is the abuse they face due to a lack of an autonomous legal status.

Article 12 - Equal recognition before the law (emphasis added)

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.¹⁴⁴

N. Caivano explains that people with disabilities can be perceived as subjects rather than objects of the law thanks to Article 3 combined with Article 12 of the CRPD¹⁴⁵. That is to say that people with LD can finally be considered as actors and right-bearers in our society which will lead them to be granted legal capacity and agency - the right to act to enforce their rights as individuals.

In this project, as the Law Professor Robert Dinerstein proposes, WWDACT understands SDM as a series of relationships, practices, arrangements, and agreements designed to assist a person with disabilities to make and communicate to others decisions about his/her life¹⁴⁶. The SDM process seeks to help the person with disabilities making and expressing his/her decisions using trustworthy people around her/him¹⁴⁷.

Scholars who have analysed the legal implications of Article 12 of the CRPD assert that this Article aims to recognise legal capacity in every person with a disability, including individuals with high-support needs. The CRPD is therefore clearly in favour of SDM and pursues the abandonment of current guardianship laws entrenched in substituted decision-making¹⁴⁸.

In English common law tradition, a person who had been deprived of legal capacity could not enter into contracts and could not commence litigation before the courts. A person who was found to lack capacity over property and affairs was also prevented from making all decisions in that realm. A person who was found to be incapable of managing their investments, for example, would also be prevented from managing their daily spending, even if they remained capable of doing so.¹⁴⁹ This approach contrasts with French and Quebec civil law systems for instance, where depending on your level of disability, one person can be prevented from managing her property but would be allowed to engage in daily spending¹⁵⁰ – although this would be voided in case of

abuse¹⁵¹.

Further, it is relevant to remark that human decisions are usually influenced and shaped by the interrelationships of decision-makers including parents, friends, teachers¹⁵². This acknowledgement is essential if one wants to change the paradigm in which human societies are currently entrenched. The social environment is very important when tackling human cognitive capacities. Hence, thanks to the diversity of human sensitivities within society, one can overcome decision-making difficulties by using these resources. That is why the support paradigm – also called universal legal capacity¹⁵³ – can empower people with disabilities. However, if support in decision-making is to be recognised as a way to finally enable the informed consent of people with LD, some safeguards should be put in place to avoid abuses – such as a third person (supporter) exerting undue influence.

In fact, most of the literature on the topic discusses the pros and cons of this SDM theory¹⁵⁴. Therefore, a monitor of the supporter could be set up as it has been done in British Columbia (Canada)¹⁵⁵. Hence, undue influence can be prevented. Further, the right to take risk and make mistakes should be ensured as well¹⁵⁶. In fact, no human being is free from flaws and empowering people also encompasses letting them make mistakes.

Dr L. Series highlights the fact that the CRPD demands a *disability neutral response to risk and vulnerability*. This means that the CRPD promotes the implementation of general regulations which would not be discriminatory against people with disabilities. Dr L. Series remarks that some coercive measures are currently perceived as acceptable because they “only” target vulnerable people who are in need of “protection”. However, it is necessary to consider how non-disabled people would feel if those regulations were applicable to the entire population as a whole¹⁵⁷. This question raises a philosophical debate but it is not superficial to ask this of ourselves. Indeed, many researchers complain and condemn the fact that people with disabilities are not heard. Further, as noticed in research tackling forced contraception and forced sterilisation, if forced sterilisation is now almost unanimously condemned, coercion remains acceptable when it is used for Long-Acting Reversible Contraception (LARC)¹⁵⁸. Current legislations are too paternalistic and impair empowerment.

Consequently, our society needs a change of paradigm which will consider people with LD as complete individuals with specific needs in relation to decision-making. These needs can be overcome through appropriate support and respect provided to these persons. The cornerstone of SDM is autonomy. As scholars have highlighted, one should not confuse “mental capacity” with “legal capacity”¹⁵⁹. Hence, “mental incapacity” should not be used as a way to take away someone’s agency. That is why the obsession for capacity assessment is actually irrelevant. For as authors already contended in 2010¹⁶⁰, the capacity test should be abandoned in favour of ability to express – in various ways of course - in order to encompass all the population. As the General Manager of Advocacy for Inclusion, Christina Ryan, said at the 2016 Conference of the Adult Guardianship and Administration Council (AGAC): *This is a bucket. It has a 10 litre capacity. Capacity is appropriate for buckets, but not for people*¹⁶¹. In her intervention, C. Ryan depicted the current reality of people deemed incapable. Some people who only have difficulty in expressing or

understanding some information will fall into a guardianship system which denies them a proper independent and autonomous legal status. Consequently, it is urgent to implement Article 12 now!¹⁶²

Moreover, much research argues that SDM, enlightened by the CRPD, focuses more on personal and biographical – rather than clinical – knowledge of a person with LD¹⁶³. Accordingly, this paradigm places greater importance in the role of family, friends and trustworthy people for accompanying and supporting someone in their choices. Such an approach is coherent and mirrors a European initiative carried out by Inclusion Europe which seeks to list efficient SDM mechanisms for people with LD. The project catalogues European as well as non-European initiatives. For instance, ACT Disability Aged and Carer Advocacy Service's (ADACAS) online tool for decision-making is proposed as an efficient model for accompanying people with LD in medical decisions¹⁶⁴.

Further, in order to help medical professionals dialoguing with people with LD, the UK implemented a health passport. It has also been recently implemented in New Zealand¹⁶⁵. The passport contains different information related to the previous diagnoses of the person as well as their decision-making support wishes. It is innovative because it explains how the person likes to be treated or not. It can be a useful tool for accompanying medical professionals in knowing the person better and having better dialogue with him/her. Further, this tool is consistent with what the ACT Law Reform Advisory Council (ACT LRAC) recommended in its 2016 guardianship report¹⁶⁶.

The social approach promotes a more evolutionary understanding of disabilities. Therefore, people categorized as incapable should be taken out of this medical box. People with disabilities must be included in their own care decisions. This is in accordance with what is asserted in the CRPD and the *Capacity Act 2015* enacted in the Republic of Ireland.

2) The Irish Capacity Act

The Republic of Ireland has signed the CRPD but not yet ratified it. Nonetheless, it appears that it has the most progressive legal framework in assisting people with disabilities in their decision-making process.

The Republic of Ireland had enacted a new Act, the *Assisted Decision-Making (Capacity) Act 2015*, which is very progressive concerning the decision-making process for adults with LD. Further, this has been welcomed by the Irish Mental Health Commission because the former Act dated from the 19th century.

The Act recognises different options for supporting decision-making for people with LD. Thus, instead of providing a sole option of a substituted power to make a decision, there are two different steps possible before this last resort solution¹⁶⁷. Those options are made possible because the Act recognises that mental capacity is not uniform and should be assessed at the time of the decision to be taken in relation to the matter in question¹⁶⁸. This approach to capacity is functional and not binary. Such an approach to capacity assessment offers a greater place to the person with disability in front of the law and for his/her own decisions. Furthermore, this concept echoes the preamble of the CRPD which seeks to recognise that disability is an evolving

concept¹⁶⁹. Notwithstanding this, one needs to recall that the capacity can be withdrawn and that substituted decision-making remains as a last resort. However, the difference with former examples is that it relies on safeguards to ensure this is a last resort solution and that the Act has jurisdiction over personal as well as property matters.

The *Capacity Act 2015* offers three types of decision-making mechanisms. Two are based on support with the assisted decision-making option and the co-decision-making option. A last one is based on substitution called the decision-making representative option.

The two first options are meant to cope with the various understanding and communication difficulties people with LD are facing. Further, those mechanisms are available for any kind of decision, whether it is related to welfare, property and finance or both. This is a very important point since most legislation differentiates property management from personal welfare in implementing SDM mechanisms.

Assisted decision-making: a person may appoint a decision-making assistant – typically a family member or carer – through a formal decision-making assistance agreement to support him or her to access information or to understand, make and express decisions. Decision-making responsibility remains with the person. The decision-making assistant will be supervised by the Director of the Decision Support Service.

This option is a true model of SDM since the person in the matter has the final word on the decision and that the assistant acts more like a translator than a parent.

Co-decision-making: a person can appoint a trusted family member or friend as a co-decision-maker to make decisions jointly with him or her under a co-decision-making agreement. Decision-making responsibility is shared jointly between the person and the co-decision-maker. The co-decision-maker will be supervised by the Director of the Decision Support Service.

This second option is mixed and sounds like the one in Saskatchewan with the authority to make a decision shared between the person in the matter and his/her co-decision maker. However, the difference relies on the supervision that is provided in order to monitor the action of the co-decision maker. Thus, the risk present in the Saskatchewan model will be hopefully overcome in the implementation of the new Irish law.

Decision-making representative: for the small minority of people who are not able to make decisions even with help, the Act provides for the Circuit Court to appoint a decision-making representative. A decision-making representative will make decisions on behalf of the person but must abide by the guiding principles and must reflect the person's will and preferences where possible. The functions of decision-making representatives will be as limited in scope and duration as is reasonably practicable. The decision-making representative will be supervised by the Director of the Decision Support Service"¹⁷⁰.

Finally, this last option is substituted decision-making but it appears heavily managed in order to limit its use. Furthermore, there is no reference to the best interest but rather refers to the will and preferences. Consequently, the progress made by the Irish *Capacity Act 2015* can be welcomed.

It is worth noting that the Act will put in place a superior body responsible for monitoring those agreements allowing SDM: the Decision Support Service (DSS). This body will be established within the Mental Health Commission. The DSS aims to support decision-making by and for adults with capacity difficulties and to monitor individuals who are providing support to people with capacity difficulties. Therefore, there will be a coherent framework organising and promoting support in decision-making for people with LD. Further, the Director of the DSS will, *inter alia*, prepare Codes of Practice for specific groups to provide guidance in relation to the Act. The Director is responsible for providing information to members of the public about the Act, and for promoting awareness of the new law on capacity¹⁷¹. Hence, one understands that medical professionals would be informed about this and that would, hopefully, limit prejudices and misinformation on the capacity of people with LD¹⁷².

The *Capacity Act 2015* significantly extends the statutory remit of the Mental Health Commission to include wide-ranging regulatory and information functions for the Director of the DSS¹⁷³. Further, it is relevant to highlight that the Mental Health Commission will have to work with the Department of Health as well as the Department of Justice and Equality and other relevant stakeholders to put in place the necessary infrastructure to make the DSS operational in a timely manner¹⁷⁴. This shows that such a reform promotes cooperation between different actors in order to take real advantage of the new legislation and effectively include people with LD within their own life's decisions.

This legal framework complies much more with Article 12 of the CRPD compared to other systems overseas. In the preliminary part of the *Capacity Act 2015*, there is a clear recognition of the different levels of LD which require different kinds of support for decision-making.

First of all, the Act uses the term functional to talk about capacity, underlining the evolving concept of disability. Thus, it provides that capacity fluctuates according to different matters¹⁷⁵. Then, in order to rebut the capacity presumed, the Act does not refer to *understanding the foreseeable consequences of the decision*. Rather, it proposes a very restricted definition which will limit the declaration of incapacity¹⁷⁶. Moreover, in order to ensure the recognition of capacity is scalable to large numbers of people, the Act states that the capacity to retain information for a short time only is sufficient¹⁷⁷.

Consequently, the Irish legislation appears to be complying the most with the CRPD. However, concerning children with disabilities, their implication within the decision making with regards to contraception remains limited.

The Irish Family Planning Association (IFPA) underlines that before the age of 16, a girl needs the consent of her parents or guardians in order to receive contraception – 16 being the age of consent for medical procedures¹⁷⁸. However, although the Irish law is very progressive and can be taken as an example when it comes to the decision-making process for adults with LD, the situation is rather different in relation to contraception¹⁷⁹.

3) Reform movement and pilot projects in Australia

Most of the legislation on guardianship, consent to medical treatment and mental health do not consider strong SDM mechanisms and are rather trapped within a substituted model of decision-making. However, this matter represents a burning issue and the new Acts in the Republic of Ireland, Northern Ireland (UK), Northern Territory (Australia), or Victoria (Australia) prove that changes are first needed, and secondly happening.

The Australian Law Reform Commission (ALRC) released a report in 2014 named *Equality, Capacity and Disability in Commonwealth Laws*¹⁸⁰. The ALRC recommends that states and territories harmonise their legislations dealing with guardianship, consent to medical treatment and mental health¹⁸¹. It asserts that in order to be consistent with the CRPD, Australian states and territories should implement SDM processes for empowering people with disabilities and granting them recognition before the law.

Further, the ALRC calls for repealing all discriminatory mental health legislation, guardianship legislation and any other substituted decision-making regimes quoting Drs Fleur Beaupert, Piers Gooding and Linda Steele:

*When restrictions are placed on the right to exercise legal capacity and the right to refuse medical treatment on an equal basis with others, the basis for supported decision-making as a remedy for disability-based discrimination is compromised. Hence, even if provisions for ‘supported decision-making’ and other measures to support the exercise of legal capacity were installed into current mental health and guardianship laws, the violation of core obligations of the CRPD would remain.*¹⁸²

In its submission to the ALRC, the Office of the Public Advocate of South Australia (OPA SA) acknowledges the fact that states and territories have responsibility in Australia to implement progressive laws in the decision-making area. It identifies that current state and territory laws do not provide for SDM arrangements.

Despite this, SA laws proposed a substituted decision-making process to people deemed mentally incapable. The OPA SA conducted a project to trial SDM mechanisms to let participants with decision-making impairment to be the final decision-makers. The project lasted for two years, from 2010 to 2012 and included people with brain injury, intellectual disability, autism, and motor neurone disease. The aim of the project was also to implement an SDM regime for those participants. This was based on non-statutory agreements made with people participants already knew. Findings of the project highlighted that the majority of the participants had increased their self-confidence as well as their decision-making capacity. The project’s conclusions stressed that support networks have improved and that participants had increased their community engagement¹⁸³.

Further, in 2013, ADACAS carried out a similar project in the ACT for people with psychosocial and intellectual disability. The ACT project was also based on participants’ communities¹⁸⁴. The report highlights that “each person’s capacity for self-determination was limited, not by their ability to

*make a decision, but by the support they received to exercise decision making.”*¹⁸⁵. Therefore, the efficiency and social benefits of the SDM process have been proven. It is now crucial to enact laws to enforce such system. Further, this echoes a system already implemented in British Columbia (Canada): Vela Microboard.

VELA Microboards have been established in British Columbia to offer a tool to plan for the future and to manage and fund a range of individualized support. This system works with 5 or 8 people in the board who know the person with LD in need of support. However, if such a collective enterprise sounds good to avoid abuse, this system does not include the supported person in the board which takes decisions *in fine*¹⁸⁶. Therefore, the ACT can inspire itself from this model but should consider including the person himself/herself within the board. This way, the board would be like a social encirclement for the person with high support needs and would allow the person to make decisions after a collective brainstorming. This also enhances the capacity of people with LD to make decisions. Consequently, in the long term, this alleviates the needs for support and empowers people with LD.

Furthermore, OPAs in Victoria and SA acknowledged the need for a SDM frame and opportunity for people with disability. However, the OPA SA asserts that a substituted decision-making should be the last resort option¹⁸⁷ when it should not be an option at all. Nonetheless, research evidenced that some people rather have a representative who would decide on their behalf¹⁸⁸. Therefore, if the substitution model might not be abolished, it should be used only when the person in question requires it. That is to say that this person would keep his/her legal capacity to decide to enter in a substitution model when wanted and that courts will never be allowed to appoint a substituted decision-maker to anyone, no matter the mental capacity alleged. This solution echoes representative agreements made in British Columbia which also mirror powers of attorney mechanisms already in place.

Also, in 2014, the OPA SA pointed out that relationships of support currently operate informally¹⁸⁹. Hence, the same year, the Victorian Law Reform Commission (VLRC) issued a report recommending, *inter alia*, to implement legal ways for supportive decision-making to take place. Finally, the GAB 2014 has been proposed in Victoria¹⁹⁰. It introduces the idea of a “*supportive guardian*”. The Bill has not been enacted yet and consequently is not passed into force. It envisages allowing Victorian Civil and Administrative Tribunal (VCAT) to issue an order of supportive guardianship¹⁹¹. This system creates a formal SDM mechanism and leaves the decision to be made by the supported person. The supportive guardian’s status mirrors the supportive attorney regime enacted in 2014¹⁹². Indeed, following the VLRC, the Victorian government implemented a legal regime regulating SDM for people with LD. However, the Bill still considers substituted decision-making situations. The GAB 2014 is a new step toward full implementation of the CRPD, however, the UN Convention requires more. The Victorian Bill can be described as schizophrenic in a way that it states that every adult has decision-making capacity while it proposes to rebut this assumption and therefore strip autonomous legal capacity off the person in the matter. In fact, the GAB 2014 acknowledges that decision-making capacity can fluctuate and that VCAT should not assume decision-making incapacity due to unwise decisions. Notwithstanding this, the Bill continues to allow full guardianship in case of decision-making

incapacity assessed. Moreover, in dealing with medical procedure, the best interest test remains the rule. Consequently, the GAB 2014 is a welcome step but could go further by proposing monitoring boards in order to ensure an effective implementation of these more progressive propositions.

Furthermore, in 2014, a SDM pilot Project has been carried out in Victoria in order to imagine the replacement of the substituted decision-making model. The project was similar to the SA and ACT pilot projects in its goal but also complementary in its findings. In SA, participants had lighter LD and knew their supporters, whereas in Victoria, people with severe and profound disabilities were participating and did not know their supporters¹⁹³. This is encouraging since most of the international literature on the subject bemoans the absence of studies including people with severe disabilities. Further, it is worth noting that choosing supporters among trustworthy people known by the person with LD is not always feasible. In fact, people with high need supports who are isolated and have few or no family/friend contacts, would remain at the margin. That is why the Irish as well as the British Columbian systems are not perfect and they keep the substituted decision-making scheme as a last resort. On the contrary, it is possible to encompass every person with LD and effectively reach a universal legal capacity free from discrimination. The Victorian experience proves it.

The Victorian project developed a model in which trained volunteers were connected with socially isolated people who wanted support to make decisions. Volunteers were trained to ease access to information and communicate the will and preferences of participants. This was done in order to promote participants' dignity and autonomy by building their decision-making capacity. The findings of this study revealed that the supporter and the supported share interdependent roles. The participant has his/her way of expressing his/her preferences while the supporter has to be responsive to these expressions¹⁹⁴. That is to say that both parties would be creating their own communication system which will be evolving and continuously nurtured. Further, in British Columbia, a specific Non-Governmental Organisation (NGO) called Nidus is the leader in accompanying people in their decision-making¹⁹⁵. They are an independent NGO which can be taken as an example for an external body capable of supporting people with LD¹⁹⁶.

Finally, the project's conclusions revealed that the relationship with the supporter appeared to have contributed to the participant's sense of self and identity and autonomy. However, other outcomes indicate that the biggest barrier to enabling participants' decision making is due to the lack of interest by staff in the participant¹⁹⁷. This finding is in total agreement with what the HLSCR observed in 2014¹⁹⁸. This highlights the fact that a relationship of trust is essential as well as an honest dedication to the person supported. Hence, in order to implement an efficient SDM system, time and training will have to be seriously considered. In fact, the life and expectations of the person supported must be known and understood by the assistant. That is why most of the legislation abroad, like in the Republic of Ireland or in British Columbia, integrate the fact that the supporter would be someone the person with a disability already knows. Therefore, the supporter would be able to communicate faster with the person with disability as well as advocating for his/her rights and wishes since he/she would know this person beforehand. Further, the pilot projects did not base their experience on a judiciary appointed supporter. This is less burdensome

and should be considered as well.

Nonetheless, even though the Victorian pilot project for SDM revealed that providing a SDM mechanism was time-consuming and required trainings¹⁹⁹, the ACT is a smaller jurisdiction and has many resources already available. Therefore, the ACT requires less investment. In addition, many leading NGOs in the sector are present in the ACT and can be integrated in programs for implementing an effective SDM process. Finally, the major outcome of the different pilot projects demonstrates that SDM mechanisms empower people with disabilities, increase their self-confidence and therefore facilitate their insertion, inclusion and participation within society.

Training medical practitioners as well as carers, teachers, parents and supporters²⁰⁰ is fundamental as well. Listening to the woman/girl with disabilities is essential in order to empower her²⁰¹. Indeed, the different pilot projects dealing with SDM in Australia as well as academic research have proved that valuing the person with LD by supporting her in making decisions will empower him/her.

In their piece, Gavin and colleagues are praising the benefits of SDM. In fact, they assert that it has positive outcomes for the person supported since more importance is given to her/him. Finally, they underline the positive effect on society as a whole since such inclusion allows a better understanding of each other and creates new relationships and networks²⁰². It is worth noting that all those academic reviews are corroborated by practical experiences that have been carried out in Victoria, SA²⁰³, and the ACT as well as in the UK, Canada and the USA. Therefore, denying the relevance of SDM results in denying reality. Further it would constitute a hurdle to achieve human rights and common respect. It is therefore socially efficient and imperative to promote and invest in SDM²⁰⁴.

C) Special focus on the ACT

In the ACT, the *Guardianship and Management Act 1991* regulates contraception grants to women with a mental disability. This Act provides that if an adult is considered to have impaired decision-making ability²⁰⁵, he/she requires to be appointed a guardian in order to accompany him/her in his/her life²⁰⁶. Hence, *inter alia*, the guardian can “*give, for the person, a consent required for a medical procedure or other treatment (...)*”²⁰⁷. However, the Act defines *prescribed medical procedure* as a medical procedure concerned with contraception. Therefore, the Act provides that one needs an order from the ACT Civil and Administrative Tribunal (ACAT)²⁰⁸ in order to grant contraception to an adult with mental disabilities.

Furthermore, in order to adjudicate, the ACAT has to look at the *best interest* of a person²⁰⁹. For this purpose, the ACAT has to take into account *the wishes of the person, so far as they can be ascertained*²¹⁰. Yet, we already described the shortcomings of the best interest test.

For girls with LD, there is no legislation regulating the granting of contraception. Therefore, parents of minors with LD can consent to granting contraception²¹¹.

It appears therefore that girls with LD remain tributary to their parents' decisions to get contraception and there is no legal framework which will ensure these girls really understand what

contraception means for them. And, what about the decision-making process? It appears that it relies on the doctor they are facing. Some doctors can be more inclusive than others when a decision over a contraceptive should be made. In fact, some doctors do not themselves understand the regulations in place in the ACT²¹².

Consequently, with regards to granting contraceptives to women with LD under guardianship, the process is very burdensome and should be repealed. Indeed, most women with LD with a guardian formerly had less straightforward access (albeit wholly by substituted decision making) to contraceptives before they were 18²¹³. Thus, when they turn 18, the law dictates that their guardians should now go to court in order to enable them to continue to use the contraceptive. This creates grey periods when a woman with LD cannot have access to contraceptive until the court agrees to it even if she previously used to take this contraceptive. In fact, this gap period will vary from one case to another depending on the contraceptive method used²¹⁴.

For example, if a girl used to have an implanon as a contraceptive, this device usually last for three years, the guardian of the young adult will have to seek an ACAT order when she turns 18. However, this order need to be reviewed for each new device put. Hence, the guardian will have to lodge another application to the same court three years later in order to require another judiciary approval for inserting the next implanon²¹⁵. In fact, this is strikingly burdensome as court orders authorizing to continue using a contraceptive have to be reviewed. Furthermore, practice can be even more complex. For instance, a certain contraceptive being used may become unsatisfactory, necessitating change to another contraceptive type. Once again, the same process has to be launched. Consequently, even if ACAT appears to be very responsive to these situations, one understands that it is not the appropriate manner to proceed.

Thus, the model adopted by the ACT government is a substituted decision-making process too. The ACT LRAC issued a report on guardianship in 2016 which confirms the current movement in rethinking guardianship and finally implementing CRPD principles. ACT LRAC's recommendations are similar to the one made by the LCO (2017) as well as the VLRC (2014). It recommends considering *the wishes and preferences of the person* with impaired decision-making ability instead of using the *best interest test*²¹⁶. It asserts that the SDM paradigm should be enforced with appropriate safeguards²¹⁷ as well. However, the ACT LRAC proposes a similar legal framework to the Irish one and therefore maintains, as a last resort, the substituted decision-making option. This last resort option is called "representative decision-making" and would require the representative to look at the will and preferences of the represented individual instead of their best interest²¹⁸. Again, words matter but euphemism should not be the rule. The term representation under civil law means substituted decision-making. Further, without proper safeguard to ensure that the actual will and preferences of the represented person are considered, this regime remains based on substitution and perpetuates the denial of the person's rights. Therefore, this last resort option cannot be accepted as a sustainable solution and should be temporary. In fact, the ACT needs a specific timeframe to totally abandon the substituted model – being called representative. The ACT can invest in capacity building as has been underlined by the same report. This way, every person with decision-making impairment will be included as complete subjects of law and ACT law will comply with the UN Conventions as well as giving effectiveness to the ACT HRA (2004).

Further, it is worth noting that some parts of ACT legislation appear to already consider human rights of people with mental health issues. In fact, the object of the *Mental Health Act 2005* aims to *promote the capacity of people with a mental disorder (...) to (...) participate in, their assessment and treatment, care or support (...), as well as facilitate [their] access (...) to services provided in a way that recognises and respects their rights, inherent dignity and needs;(...)*²¹⁹. Therefore, the ACT provides a legal framework willing to ensure the human right of people with LD.

Yet, when one looks at practice, it seems that the law is more or less well implemented according to the practitioner that one faces²²⁰. Thus, even if the law reveals some interests in the wishes of the represented person, as the HLSCR demonstrated, without safeguards, a progressive statute is not implemented. Therefore, safeguards are needed to better implement human rights for people with disabilities. This arises especially from Article 12 of the CRPD which seeks to implement an *equal recognition before the law*, which means to be a person with full legal capacity, with rights and the right to act before the law to enforce those rights.

Moreover, Article 12 of the CRPD underpins the *right to equality* in the ACT HRA²²¹.

Notwithstanding the fact that the Act notes that “*all rights may be subject to reasonable limits (...)*”, limitation of the recognition of a person before the law cannot result in total denegation of this right. Therefore, SDM procedures appear to be the sole effective solution which is consistent with the ACT HRA as well as the CRPD. Moreover, acknowledging the fact that there are as many disabilities as there are people, the law cannot be binary when considering mental capacity. The Irish new *Capacity Act 2015* proves that such recognition is possible²²².

Hence, a revision of the concept of capacity is needed. The ACT Human Rights Commission (ACT HRC) says that a lawful consent can be understood at the light of VLRC which described capacity to consent as *a legal concept that describes the level of intellectual functioning a person requires to make and accept responsibility for important decisions that often have legal consequences*.

Accordingly, different levels of capacity can be envisaged which would trigger different level of support. However, level zero of capacity should never be accepted.

Indeed, the ADACAS 2013 pilot project on SDM investigates this. Participants’ capacity for self-determination was impaired by the support they received to exercise decision-making and not by their ability to make a decision²²³. This reinforces the call for changing the paradigm and working on adapting society to include people with disabilities rather than discrediting them and preventing their full participation. ADACAS’ recommendations focused on the importance of recognising a wide variety of supports for decision-making. This would allow the ACT to really include different needs and disabilities. This will fit the realities of disabilities which is evolving and fluctuating. That is why, as ADACAS advises it, as well as the VLRC, legislation should provide formal as well as informal SDM mechanisms in order to encompass and reach every need in the ACT. Finally, as Dr A. Arstein-Kerslake highlights it describing ADACAS’ findings: “*cultural change needs to be done to normalise the active participation of people with cognitive disability in decision making*”²²⁴.

Further, court judgements appear, like in Canada, to be more progressive than statutes. The ACT HRC highlights that in 1992, in *Re T (An adult: Consent to Medical Treatment)*²²⁵, Butler-Sloss LJ held that: *A man or woman of full age and sound understanding may choose to reject medical advice and medical or surgical treatment either partially or in its entirety. A decision to refuse medical treatment by a patient capable of making the decision does not have to be sensible, rational or well considered.* Moreover, the ACT HRC underlines that this statement has been cited with approval in other Australian courts²²⁶.

Furthermore, ACAT rulings have already been progressive and were heading toward a more comprehensive understanding of consent for people with LD since 2015. In *In the Matter of ER [2015] ACAT 73*, a person with mild and moderate disabilities and a bipolar diagnosis was under a guardianship regime. The question raised in the matter was to know if this person could consent to psychiatric treatment or not due to her alleged incapacity assessed under the *Guardianship and Management Act 1991*. ACAT acknowledged that capacity to consent can fluctuate over time and that capacity to consent should be assessed for every question²²⁷. That is to say that a person under a guardianship regime cannot be deemed incapable to decide for any situation she/he encounters in her/his life. Further, as underlined by Sean Costello, the ruling based itself recalling common law tests regarding capacity assessment. This includes:

- *A presumption that a person has capacity to make a decision;*
- *Capacity may fluctuate;*
- *Capacity must be assessed in relation to the decision to be made;*
- *The assessment of capacity is specific to the relevant decision;(...)*
- *The person making the decision should be given the necessary support to make the decision;*
- *The onus is on the applicant to rebut the presumption of capacity*²²⁸.

Finally, one should bear in mind that the ACT has been a human rights jurisdiction since 2004. Further, Section 30 of the ACT HRA requires a Court or Tribunal to adopt a “human rights consistent” interpretation within the “purpose” of the statute. However, implementation of the CRPD relies largely on the good will, and especially the political will, of states and territories to do so. Furthermore, Section 36 of the *Guardianship and Management Act 1991* (ACT) demonstrates the medical approach of the ACT toward mental incapacity and therefore the denial of right to have an autonomous status before the law. If court cases appear progressive, the law which judges and medical practitioners are facing is far too paternalistic and yet impairs the realisation of women with disabilities’ human rights to choose their contraception.

II) Reproductive rights of women with disabilities

This second part focuses on the reproductive rights of women with disabilities which are entrenched in the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). Women with disabilities, being women, are entitled to reproductive rights encompassing contraception (A) as well as access to sexual health education (B). Finally, a special focus on the ACT will be provided (C).

A) Contraception and women with disabilities

Accessing contraceptive is a right protected by international law under the CEDAW as it promotes the right to family planning for all women, without discrimination. However, reproductive rights are hard to achieve for women with disabilities due to different barriers, mostly societal which are translated into paternalistic regulations. This part first presents the different contraceptive options offered in general (1). Then, the paper focuses on women with disabilities' experiences with contraception (2) and finishes depicting the different barriers encountered by women with disabilities related to contraception options (3).

1) Reproductive rights and contraceptive options

Since 1994, following the Programme of Action of the International Conference on Population and Development (ICPD) held in Cairo, Egypt, the international community agreed, *inter alia*, to recognise a universal access to a full range of reproductive health services, including family planning, as a fundamental right ²²⁹. Therefore, states have the duty to ensure this right and should enact laws which go in this sense.

CEDAW provides that states parties to the Convention should ensure “*access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning*”²³⁰. Then, Article 12 underlines that “*States Parties shall take all appropriate measures to ensure access to health care services, including those related to family planning (...)*”²³¹. Accordingly, one understands that sexual health education, if well implemented, is the perfect way to enforce these rights. However, without legal capacity recognised for women/girls with disabilities, these rights cannot be enforced by them. This constitutes therefore a blatant discrimination and infringes CRPD²³², CEDAW²³³ as well as discrimination acts in the ACT²³⁴ and at the federal level²³⁵. Women/girls with disabilities have to be subjects of law in order to be fully entitled to those rights.

Further, concerning contraception for women/girls with disabilities, Australian state and territory statutes dealing with guardianship, medical consent and health care are really evasive when it comes to contraception. In the NSW *Disability service and guardianship Act 1987* (DSGA), “medical treatments” are broadly defined²³⁶. Therefore, it is hard to know if contraception is included or not within the definition. Moreover, the DSGA also deals with “major treatment” which include some contraceptive methods, like injectable hormonal substance²³⁷, but not all of them. Further, the prescription of a pill does not seem to be included within the meaning of major treatment. Moreover, for under 18 years old, the *Children and Young Persons Protection and Care Act 1998*²³⁸

includes contraception within “*special medical treatment*”²³⁹. Therefore, this shows the blurriness of the law dealing with contraception for women/girls with disabilities. Three different terms encompass different kinds of contraceptives and some even overlap each other. Special treatment for girls encompasses every kind of contraceptive, major treatment for adult includes only a few kinds. More development will be done on this matter in the next part of this paper.

However, Australia, like the other countries studied in this project, legalised access to various contraceptives. The different kind of legal contraceptives include diaphragms, Progestogen Only Pill (POP), Copper Intrauterine Device (IUD), Hormone Releasing Intrauterine Device (Mirena IUD), Male and Female condoms, emergency contraception, contraceptive injection (DPMA), Implanon, the Pill, vasectomy and hysterectomy. Further, it is also worth noting that injections, IUD as well as implants from a specific category of LARC are available. These are not spread enough in Australia. Finally, some traditional techniques of contraception can be highlighted since the United Nations (UN) encompass them in their studies: withdrawal and rhythm. Those methods are the least efficient ones.

The following tables, coming from the UN Department of Economic and Social Affairs, illustrate the contraceptive prevalence by method in Australia, the UK, Canada, Ireland and the United States of America (USA) in 1994 (Table 1) and in 2015 (Table 2)²⁴⁰. The year 1994 coincides with the ICPD and the recognition of reproductive rights as human rights and therefore as a political call for developing access to contraceptives as a means to control family planning to improve human development.

The evolution within 20 years is striking concerning female sterilisation as a mean of contraception. Its use has dropped in every country studied, especially in Canada where the proportion decreased by two thirds with a reduction of 20 percentage points. However, this data does not identify where there may be continued practice of sterilisation as a means of contraception used on women and girls with disabilities. WWDACT maintains the call for national uniform legislation in Australia to prohibit non-therapeutic sterilisation of minors except in cases where there is a serious threat to life or health²⁴¹. Australia and Ireland also notably improved their situation in this matter with the practice of female sterilisation diminishing by approximately half of its former rate. On the other hand, the UK and Canada have seen increases in the rates of male sterilisation. This question deserves to be raised but it will not be analysed in this research. Another interesting and surprising element is that the use of condoms has decreased in the UK as well as the USA, as other means of contraception have increased. This might reveal a lack of knowledge or awareness about the transmission of Sexually Transmitted Infection (STI). The “AIDS generation” was very informed about it but a new generation, from late 1990’s and after, may have become inured to improved treatments of Human Immunodeficiency Virus (HIV) and do not pay attention to condom use as much as they should²⁴².

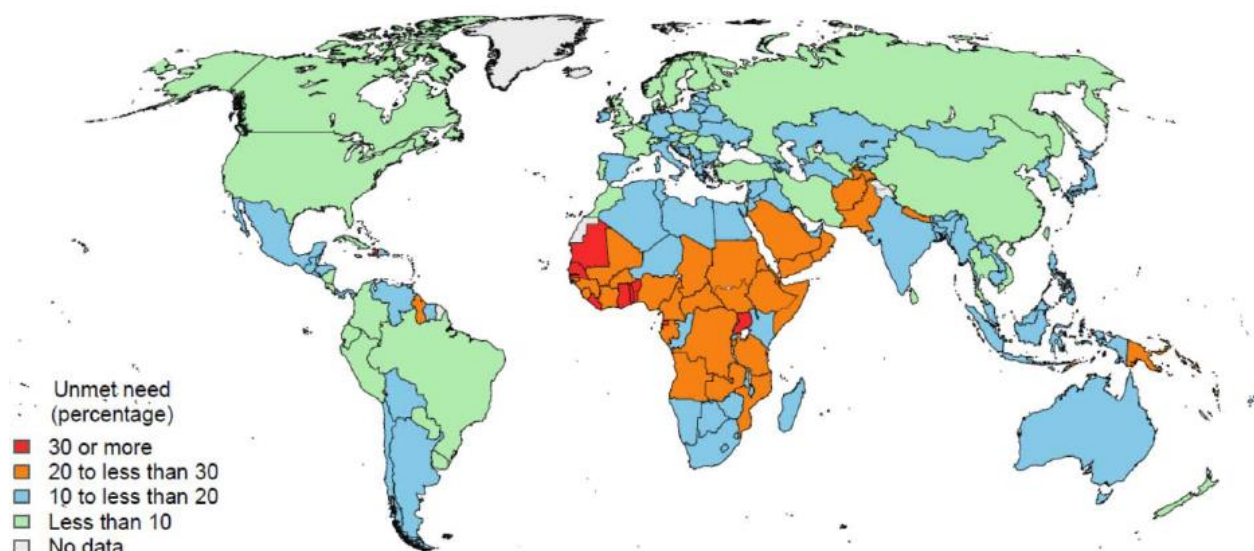
Table 1: Estimates of contraceptive prevalence by method among married or in-union women aged 15 to 49 (percentage), 1994												
Countries	Any method	Female sterilization	Male sterilization	Pill	Injectable	Implant	IUD	Male condom	Vaginal barrier methods	Other modern methods	Rhythm	Withdrawal
United Kingdom	80.3	14.0	18.0	22.9	0.0	0.0	6.0	15.0	3.0	0.0	0.5	1.0
Ireland	71.0	7.2	8.4	22.7	0.1	0.0	1.3	21.3	0.5	0.0	3.3	2.7
Canada	75.3	30.7	15.2	14.4	0.0	0.0	2.9	9.4	0.8	0.0	0.7	0.8
USA	74.9	23.4	13.0	15.3	1.4	0.7	0.7	13.1	1.8	0.0	2.2	2.2
Australia	68.7	13.3	10.1	27.7	0.0	0.0	2.1	12.1	0.7	0.3	1.8	0.6

Table 2: Estimates of contraceptive prevalence by method among married or in-union women aged 15 to 49 (percentage), 2015												
Countries	Any method	Female sterilization	Male sterilization	Pill	Injectable	Implant	IUD	Male condom	Vaginal barrier methods	Other modern methods	Rhythm	Withdrawal
United Kingdom	81.3	8.0	21.0	28.0	2.0	1.0	10.0	7.0	1.0	2.0	0.5	0.8
Ireland	67.2	3.1	7.3	17.5	0.7	0.4	8.5	23.7	0.1	1.1	2.9	1.8
Canada	73.3	10.9	21.7	20.7	1.0	0.0	1.0	14.8	1.0	0.0	0.8	1.5
USA	75.1	21.8	10.8	16.0	0.0	1.0	5.1	11.6	0.2	2.7	1.3	4.6
Australia	68.4	6.3	8.9	28.8	2.0	2.7	1.5	14.0	0.8	0.3	1.2	1.7

If global evolution raises some questions such as the increase of male sterilisation or the decrease of male condom use, Australia appears to be on the right track. The Australian situation has improved in some domains, notably female sterilisation. Further, the use of condoms has increased as well. Moreover, different methods are used even if the Pill remains the most used contraceptive since it represents almost 30% of the method use compared to less than 3% for LARC. Therefore, even if the contraceptive prevalence in 2015 was above 70% in the UK, Canada and the USA, and below 70% in Australia²⁴³, a positive evolution must be highlighted. Moreover, it is nevertheless advisable to place a caveat on the high contraceptive prevalence rate in the UK due to the high prevalence rate of sterilisation for men and women (respectively 21% of and 8% in 2015). The same critique can be done on Canada. Ireland on the other hand is particularly a good student in the matter since its prevalence of contraception rate has increased while sterilisations have decreased. However, even though traditional methods have decreased, they remain high, representing 5% of contraceptive method use. This is mostly due to the conservatism of Irish regulation in family planning. Irish people had to wait the *Health (Family Planning) (Amendment) Act 1993* to be allowed to sell and supply condoms with no restriction of places nor age to buy them²⁴⁴.

Nonetheless, if the Australian trend looks good in improving access to contraception other than sterilisation, some inequalities remain. It is worth noting that Australia counts between 10% to 20% of women with an unmet need for family planning among those aged 15 to 49 who are married or in a union in 2015²⁴⁵ (UN map). This means that Australia is behind Canada, the USA, and Western Europe in terms of providing family planning, including contraception. Further, the report on Australia from the Committee on the Elimination of Discrimination against Women (CEDAW Committee) denounced that Australia does not provide desegregated data concerning Islanders and Aboriginals as well as women with disabilities²⁴⁶. Therefore, lacking this kind of information, NGOs are left with assumptions that these populations have less access to family planning information, counselling and education.

UN map²⁴⁷: Percentage of women with an unmet need for family planning among those aged 15 to 49 who are married or in a union, 2015



The last recommendations from the CEDAW Committee for Australia dates from 2010. Australia has provided the Committee with its national report in December 2016. Hence, there is no UN recommendations updated yet. In 2010, the Committee underlined the “almost entire absence” of women with disabilities from key leadership and decision-making positions. Further, it highlighted that women with disabilities were disadvantaged with regard to educational and employment opportunities²⁴⁸. The Committee urged Australia to undertake measures to ensure that women with disabilities are better represented in society. This directly underpinned the necessity to grant legal capacity to those women – and men with disabilities – in order to foster their self-confidence and consequently their participation within society.

In the 2016 Australian report submitted to the CEDAW Committee, Australia does not inform the Committee on forced sterilisation, forced contraception nor on access to sexual health education for women with disabilities²⁴⁹. This might be due to a lack of data on that very topic since most of the reports denounce the scarcity of information regarding women with disabilities²⁵⁰.

In 2013, the United Nations Population Fund (UNFPA) and the United Nations Economic Commission for Europe (UNECE) asserted that the promotion and protection of sexual and reproductive health and rights are essential to achieving gender equality, social justice and sustainable development. They also called for “gender sensitive” and “life-skills” based comprehensive sexual health education. This is needed in order to promote values of tolerance, mutual respect and nonviolence in relationships. It would include dealing with every sexual behaviour, without discrimination, including talking about people with disabilities as sexual beings with sexual needs and wishes²⁵¹.

Last year, the UN agency International Planned Parenthood Federation (IPPF) had also called for such engagement from states. It encourages sexual health education outside of schools too in order to be able to reach every young person. Further, learning about sex before being confronted with it empowers people and enables them to refuse and denounce abuses²⁵².

Furthermore, in 2013, the Family Planning NSW (FPNSW) released a document informing about reproductive and sexual health in Australia²⁵³. However, its report underlines that, *inter alia*, very little data was available concerning the reproductive health and access to contraception for women with disabilities. Moreover, two years later in 2015, the Family Planning Alliance Australia (FPAA) also called for further research targeting people with disabilities concerning contraception use²⁵⁴. Further, in a 2016 report called *A health system that supports contraceptive choice*, the Australian Healthcare and Hospitals Association called for the creation of appropriate guidelines to support medical practitioners in assisting women with disabilities in their contraceptive choice²⁵⁵. Therefore, the need for more accurate data in this field becomes urgent.

FPNSW’s 2013 report states that very few women used LARCs²⁵⁶. However, international surveys reveal an over representation of these contraceptive methods among women with disabilities. It would be relevant to look at the information given to women with learning disabilities about these contraceptives. If it can be useful to not have to think about taking the contraception every day, it

might be interesting to look at the actual information given to women with disabilities.

Further, a US research paper reveals that counselling prior to choose a contraceptive helps women achieve their reproductive rights²⁵⁷. Researchers designed an interactive program accessible on tablet, which focuses on women's needs, concerns and questions about the different kinds of contraception. The outcome is very positive and demonstrates that shared decision-making enhances the efficiency of the contraceptive method chosen and therefore, of the women's empowerment. Even though the study did not encompass women with disabilities, one can contemplate the idea adapted for women with disabilities.

As Women With Disabilities Australia (WWDA) recalls it: *"The Australian government has agreed to take action to make sure all women and girls with disability enjoy all the human rights described in the Conventions, Treaties, Covenants and Declarations it has agreed to or supported."*²⁵⁸ However, very few reforms have been actually implemented to improve women with disabilities' achievement of their reproductive rights. That is why WWDAA calls for the ACT to take action and be a pioneer in this path to achieve reproductive rights of women and girls with disabilities. The ACT should take advantage of its small size and its reach in the community sector already active in the field. The ACT government has the power, as well as the duty, to finally ensure the human rights of women and girls with disabilities.

2) Women with disabilities' experiences with contraception

Dr Michelle McCarthy, in her piece *"I have the jab so I can't be blamed for getting pregnant"*: *Contraception and women with learning disabilities*, acknowledges that women's rights to control their reproductive rights have improved over the last few decades. However, she also sheds light on the fact that women with disabilities have been left behind. According to Dr M. McCarthy, there are four main reasons for this situation. First of all, she points out that feminism and disability rights campaigns are entrenched in liberal ideologies of autonomy and independence when support can be empowering tackling decision-making for people with disabilities. Then, she recalls that the eugenic paradigm remains a reality²⁵⁹. Thirdly, due to greater exposure to sexual abuse and rape, unintended pregnancy is a high risk and therefore contraception is granted to those women without much explanation. Finally, "the lack of voice" and inclusion of those women in researches on this matter leads society to ignore their realities²⁶⁰.

Furthermore, statutes dealing with guardianship and consent to medical treatment are not always clear. Australian's situation reveals some reluctance to providing a clear legal framework to access contraception for women with disabilities. For instance, NSW has a sort of legal vacuum regarding granting contraceptive to young woman, between 16 and 18 years old. NCAT provides explanations regarding its jurisdiction for both adults²⁶¹ and children²⁶² without including young persons – between 16 and 18 years old. This leads to only apply common law principles. In fact, on the one hand, for girls under 16, a medical practitioner shall obtain a NCAT order to grant a contraceptive²⁶³. On the other hand, NCAT order is not necessary for women above 18. Yet, there is no legislative options for young persons to be granted contraception. Consequently, one will assume that young

persons with LD will see their contraceptive choices decided by their parents, as they have parental responsibility for their child.

This oversight might be due to the fact that the *Children and Young Persons Protection and Care Act 1998* deals with children in general and not with children with disabilities in particular²⁶⁴. Hence, maturity is assumed at the age of 16 but how is maturity assessed for an adolescent with LD? In fact, they suffer attitudinal barriers which, in the case of contraception, limit their control over their reproductive rights. This shows that the need for a more individualised approach for people with disabilities is disregarded, especially when it comes to reproductive rights.

Further, in Victoria as well as in WA, Tasmania, Queensland, NT and SA, statutes dealing with guardianship and consent to medical procedure do not precisely outline under which category contraception falls²⁶⁵. Most of the documentation provided tackles very invasive medical procedures and undermines access to contraception as well as its definition²⁶⁶. Furthermore, the *Adult Guardianship Act 1988* (NT) stated that guardians cannot decide on behalf of the adult they represent in regard to major medical procedure including contraception. However, in the GAA 2016, the notion of “health care actions” is the only term used and the term contraception does not appear any more. Thus, only the ACT is clear on the matter even though the procedure for women, as it has been underlined, is very burdensome.

This observation is consistent with the World Health Organisation (WHO)’s findings. In 2011, the WHO already bemoaned that women with disabilities were less likely to get information on contraceptive uses and options²⁶⁷. Since statutes are not clear, access to rights is impaired.

Nonetheless, most of the countries studied for the purpose of this research allow access to contraceptive for women with disabilities even though WWDACT demonstrated that the women themselves do not always decide due to the substituted decision-making regime established under guardianship. Further, sexuality and disability remain taboo subjects which do not mix very well. Therefore, many legislations do not concretely deal with contraception for women with disabilities or tackle it partially only. Furthermore, Irish policies on the topic provide a strong example to grasp sexual realities of women with disabilities.

i. Irish specificity

The history of reproductive rights and sexuality is quite complicated in Ireland. In 1929, the *Censorship of Publications Act 1929* was enacted and the selling, publishing, distributing or importing any publication that relates to contraception or abortion was prohibited. Irish people had to wait 1979 and the *Health (Family Planning) Act 1979* in order to see the legalisation of contraception. However, the Act specifies that contraception, including condoms, are only available on prescription from a doctor. Moreover, the doctor had to be satisfied that the person was seeking the contraceptives for *bona fide* family planning purposes. That is to say that one needed to be married. It is worth noting that condoms were not easy to access before 1993 and the *Health (Family Planning) (Amendment) Act 1993*. It allowed the sale and supply of condoms with no restriction of places nor age to buy them. Finally, it is only in 2011 that the Irish Medicines Board

grants over-the-counter status to the emergency contraceptive pill Norlevo²⁶⁸. Hence, even though the Irish *Capacity Act 2015* is very progressive, information about contraception continues to suffer societal barriers.

In fact, a 2011 thesis tackling, *inter alia*, contraception and consent for women/girls with disabilities in Scotland sheds lights on these barriers. It highlights the fact that Scotland remains rooted in societal and social stereotypes concerning people with disabilities and sexuality. The thesis recalls that the sexuality taboo in Western societies impairs access to a meaningful education on the matter. It also underlines the necessity to teach about sex to people with learning disabilities in order to empower them. People with LD need sexual health education as much people without LD. Indeed, academic as well as scientific research demonstrated that biological maturity and social/emotional maturity often leads to a denial of people with disabilities sexual needs²⁶⁹.

Ireland is a striking example of that. Indeed, the recognition of people with disabilities as sexual beings is far from being acquired. In February 2017, the Seanad – the Irish Congress – finalised and allowed the enactment of a new Bill concerning Criminal Law, the *Sexual Offences Act 2017*, which remains “narrow and paternalistic” according to Inclusion Ireland, an NGO which promotes empowerment of people with disabilities²⁷⁰.

According to the NGO, the “*New Bill leaves people with intellectual disabilities pre-judged in the eyes of the law*”. Indeed, under the *Sexual Offences Act 2017*, people with disabilities remain unequally treated. In fact, “protected person” remain forbidden to engage in any intercourse. Hence, as the Inclusion Ireland Campaigns and Policy Leader, Sarah Lennon, says ruefully, the new Bill will not erase “*the ‘chilling effect’ of the legislation with educators and advocates afraid to provide support to individuals with disabilities or provide education for fear of encouragement of law-breaking*”²⁷¹. Moreover, the Irish government made a terrible counter sense of CRPD requirement since the Irish Minister for Justice repeatedly referred to the CRPD to justify the use of ‘protected person’ in the Bill – which has not been amended in the Act. However, as underlined before, protecting people with disabilities can be tricky. The CRPD aims to protect people with disabilities from societal prejudices which marginalise them. Thus, it does promote equality rather than discriminatory treatment. Support can be put in place to accompany people with disabilities to make themselves understood by others. The kind of protection promoted by the CRPD is to ensure people with disabilities’ rights to express themselves. In no circumstances, can protection be translated into a paternalistic view consisting of deciding about what is good or wrong, acceptable or not, on behalf of a person. As the different pilot projects in Victoria, SA and the ACT demonstrated, making decisions is a skill that requires training. People with disabilities are not incapable of making decisions. However, they have been deprived of this right which has resulted in impairing their decision-making skills. That is why self-advocate training should be implemented in this regard.

Consequently, the *Sexual Offences Act 2017* maintains the ban for “protected persons” to have romantic sexual relationships. A “protected person” is described as a person “*incapable of (a) understanding the nature, or the reasonably foreseeable consequences, of that act, (b) evaluating*

relevant information for the purposes of deciding whether or not to engage in that act, or (c) communicating his or her consent to that act by speech, sign language or otherwise”²⁷². One notices that this “protected person” test shares the failings of mental capacity tests in Canada which strips people with LD of their legal capacity. Further, this restriction is made for the sake of protection. Once again, categorizing people within boxes of “protected people” leads to marginalisation and disregard of their humanity, human needs and human rights.

Accordingly, one understands that contraception and sexual health education will hardly be accessible for “protected persons”. Hence, depending on their disability, some Irish adults will be able to enjoy a SDM scheme when they will be able to consent to medical treatment, like contraception, whereas others, like “protected Irish” will be excluded.

Moreover, even though accessing contraception has improved in Ireland, major issues remain concerning sexual health education provided to women with LD – let alone “protected women”. Charlotte Ryan, feature editor of University Times, tackled sexual rights of people with disabilities. She refers to the Irish movie, *Sanctuary*, which depicts the sexual reality of two persons with disabilities, she remarkably highlights that:

The focus on what people with disabilities cannot do is a narrative found at the core of the Criminal Law (Sexual Offences) Act 1993²⁷³. Indeed, it endeavours to protect people from situations which they can’t understand or navigate, rather than providing a framework for experiencing things they can consent to. Rethinking what people with disabilities are capable of doing depends on how they are represented, something that Sanctuary addresses directly. There is something to be said for seeing the romantic interactions of two actors with disabilities performed on a stage – aside from showing the subtle differences of such an interaction, it quickly becomes clear how relatable it is. There’s still the over-eager-and-slightly-nervous fumbling, the comic embarrassment about contraception and the pervading sense of tenderness made all the more potent by the play’s honesty²⁷⁴.

Finally, it is worth noting that the 2017 CEDAW report on Ireland demands the Irish government to implement laws ensuring access to contraception as well as sexual health education to women in general²⁷⁵. The report highlights the need for more data concerning women with disabilities in order to be able to better assess the need for legislation to ensure their human rights. Therefore, one understands that Ireland is not a model to consider in terms of accessing contraception for women with disabilities.

ii. Other experiences

Notwithstanding the fact that Ireland provides an extreme situation for women with disabilities accessing contraceptive and sexual relationships, experiences in other Western countries are not free from criticism. The following development will shed light on a social regulation mindset when women/girls with LD’s reproductive rights are at stake.

In the USA as well as in the UK, researchers have identified the same reasons why contraception would be granted to a woman/girl with LD²⁷⁶. It is granted on the ground that it will help overcome physical or behavioural problems related to menstruation. Also, Depo-Provera, which is not self-administrated, is overused even though medical studies shows that it can have very bad side effects on women²⁷⁷. Scholars argued that the way we practice healthcare is “*a means by which we demonstrate the value we place on other people's lives*”²⁷⁸. In the case of people with disabilities, it clearly appears that little value is given. In fact, some contraceptives have more dangerous side effects that should be taken into consideration when dealing with certain disabilities²⁷⁹. Women with disabilities should be informed as well and offered the possibility to make an informed decision on this matter. It can be explained through images and support, as it has been promoted in the last Canadian handbook of Action Canada for Sexual Health and Rights²⁸⁰.

Further, some justifications for granting a contraceptive to a girl/woman with LD rely on wishing to avoid unintended pregnancy. This last argument raises controversy. Moreover, it is also worth noting that in case of an abuse, if pregnancy is avoided, transmission of sexual transmitted diseases (STI) is not²⁸¹. Again, the USA’s findings regarding access to sexual health education mirrors the UK ones. Both countries lack medical care knowledge on the side effects of some contraceptives on women with disabilities. Reports note that medical professionals do not pay thorough attention to the complete medical histories and needs of young women with disabilities when prescribing contraception²⁸². Finally, both reports note that knowledge about contraception varies with age – younger girls/women being less informed. This situation hinders an informed access to contraception since women/girls with LD are not provided with enough information in order to make a decision and give their effective consent.

Recent research tackling contraception and consent has been carried out by the Open University in the UK and published in 2015. The research entitled *Contraceptive choices for women with learning disabilities* provides some very important insights regarding women with LD’s experiences in receiving contraceptives. In fact, the research stresses that people labelled as vulnerable must be included within projects dedicated to them. Otherwise, protection that governments want to offer becomes a tool for increasing vulnerability and isolation²⁸³. Research findings revealed that in most of the cases, contraception was granted “just in case” without seeking the actual consent nor understanding of the clinical and social implications for the woman²⁸⁴. Further, again, scholars shed light on the fact that there is a lack of medical knowledge about the effect of contraception on women with disabilities. Therefore, best practice knowledge and guidelines are missing²⁸⁵.

The report starts by recalling that forced sterilisation used to be the biggest issue. Now, forced contraception must be scrutinized since women’s control over their own bodies has been taken from them with LARC. Three main reasons why sterilisation, and now contraception, have been regarded as “acceptable” are developed. First, there is societal fear around parenting for people with LD, second, negating the consequences of sexual abuse amongst women with LD and finally management of menstruation²⁸⁶. This perfectly echoes other research on this topic.

Hence, this report returns to forced sterilisation policies implemented in the UK and worldwide. It explains how women with disabilities were systematically denied the right to understand what happens to them, their bodies and their sexuality²⁸⁷. Consequently, one understands that women with LD were and remain kept as eternal children. This impairs access to adulthood and enjoyment of reproductive rights. Hence, by hindering access to or hiding information on sexual practices and contraception, society manages to prevent those women from becoming pregnant. Indeed, the report highlights the fact that LARCs have replaced sterilisation “as the ‘acceptable’ face of dealing with the problem of procreation by women with learning disabilities”²⁸⁸. This shows that the harm has been rendered socially acceptable whilst “consent” remains left aside.

Furthermore, in its General Comment No. 3, the Committee of the CRPD pointed out that Article 6 of the Convention condemned forced contraception for women and girls with disabilities²⁸⁹. Indeed, Article 6 asserted that women and girls with disabilities are subject to further discrimination and this include denying them the realisation of their reproductive rights.

Moreover, all studies showed that women with disabilities are much more likely to be abused sexually²⁹⁰. Most of the decisions concerning sexuality and contraception are taken on behalf of the women with LD by parents, carer or professionals²⁹¹. People with disabilities should be better informed about their rights, especially women who devalue themselves and ignore or reject their sexuality²⁹².

Current practices in the UK remain based on coercion when it comes to contraception²⁹³. Obviously, there is a need for safeguards to ensure access to information. One can think of a commission composed of women with disabilities (both learning or/and physical) as well as advocates in the disability sector who would be trained and able to communicate and sincerely inform women with LD about their sexual and reproductive rights. For instance, the program TOPSIDE organises trainings for people with disabilities to be mentors for others²⁹⁴. This project has been launched in 2011 and has been developed with six different European Countries, including the UK. This empowers people with disabilities to become self-advocates. Moreover, as underlined by Professor Colin Morrison in his 2011 thesis *From disability to capability: sex and relationship learning for children and young people with a learning disability*, self-advocacy represents a powerful tool for people with LD who, as a marginalised group, are too often regarded as passive victims whereas they are also people with agency, feelings and relationships²⁹⁵.

The Open University study²⁹⁶ reveals that knowledge and understanding of contraception vary a lot between women with LD. Contraception can be perceived as medication for some woman when it is used to reduce menstrual pain. WWDACT is planning to undertake similar interviews with women with disabilities in order to assess their experiences and level of knowledge with regard to contraception in the ACT. However, it is worth highlighting that DPOs working with women with disabilities have already denounced the same realities for women with disabilities in Australia. Thus, forced sterilisation remains the rule and denial of information on their reproductive rights continues to be perpetuated²⁹⁷.

Further, when asked who took the decision to take a contraceptive, one participant in the British survey answered: *“My decision, I did not want children. Teachers said it was my decision”*. This answer is disturbing when we read her last sentence. This highlights the risk of coercion and undue influence some people can have over a person with LD when it comes to choices and consent. Moreover, consent to contraception can be led by fear. For instance, another participant in the project, who was 25 years old in 2011, said that she was taking contraceptives because she feared the child she would have would be taken away from her again.

“I never want children would be too hard for me and social worker would take them away... My babies were taken away.”

Nonetheless, some progress seems to have been achieved since the 1970's. A striking example of forced contraception practices in the 70's in the UK has been described by one woman, with high support needs, participating in the project. She explained that because she refused to take the pill - because she did not have sex - “carers” tricked her to force her to have an implant. They had told her that they were going to a restaurant when they actually took her to a hospital, blindfolded her and strapped her to the bed while inserting the implant. She was in pain but no-one cared about her²⁹⁸. She finally left this “care house” and now, she has someone who supports her, trusts her and talks to her too. Therefore, this helps her in choosing her own contraception without coercion²⁹⁹.

Most of the women interviewed were not trusted or believed when they said they would not have sex. This shed lights on misconceptions society has about people with LD as not coherent beings. Further, contraception is also widely used to avoid the outcomes of a rape. However, raising awareness on rapes against women with LD sounds like a more effective and relevant practice to fight against them rather than hiding rapes behind contraception.

3) Barriers in accessing contraception for women with disabilities

Consequently, social as well as societal prejudices hinder accessing contraceptive for women with disabilities. Moreover, women with disabilities have to cope with physical and attitudinal barriers³⁰⁰ before accessing contraception. A 2017 International Planned Parenthood Federation (IPPF) report acknowledges that women with disabilities are not recognised as sexual beings and that they lack information regarding family planning and contraception. This observation is reinforced by academic research made in 2006³⁰¹ and in 2015³⁰² which both bemoaned attitudinal barriers from doctors reducing access to contraception for women/girls with disabilities.

In fact, it is relevant to remark that SDM in relation to access to contraception is monitored by doctors. They represent primary actors for an effective inclusion of women with disabilities within their own medical decisions. However, as underlined by a collective paper from the University of Sydney: *“Undergraduate health students’ exposure to SDM teaching and learning is patchy and largely reliant on local champions with expertise to drive this into local curricula”*³⁰³. Furthermore, access to health can also be challenged by the shortage of medical workforce in certain areas, in particular in rural areas³⁰⁴. Therefore, one can grasp the extent of the issue and the need for training at all levels. Further, as described in 2006 by the scholar Clair Kaplan, women with

disabilities face attitudinal barriers with doctors. They feel treated like children and like “a disability” rather than a human being³⁰⁵. The women interviewed also reported that they were treated as asexual beings and therefore very little information of contraception was delivered to them.

Therefore, women with physical disabilities can face different hurdles when accessing medical facilities or during gynaecologist tests³⁰⁶ since some positions necessary for physical examination can be hard to do. Further, it appears that some medical professionals do not include women with LD in the decision-making process assuming that they cannot comprehend it. This prejudice is a systemic issue. Women with LD are deprived of choosing for themselves and therefore lack training for making decisions. Hence, it makes it harder to reach an informed consent regarding contraception. A huge amount of awareness and training should be put in place in order to achieve good practice. For instance, the General Medical Council in the UK provides doctors and student in medicine with a good practice tool kit explaining how they should deal with a person who seems to lack full capacity. The guide insists on the fact that doctors should not be biased and should assume full capacity of the patient³⁰⁷.

However, the HLSCR raises the issue of prejudices faced by women with physical disabilities. The report highlights that some medical professionals have been assuming a lack of mental capacity of women with physical disabilities³⁰⁸. Because a woman shows some difficulties to express herself, due to muscular impairment and not LD, some medical professionals will not deal with the patient directly but rather talk to the parents or the guardian.

Moreover, a recent survey in the UK pointed out that women with LD are usually not well informed about contraception or sometimes misinformed. For instance, emphasis is given to menstruation management and sexuality questions are avoided³⁰⁹. The survey notes that little is known about contraceptive choices of women with high support needs. Further, it highlights research tackling women who are subject to MCA 2005 legislation in the UK is almost inexistent. This finding echoes other academic work worldwide. Therefore, it is urgent to tackle this issue now.

Furthermore, women with disabilities lack access to sexual health offices like family planning to inform them on contraception and relationships. This situation increases the risk of exclusion and denial of rights. Hence, women with disabilities cannot fulfil their sexual and reproductive rights. Another interesting point concerns the costs of sexual health. In fact, researches and studies reveal that people with disabilities suffer a higher level of poverty than “abled people”. Hence, another obstacle hinders access to contraception when this is not affordable³¹⁰.

Moreover, it is worth noting that, according to MenCap, a British NGO advocating for people with disabilities’ rights, 75% of GPs have received no training to help them treat people with a learning disability³¹¹. Further, some of the doctors in the ACT are not aware about the procedures for granting contraception to women/girls with LD³¹². WWDACT has anecdotal evidence in the ACT that the trend might not be different in Australia. In one case, a young woman with disabilities sought and underwent an implant operation without going through the ACAT process. This is in breach of the law and shows that the doctor in the matter was not trained to work with women with

disabilities. This situation is not dramatic because implants appears to be one of the less risky methods for contraception with the smallest side effects possible. However, one can wonder about the kind of information provided to this woman regarding contraception and sexual relationships. Did the doctor make sure that she was aware of what the device does entail? Accordingly, one needs to think about implementing global policies and training for doctors in this particular field of disabilities for ensuring and fostering good practices.

Furthermore, people with LD tend to be accompanied by their parents more often and for a longer period of time which inhibits relationships being created. Further, according to MenCap: *“Many people with a learning disability say that relationships are important to them – yet only 3% of people with a learning disability live as a couple, compared to 70% of the general adult population”*³¹³. Moreover, studies reveal that women with LD do not consider themselves as proper women. They do not think that sex is a good thing for them even if they admit that it can be good for others³¹⁴. Comprehensive sexual health education for women with LD should include self-advocacy programs which let women develop positive body image. Infantilization of women with LD is counterproductive for their wellbeing as well as for society.

Accordingly, women with disabilities’ biggest enemy is not their disability but societal prejudice. Because of different stigma like “asexualism”, childish demeanour, inability to comprehend new information, women with disabilities are enclosed behind a disabled wall which prevents them from accessing information and making their voice heard.

B) Sexual health education and women with disabilities

In this part, a focus on sexual health education will be made (1) in order to develop benefits expected from more inclusive and comprehensive sexual health education program (2).

1) What is sexual health education?

Sexual health education represents an international requirement³¹⁵. WHO defines sexual health *“as a state of physical, mental and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.”*³¹⁶.

Other UN instruments refer to it as a comprehensive sexual education system which would provide *“opportunities to explore one’s own values and attitudes and to build decision-making, communication and risk reduction skills about many aspects of sexuality.”*³¹⁷ Consequently, it is crucial to address the issue and implement legal mechanisms to enforce this right to access sexual health education for all. Therefore, a monitoring entity should be put in place in order to evaluate and enforce the implementation of sexual health education curricula.

It is worth noting that the FPAA understands comprehensive relationships and sexual health education the way the UN defines it. That is to say that sexual health education programs should

recognise the possibility of pleasurable and safe sexual experience, based on a foundation of mutual consent and free from coercion and violence³¹⁸. Therefore, sexual health education should encompass practical sexuality and not only scientific analysis of STIs.

Recent studies in Australia confirmed that sexual health education lacks erotic forms of knowledge³¹⁹. One research study focused on teenagers between 14 and 16 years old in Queensland. The results show that teenagers feel that they are taught that sex is bad. Therefore, preparing for it, like buying condoms, is perceived as “frowned upon”³²⁰. This hinders safe sex practices and alerts us to the need for better Relationship and Sexuality Education (RSE) programs³²¹.

Teenagers face difficulties learning about sex because of inappropriate programs which are too “scientific”. Hence, teenagers with disabilities suffer the same disadvantage in addition to having a disability stigma. Therefore, when it comes to sexual health education and contraception, disabled young women carry the intersectional burden of being a female, being disabled, and being adolescent. That is why specific endeavours should be given in order to provide a safer environment for those women.

Furthermore, research on sexual health education worldwide, show that adolescents are hardly understood as sexual beings by their parents or teachers³²². One study cross-matched results from various countries including the UK, Ireland, the USA, Australia, New Zealand, Canada, Japan, Iran, Brazil and Sweden and highlighted the fact that RSE programs are not adapted for teenagers’ needs and are too heterocentrist³²³. Therefore, sexual health education remains a burning issue and it may be finally time to be more progressive about it. Our societies are made of a variety of different people. One needs to recognise them all in order to reach a “living together” mentality. Including people with disabilities within sexual health education programs and ensuring access to sexual health education for all should be the leading measure when dealing with contraception and consent for women with disabilities. Indeed, one easily understands that choices are made harder when one lacks relevant information.

Finally, a 2011 British Court of Protection case involving a man with high-support needs who engaged in a sexual relationship with another man is worth noting. In this case, the local authority sought a declaration establishing that the man did not have capacity to consent to sexual relations³²⁴. Even though the Court admitted his incapacity to consent to sex, Justice Mostyn decided to require sex education for the man in question so that he would gain capacity³²⁵. This decision shows that there is a positive evolution in comprehending capacity because the Court sought to enable the man to be capable of consenting to sex. Therefore, capacity as an evolving concept and education as a way to empower people is recognised. Consequently, one needs sexual health education programs which are effectively implemented and include people with disabilities.

2) Expected outcomes of inclusive and comprehensive sexual health education

A recent submission from Action Canada for Sexual Health and Rights (ACSHR), a lobbyist NGO advocating for raising awareness on accessing sexual health for all, to the Canadian Federal Parliament³²⁶, establishes a synthetic overview of the situation in Canada regarding access to sexual health education for people with disabilities. Sexual health education aims to avoid transmission of STIs but is not limited to this. It also, teaches children how to decide to enter into a relationship or not. In fact, sexual health encompasses a psychological state which focuses on consent to sex as well as protection against diseases or pregnancies. According to the ACSHR's report, Canada is not fulfilling its obligations under international treaties such as the CRPD or CEDAW.

In Canada, like in Australia, the different provinces and territories are responsible for implementing sexual health education and contraception programs. These are often left to schools' choice³²⁷ which creates huge discrepancies in accessing sexual health information. In fact, the ACSHR's report regrets that the Public Health Agency of Canada (PHAC) program, which proposes guidelines for sexual health education, has not been properly implemented due to this situation. Moreover, those guidelines have only been revised ten years ago in 2008. Therefore, even though they advocate for a comprehensive evidence-based sexual health education, the program is outdated. Finally, there is no national standard to monitor and evaluate sexuality education curricula³²⁸.

Further, ACSHR's report recalls the underestimate fact that sexual health education reduces risk for people, including people with disabilities, to endure sexual abuse. That is why it is urgent to implement regulations promoting sexual health education and including people with disabilities in those curricula. Far more striking, the report notes that people with mental disabilities are even absent – or almost – from Canadian programs in the field.

In order to limit abuse and support people with disabilities to engage in healthy relationships, it is essential to support people with LD to understand respectful relationships. Programs tackling safeguarding, consent, what is appropriate in private and public spaces, and what the differences are between good and bad touch are necessary for promoting healthy relationships³²⁹. In the ACT, SHFPACT already proposes training dealing with those issues³³⁰. Again, ACT has many resources and only needs a political push to comprehensively and effectively implement inclusive legislation which would enhance a more respectful society toward people with disabilities.

Moreover, much research raises the alarm on the critical need for sexual health education and inclusion of people with disabilities within a sexual narrative. It is necessary to empower people with information³³¹. Thus, a massive campaign on sexual health education for people with disabilities should be launched, like the ACSHR with its campaign "Sexual and Reproductive Health Awareness Week" (SRH Week). ACSHR proposes a handbook³³² tackling various issues including sexuality and disability. It promotes, *inter alia*, the role of DPOs in supporting people with disabilities to realise their sexuality and in training staff from other structures to raise awareness on the needs of people with disabilities in this field. The handbook highlights that programs tackling sexuality should encompass disabilities and should not necessary be separated from sexuality for

non-disabled people. Further, information on sexuality should be available in various formats such as Braille, large print, in simple language, and pictures. Hospitals and other clinics should ensure accessibility to their services. Finally, if some professionals or NGOs do not have their own leaflets on sexuality for people with disabilities, they should be able to indicate to the patient/client where to get appropriate information³³³.

A recent paper on *Sexual and Reproductive Health of Women with Disability* has been released in February 2017. This paper focuses on access to sexuality education for women with disabilities in foster care in the USA. However, recommendations of the paper are relevant and are worth noting for empowering women with disabilities and helping them to recover control over their bodies.

The research points out that parents, and one can extend it to carers and foster families, should be prepared to address sexuality for the girl with disabilities in an informed and comfortable manner³³⁴. In fact, people surrounding women and girls with disabilities should have open discussion about sexuality in order to show acceptance for the woman/girl with LD and to make sure that she has appropriate information. Moreover, the report embraces the WHO's sexual health education definition³³⁵ as not solely entailing the absence of diseases. In fact, sexual health education programs should focus on maintaining psychological and social well-being while in a relationship³³⁶.

Further, promoting sexual health among youth with disabilities requires skills in friendship, intimacy, side effects of medications, social and protective skills, and assertiveness training. Moreover, researchers emphasise that the prevalence of abuse among women/girls with disabilities necessitates including accurate vocabulary to identify emotions such as fear or anger³³⁷. For this, different formats can be used to provide information. For instance, pictures, anatomically correct dolls and models, puppets or videos, and simplified language can be used as well as providing positive reinforcement to encourage skill retention.

Recommendations include fostering cooperation between organisations working in the disability sector with those working on sexual health education. Joint programs could be thought through in order to ensure access to sexual health education programs³³⁸. Similar solutions have been promoted in Canada³³⁹ as well as in Australia³⁴⁰.

Finally, some women, with high-support needs revealed that others chose their contraception on their behalf. They were told what was "best for them" but most of them asserted that they would have liked more information. Sexual health education was limited even though the education that was given, was sometimes useful. Sexual health education was effective and appreciated when it came with leaflets that women could take home. WWDACT demands easy read leaflets to be widely distributed. Moreover, studies have revealed that some women with LD go on the internet to get information on sexuality and contraception³⁴¹. Accordingly, providing easy-read information on the internet might help people accessing such information as well – even if it cannot be the only means used. Further, the Open University inquiry concludes acknowledging that "*Women can make good choices about contraception when they are well supported by friends, family, carers, doctors and*

others. Many women said they want more information and that it should be easy to read and have pictures.”. This affirmation corroborates what the WHO recommends in order for women to make good decisions in their sexual lives, “comprehensive information, counselling and support should be accessible for all people”.³⁴²

C) Special focus on the ACT

The ACT government encourages parents to talk about sex to their children. However, this subject can remain taboo and some children can miss information that parents do not feel comfortable to address or simply do not want their children to be engaged in these conversations. However, research worldwide demonstrate that talking early about sex to children reduces unsafe sex practices. Therefore, it might be relevant to think about a common program on sexual health education delivered in and out of ACT schools. These programs could be based on family planning organisations such as SHFPACT or other organisations skilled in teaching about sexual health. For instance, SHFPACT addresses more than ten different topics in its sexual health courses including puberty, human reproduction, relationships, sexual development, human sexuality and diversity, gender roles, decision-making and negotiation skills, reproductive health, pregnancy and personal safety.

Further, in 2016, the ACT government launched the ACT Women’s Plan 2016-26. Yvette Berry, the Minister of Women, presented the Plan noting that women with disabilities constitute one of the groups that are the most isolated and struggling in accessing health facilities³⁴³. Moreover, the Minister acknowledges the intersectional grounds of discrimination that women with disabilities are facing. Therefore, WWDACT welcomes the initiative to envisage a specific focus on accessing health facilities for women with disabilities³⁴⁴. It is indeed crucial in relation to contraception and achieving reproductive rights. Finally, the Minister highlights and cautions that:

Women with disability continue to face discrimination and exclusion in employment, education, in leadership and in social spheres. Making improvements to reduce attitudinal and structural barriers to the full participation of women with disability is vital to ensure all women are afforded their full human rights.

*Violence against women with disability can go undetected, unreported or investigated and there can be particular barriers to accessing crisis accommodation and other supports. While it is not yet possible to adequately quantify the level of violence against women, **there is evidence to suggest that up to 90 per cent of women with intellectual disability experience sexual assault at some time during their lives.***

The forms of discrimination and disadvantage women with disability face are multiple and can have a compounding effect. Women with disability who face additional barriers require special consideration to effectively prevent them from exclusion and vulnerability to a range of disadvantages including poverty and violence. For example, a refugee woman with a disability may face discrimination on account of her gender, her disability and her ethnicity.

Having recognised the situation is a first step for improving women with disabilities' lives. However, women with disabilities need concrete actions in order to enjoy their human rights. That is why WWDACT recommends the ACT government launch a movement of recognition of legal capacity for women with disabilities – and *a fortiori* men with disabilities. This is based on every outcome from every project trialling the support of people with disabilities in their decision-making. Those projects enabled people with disabilities to take decisions for themselves, with appropriate support and not mere representation. Findings³⁴⁵ proved that such system help to empower people who would be, *de facto*, less vulnerable and better included in the society. Further, this empowerment goes hand in hand with building self-esteem and fostering people's capacity to engage in relationships, whether sexual or not. This is crucial for improving people's daily lives on the long term.

Supporting access to information concerning contraceptive use and options for women *and* girls with disabilities is consistent with the ACT Women's Plan 2016-26 since one of its aims is to include women with disabilities within its scope of action³⁴⁶. Therefore, to empower women/girls with disabilities in this regard, a more inclusive and comprehensive sexual health education program should be implemented.

The program "SoSafe!" delivered by SHFPACT, as well as Family Planning Tasmania, deals with consent to sexual relationships. The program organises training for carers, parents and other professionals working with people with disabilities. It is based on Easy English and images which allow people with disabilities to understand which behaviours are acceptable or not. SoSafe! tackles but is not limited to information on sexuality. It includes information about different interaction possibilities during a person's life. The program also has information about contraception. Such programs should be endorsed by political support. SHFPACT has agents called Community Education and Health Promotion Officers who go into schools to teach about puberty or sexual health in a comprehensive manner. ACT government policy and legal framework could be strengthened to enable broader intervention including training medical professionals, health care providers, teachers as well as carers in order to foster non-discriminatory attitudes. This has been recommended by the UNFPA and UNECE as well in 2013³⁴⁷. Of course, this is possible through advocacy and NGO's work but policy makers and parliamentarians have a huge role to play to foster an enabling environment for the full and equal enjoyment of human rights, including sexual and reproductive health and rights. That is why WWDACT asks the ACT government to consider its recommendations for reform.

Furthermore, the UN recognises parents as having a major role in accompanying their children in learning about sexual health. Assistance should be provided to them too in order to train them and to increase their awareness of the benefits of comprehensive sexuality education for their children³⁴⁸. Moreover, sexual health education provided to children without disability must be provided to children with disabilities as well. In this regard, Section 11(2) of the ACT HRA states that *every child has the right to the protection needed by the child because of being a child, without distinction or discrimination of any kind*³⁴⁹. Yet, not providing the knowledge or the tools to

women/girls with disabilities to deal with their sexuality, feeling, wishes and limits, hinders their empowerment. Therefore, they remain discriminated against and the over representation of sexual abuses against women/girls with disabilities³⁵⁰ is an alarming sign that should attract political attention in order to take action now.

It is also important to include boys and men in this awareness work. Women's rights to control their body and life should be acknowledged by everyone. That is why men should also be targeted by support programs to sensitise them to gender equality and rights issues³⁵¹.

Further as underlined by Mrs. Susan Salthouse, the WWDACT's chair:

today's adults with disabilities who experienced segregated schooling first-hand testify that their curriculum lagged disgracefully behind that which was required of their mainstream peers. As a result, overcoming knowledge gaps has taken personal resolve and effort, not to mention the recovery of a sense of self-worth³⁵².

Exclusion from information and education results in the establishment of a discriminatory system which cannot be acceptable. Moreover, one has to bear in mind that Article 24 of the CRPD states that signatories to the CRPD shall ensure an inclusive education system at all levels including access to lifelong learning in order to enhance our sense of dignity and self-worth and to enable us to participate effectively in a free society. Therefore, access to inclusive education is a human right that should be implemented in order to overcome intersectional discrimination that women with disabilities are facing³⁵³.

Concerning the access to contraceptive in the ACT, minors can have access to contraception if doctors are satisfied of their maturity³⁵⁴. There is no age limit to access barrier contraception like condoms in the ACT nor to accessing medical advice about contraception without parental consent. With regards to the contraceptive pill for instance, an individual only needs a prescription from her doctor. For any medical treatment, before prescribing it, doctors should be satisfied that their patient understands the different consequences of the prescription - risks and side effects as well as the way to use the drug - and that it can be in the best interest of the child to be supported independently of his/her parents³⁵⁵. This question is raised in relation to privacy issues. Some adolescents do not want their parents or guardians to know about their sexual life or questions. Therefore, doctors should be trained to be able to guide adolescents in their decision-making. This is also true when doctors are dealing with people with disabilities. Medical professionals need to be trained to be able to deal appropriately with women with disabilities as well as adolescent and young women with LD.

Further, and in compliance with what the 2016 ACT LRAC report on guardianship proposes ³⁵⁶, informal support should be developed in the ACT. For instance, one can think of a program which could organise training for people with disabilities to be mentors for others. This has actually already been implemented in Europe with the TOPSIDE program³⁵⁷ discussed earlier. This will enhance capacity building for people with disabilities and foster their self-advocacy skills³⁵⁸. In the

ACT, INVOLVE as well as Advocacy for Inclusion³⁵⁹ and ADACAS would be great organisations to work with in order to implement such a system. Moreover, ADACAS has already an online tool as well as trainings to assist people with LD to make decision and Advocacy for Inclusion proposes an application to support people with LD making decisions too³⁶⁰. Therefore, the ACT appears to have strong capacity building potential with NGOs already innovating in the field.

Finally, it is worth highlighting that WWDACT's work and proposals are consistent with the ACT Women's Plan 2016-26 approved by the Legislative Assembly for the ACT³⁶¹. The Plan acknowledges the necessity to ensure access to reproductive rights to all women in order to empower them. It also recognises that ACT needs to support women facing intersectional discrimination such as disability. For this, the strategic purpose of the ACT Government includes removing barriers to the full and equal participation of women and girls in societal life. This sounds like implementing Article 12 of the CRPD for women and girls with disabilities. Further, principles guiding the ACT Women's Plan 2016-26 encompass equality, non-discrimination, intersectionality, common responsibility, diversity and safety. Those principles are also the ones that WWDACT considered before providing its recommendations regarding accessing contraception for women with disabilities. Further, the action plan depicts its priority area of action for 2017-2019 to be health and wellbeing. WWDACT understands this as including sexual health education, reproductive rights and full information on different contraceptive possibilities for women with disabilities as well.

Conclusion

People with disabilities have always been denied the right to be individuals deserving of equal legal rights. In fact, they have always been treated as recipients of welfare, health, and charity programmes³⁶². That is why it is time, more than 10 years after Australia having signed the CRPD at the UN, to finally achieve these human rights - whether it is in terms of legal capacity and in terms of reproductive rights.

With the appropriate support, every single person, no matter the level of his/her LD, can make decisions³⁶³. However, it requires training and a shift in attitudes. Training for medical professionals, for support workers, for parents and for people with LD themselves is essential. People with LD's capacity have been disregarded for too long even though experience proves that becoming a self-advocate is possible. By the same token, empowering people makes them more independent and autonomous. SDM solutions do not generate more spending but rather foster social investment for a more sustainable future with reduced inequalities.

Moreover, forced contraception should be eradicated as women with LD should be trusted as capable of learning about sexuality. International academic research and surveys demonstrated that women with LD, even with high support needs, wanted to have access to information about contraception and sexual relationships. Social prejudices should be overcome and more comprehensive sexual health education programs should be provided in this sense. Women with

disabilities are sexual beings and global awareness must be raised on that topic. Embarking on this progressive path will be a long journey and that is why a step-wise implementation of new decision-making systems as well as inclusive sexual health education programs should start now and cannot wait another decade.

Finally, beyond the philosophical debate condemning the denial of the abstract notion of “legal capacity” as a way to deny a part of humanity to people with disabilities, there are concrete social consequences. This situation leads to marginalisation which prevents us from breathing capacity-building into people with disabilities. People with disabilities are human beings with as much needs of social links, esteem and love as people without disabilities. Human beings live in groups, and our differences, particularity and diversity are our wealth. Let’s not forget this.

Recommendations

Australia is slow in changing its legal framework into a supported decision-making paradigm³⁶⁴. The ACT can be innovative and pioneer in launching concrete action in Australia now. It is worth noting that some of the following recommendations are taken from other research as well.

❖ Regarding decision-making

Principal recommendations

- 1)** Legal capacity shall not be removed in any circumstances.
- 2)** People with high support needs shall be supported through SDM mechanisms.
- 3)** Substituted decision-making shall be totally repealed in the long run (10 year time frame).
- 4)** The law shall allow informal SDM mechanisms.
- 5)** The law shall establish different kind of formal SDM mechanisms:
 - **Supported decision-making:** The decision-making framework requires and provides support for decision making based upon the will, preferences and rights of someone whose decision-making ability is impaired. For instance, one person would assist another to make a decision and communicate it to others.
 - **Co-decision making:** Where impaired decision-making ability makes the exercise of decision making ability with support difficult, additional support shall be provided to allow the person to properly exercise their decision-making ability. This could be through helping them to obtain and understand information relevant to the decision, talking through the pros and cons of different available options, or helping a person to communicate with others³⁶⁵.
 - **Collective decision-making:** In a case where a person is isolated, a board of supporters could be established in order to collectively assist a person with high support needs.
- 6)** Strong safeguards shall be implemented in order to avoid abuse and undue influence.
 - The individual should be able to refuse or request a change of support³⁶⁶.
 - A monitor can be appointed in order to control the supporter's action.
 - Even if the final decision shall be kept with the person assisted, friends or family or any close person to the principal, or a habilitated NGO should be able to challenge the decision in case of alleged abuse.

- A special body can be created in this regard at the Human Rights Commission.

Subsidiary recommendations

- 7) In case a last resort substituted decision-making mechanism is kept, strict safeguards shall be implemented:
 - Use of a capacity test shall be limited and reasoned.
 - Medical professionals entitled to assess mental capacity shall undertake the test in conjunction with a social worker sensitized to disabilities.
 - Appeal can be made on the capacity assessment provided.
 - The person represented shall have the right to challenge the decision at any time (and therefore not be stripped off her/his agency).
- 8) Consider that female supporters can be preferred with regards to contraceptive decisions.

❖ Regarding capacity

Principal recommendations

- 9) Capacity test shall not allow the withdrawing of legal capacity.
- 10) Capacity shall be understood as an evolving concept and a functional approach shall be implemented in order to include every kind of disability according to the specific decision at stake.
- 11) Capacity test shall only inform the level of support that one needs.
- 12) An official guideline for capacity assessment shall be implemented in order to avoid discretionary assessments³⁶⁷.
- 13) Capacity assessment shall also be carried out with a close relative or a social worker sensitized to disabilities if there is no primary relative available.
- 14) Capacity test shall be withdrawn and “ability to express” shall be used instead to assess the level of support needed³⁶⁸.

❖ Regarding best interest

Principal recommendations

- 15) The best interest test shall be removed and replaced by looking at the rights, will and preferences of the person supported.

- 16)** Good practice guidelines will be provided for supporters and medical practitioners as well as the right for a person supported to challenge his/her supporter at the ACT HRC³⁶⁹.

❖ **Regarding Capacity building**

Principal recommendations

- 17)** An intermediate system between formal and informal support can be envisaged.
- Following the Swedish model with the Personal Ombudsman (PO)³⁷⁰. The PO is not related to state authorities nor has a contract with the person he/she assists. However, the PO should also play a role of an advocate for the person's rights at courts or other instances. This model has been created for people with psychosocial disabilities but can be used as a model for very isolated people who have been institutionalised for too long. These propositions are collected by Choice, a European platform which gathers different good practices of SDM consistent with the CRPD³⁷¹.

❖ **Regarding sexual health education**

Principal recommendations

- 18)** Global awareness program on the sexuality of people with disabilities shall be undertaken.³⁷² For people with and without disabilities.
- Sexual health education programs shall have the characteristics of: questioning the orthodoxy in sex and relationships learning³⁷³; raising self-esteem and breaking down the “taboos” about expressing feelings.
 - Out of school programs with NGOs or institutions specialised in sexuality (e.g. SHFPACT) shall be supported and resourced.
 - Start early and talk often about sexuality to people with learning disabilities³⁷⁴.
- 19)** Create programs where both people with and without disabilities learn about sexual health.
- 20)** Increase exchanges between institutions and build network-crossing knowledge.
- 21)** Provide more easy-read information with pictures relevant for ensuring effective access to sexual health education and contraception. This lack of information for women with disabilities “serves to perpetuate a lack of control over reproductive choices just as forced sterilisation did in the past”³⁷⁵.
- 22)** Doctors and medical professional must be trained as well on the real capacities of women with LD.

- They should be taught about the negative contraindications of some contraceptive devices if granted to certain women with certain disabilities. Doctors and other health care practitioners need to be better informed about the lives, needs and capabilities of people with LD.
- Regular reviews of contraceptive use should also be implemented, so that the actual need for contraception can be reviewed³⁷⁶.

23) Women with disabilities, when appropriately supported can be great parents. Hence, an education program should stop stigmatising people with disabilities as incapable people.

- Global awareness should be raised concerning the capability of parenting for some women with LD. Much research show that appropriate support to women with LD helps them to successfully become, and remain, good parents to any children they do have³⁷⁷.
- Adequately resource parent support programs for women with LD.

❖ **Regarding contraception:**

Principal recommendations

- 24)** Requiring court orders for granting contraceptives shall be repealed as they are currently too burdensome
- 25)** A supporter shall assist but not make decisions for the woman/girl about contraception. They may explain and be pedagogic about the reasons and effects of using contraceptives.
- 26)** Provide parents with information about the importance of discussing contraception and give them access to a supporter, such as the PO in Sweden, when they are not comfortable with this topic themselves.
- 27)** Establish a superior bureau for supervising, monitoring contraceptive, or health decision in general. This bureau would be extra-judiciary and could include doctors and DPO members. The Human rights commission could be a good place to organise such commission.

Endnotes

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²¹ *Assisted Decision-Making (Capacity) Act 2015*, Republic of Ireland, [*Capacity Act 2015* (Ireland)]

²² The wording varies from legislations to another. The ACT one has been chosen as a reference. Guardian can also be called curator, tutor, trustee...; Manager can be called administrator too

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²⁵ *Mental Capacity Act 2016* (Northern Ireland) [MCA 2016 (Northern Ireland)], Part 1, (3)

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³⁹ *MCA 2016* (Northern Ireland), Part 1 (7)

⁴⁰ Harper, C., Davidson, G., & McClelland, R., (2016). *No Longer 'anomalous, Confusing And Unjust': The Mental Capacity Act (Northern Ireland) 2016*, (International Journal of Mental Health and Capacity Law), (22), 57-70, p63

⁴¹ Jill Stavert, (2015). *The Exercise of Legal Capacity, Supported Decision-Making and Scotland's Mental Health and Incapacity Legislation: Working with CRPD Challenges*, *Laws*, 4, 296–313; doi:10.3390/laws4020296 - ISSN 2075-471X - www.mdpi.com/journal/laws/, (Academic Editors: Kelly Purser and Shih-Ning Then), p303

⁴² Mental Welfare Commission of Scotland, *Good Practice Guide – Supported Decision-Making*, November 2016

⁴³ The same observation has been made by the ACT Law Reform Advisory Council (2016) as well as the Victorian Law Reform Commission (2014)

⁴⁴ Comprehensive information about the *NDIS Act 2013* (Cth) and SDM can be found at <http://www.advokit.org.au/decision-making/>

⁴⁵ *NDIS Act 2013* (Cth), Chapter 4, Part 5, Division 1, Section 80

⁴⁶ Comprehensive information about the *NDIS Act 2013* and its relation to the CRPD can be found at <http://ndisrights.org.au/fact-sheet/decision-making/>

⁴⁷ Office of the Public Advocate (SA) and Office of the Public Advocate (Vic), (2014). *Submission to the Australian Law Reform Commission Discussion Paper Equality, Capacity and Disability in Commonwealth Laws*, [OPA SA Vic / ALRC (2014)], p25

⁴⁸ Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, FINAL REPORT, ALRC Report 124, 2014 - ISBN: 978-0-9924069-3-6 - © Commonwealth of Australia 2014 [ALRC (2014)], p94

⁴⁹ Terry Carney, (2015). *Supported Decision-Making for People with Cognitive Impairments: An Australian Perspective?* (Laws 2015, 4, 37–59); doi:10.3390/laws4010037 - ISSN 2075-471X - www.mdpi.com/journal/laws/, (Australia - Academic Editors: Lindy Willmott, Kelly Purser and Shih-Ning Then), [Carney, T, *SDM for People with Cognitive Impairments* (2015)], p50

⁵⁰ Terry Carney and Fleur Beaupert, (2013). ‘*Public and Private Bricolage—Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making*’ (36 University of New South Wales Law Journal 175)

⁵¹ Alberta (AB), British Columbia(BC), Manitoba(MB), New Brunswick (NB), Newfoundland and Labrador (NL), Nova Scotia (NS), Ontario (ON), Prince Edward Island (PE), Quebec (QC), and Saskatchewan (SK)

⁵² Northwest Territories (NT), Nunavut (NU), and Yukon(YT)

⁵³ More information about Canadian statistics can be found at <http://www.statcan.gc.ca/pub/89-503-x/2015001/article/14316-eng.htm>

⁵⁴ Kaiser HA., (2009). *Canadian Mental Health Law: the slow process of redirecting the ship of State*, (Health Law J.);17:139–94. quoted in Hoffman, S.; Sritharan, L.; Tejpar, A., *CRPD Impacting Mental Health Laws and Policies* (2016), *op. cit.*, pp 6 and 7

⁵⁵ *Canadian Charter of Rights and Freedoms 1982*

⁵⁶ *CRPD* (2006), Canada reservation on Article 12: “(...) Canada declares its understanding that Article 12 permits supported and substitute decision-making arrangements in appropriate circumstances and in accordance with the law.

To the extent Article 12 may be interpreted as requiring the elimination of all substitute decision-making arrangements, Canada reserves the right to continue their use in appropriate circumstances and subject to appropriate and effective safeguards. (...)."

⁵⁷ Hoffman, S.; Sritharan, L.; Tejpar, A., *CRPD Impacting Mental Health Laws and Policies* (2016), *op. cit.*, p8

⁵⁸ *CRPD* (2006), Australia reservation on Article 12: "(...) Australia declares its understanding that the Convention allows for (...) substituted decision-making arrangements, (...), only where such arrangements are necessary, as a last resort and subject to safeguards; (...)"

⁵⁹ *Substitute Decisions Act 1992* (ON), SO C 30; *Guardianship and Trusteeship Act 1994* (NT), SNWT, c 29, <<http://canlii.ca/t/52wcv>> retrieved on 2017-06-16; *Content to Treatment and Health Care Directives Act 2010* and *Mental Health Act 2013* (PE); *Personal Directives Act 2008* (NS); *Advanced health care directives Act 1995* (NL); *Mental Health Act 1973* (NB), RSNB, c M-10, <<http://canlii.ca/t/52vw7>> retrieved on 2017-06-19 and *Infirm Persons Act 1973* (NB) RSNB, c I-8, <<http://canlii.ca/t/52r4x>> retrieved on 2017-06-19 ; *Personal Health Information Privacy and Access Act 2009* (NB)

⁶⁰ Ontario, Yukon and New Brunswick - New Brunswick Association for Community Living – Chapter 14 Decision making and your child; Prince Edward Island - <http://peiaci.org/prince-edward-island-supported-decision-making/>; Nunavut, *Guardianship and Trusteeship Act*, SNWT (Nu) 1994, c 29; for children: *Medical Consent of Minors Act*, SNB 1976, c M-6.1, <<http://canlii.ca/t/52m20>> retrieved on 2017-06-19

⁶¹ Representation, under civil law, means that someone is vested with power to decide on behalf of another. It can include mandates, but also guardianship; curatorship or tutorship within Quebec law.

⁶² *Civil Code of Quebec 1991*, CHAPTER III PROTECTIVE SUPERVISION OF PERSONS OF FULL AGE

⁶³ *Ibid*, Articles 281 et seq.

⁶⁴ *Ibid*, Articles 285 et seq.

⁶⁵ *Ibid*, Articles 291 et seq.

⁶⁶ Le Curateur public du Québec, *My protection mandate*, p8

⁶⁷ Le Curateur public du Québec, *A Close Relative or Friend Becomes Incapacitated - How Can You Protect Them?*, À la rencontre de la personne, p7

⁶⁸ *Representation Agreement Regulation 2001* (BC) Reg 199/2001[RAA 2001 (BC)]

⁶⁹ Law Commission of Ontario (LCO), *Legal Capacity, Decision-making and Guardianship: Final Report*, (Toronto: March 2017) [LCO 2017], p99

⁷⁰ *Ibid*

⁷¹ *RAA 2001* (BC), Part 1 (2)

⁷² Ibid, Section 8

⁷³ Ibid, Part 1 (3)

⁷⁴ Ibid, Sections 7 and 9

⁷⁵ Ibid, Sections 16 and 20

⁷⁶ Ibid, Part 1 (8)

⁷⁷ *The Vulnerable Persons Living with a Mental Disability Act 2014* (MB)

⁷⁸ *Adult Guardianship and Trusteeship Act, SA 2008, c A-4.2.* [AGTA 2008 (AB)]

⁷⁹ Ibid, Part 2, Division 1 and Division 2

⁸⁰ Government of Alberta, Human Services, *Supported Decision-making, Adult Guardianship and Trusteeship Act, Guiding Principles Brochure*

⁸¹ Government of Alberta, Human Services, *Decision-making options, Adult Guardianship and Trusteeship Act, Guiding Principles Brochure*

⁸² Government of Alberta, Human Services, *Specific Decision-making, Adult Guardianship and Trusteeship Act, Guiding Principles Brochure*

⁸³ AGTA 2008 (AB), Part 3, Division 1, Section 97

⁸⁴ *Adult Guardianship and Co-decision-making Act 2009, (SK), [AGCDMA 2000 (SK)], PART I*

⁸⁵ Ibid, Section 17

⁸⁶ Ibid, PART I

⁸⁷ *Decision Making, Support and Protection to Adults Act 2003, (YT) [DMSPAA 2003 (YT)] PART 1*

⁸⁸ Ibid, SCHEDULE B, CARE CONSENT ACT PART 1, Division 1 (6)

⁸⁹ Ibid, SCHEDULE B, CARE CONSENT ACT PART 1, Division 1 (7)

⁹⁰ McGill Centre for Human Rights and Legal Pluralism, (2017). *SUBMISSION TO THE UNITED NATIONS COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES, 17th Session, March 20 – April 12, 2017, Canada's compliance with Article 12 of the Convention on the Rights of Persons with Disabilities* [McGill Centre for Human Rights and Legal Pluralism, *Submission to the CRPD Committee, (2017)*]

⁹¹ The following cases have been taken from McGill Centre for Human Rights and Legal Pluralism, *Submission to the CRPD Committee, (2017)*: **Gray v. Ontario (2006)**: “Where alternatives to the appointment of a guardian will allow for decisions to be made concerning an individual’s personal care, this is to be preferred to a guardianship order, which requires a finding that the person is incapable of personal care.”; **Kacan v. Ontario Public Service Employees Union (2010)**: Human Rights Tribunal of Ontario affirmed the significance of promoting the autonomy and dignity of people with disabilities, even where supports were required to exercise such autonomy, at para. 22.;

Starson v. Swayze (2003) interpreted the statutory test for mental capacity in Ontario's *Health Care Consent Act* to have a relatively low threshold of decision-making ability; **Cuthbertson v. Rasouli (2013)** reaffirms the objective of the *Ontario Health Care Consent Act* to uphold the patient's autonomy interest as much as possible and allow the substitute decision-making model to be used only when absolutely necessary due to the patient's incapacity to make decisions.

⁹² *Substitute Decisions Act 1992* (ON)

⁹³ Ministry of the Attorney General of Ontario, *Capacity Assessment Office, "Guidelines for Conducting Assessments of Capacity"* (May 2005) I.1, online: <<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/capacity/2005-05/guide-0505.pdf>> (last accessed: 7 October 2010)

⁹⁴ *AGCDMA 2000* (SK), PART I

⁹⁵ Caivano, N., *Conceptualizing Capacity* (2014), *op. cit.*, p. 5

⁹⁶ *Ibid*, p19

⁹⁷ Ontario Human Rights Commission, (2014). *Policy on preventing discrimination based on mental health disabilities and addictions, Consent and capacity*, p67, ISBN: 978-1-4606-4112-5 (Print), Retrieved from

http://www.ohrc.on.ca/sites/default/files/Policy%20on%20Preventing%20discrimination%20based%20on%20mental%20health%20disabilities%20and%20addictions_ENGLISH_accessible.pdf

⁹⁸ *Calvert (Litigation Guardian of) v. Calvert* 1997 27 R.F.L. (4th) 394 at para 56 (Ont. Ct. (Gen. Div.))

⁹⁹ LCO 2017 *op. cit.*

¹⁰⁰ *Ibid*, Reducing or tailoring the use of guardianship (Chapters 4, 8), Recommendations 3 – 9 and 40 - 46

¹⁰¹ *Ibid*, CHAPTER 11 Priorities and timelines Recommendations 10 (24), p347

¹⁰² McGill Centre for Human Rights and Legal Pluralism, *Submission to the CRPD Committee*, (2017), *op. cit.*

¹⁰³ LCO 2017 *op. cit.* note 49.

¹⁰⁴ McGill Centre for Human Rights and Legal Pluralism, *Submission to the CRPD Committee*, (2017), *op. cit.*, p 9

¹⁰⁵ LCO 2017 *op. cit.*, Chapter 6, Recommendations 21 – 23

¹⁰⁶ Carney, T, *SDM for People with Cognitive Impairments* (2015), *op. cit.*, p41

¹⁰⁷ Hoffman, S.; Sritharan, L.; Tejpar, A., *CRPD Impacting Mental Health Laws and Policies* (2016), *op. cit.*, p8

¹⁰⁸ Caivano, N., *Conceptualizing Capacity* (2014), *op. cit.*, p18

- ¹⁰⁹ Canadian Civil Society, *Parallel Report*, CRPD Committee 17th Session - March 20 - April 7, 2017, Available online at <http://cad.ca/wp-content/uploads/2017/04/Canadian-Civil-Society-Parallel-Report-Canada-English.pdf>
- ¹¹⁰ Caivano, N., *Conceptualizing Capacity* (2014), *op. cit.*, p21
- ¹¹¹ Hoffman, S.; Sritharan, L.; Tejpar, A., *CRPD Impacting Mental Health Laws and Policies* (2016), *op. cit.*, p12
- ¹¹² *R v Morgentaler* 1988, 1 SCR 30 at para 240; quoted in Caivano, N., *Conceptualizing Capacity* (2014), *op. cit.*, p21
- ¹¹³ *Starson v Swayze* 2003, Supreme Court of Canada - 32 at para 7 quoted in Caivano, N., *Conceptualizing Capacity* (2014), *op. cit.*, p21
- ¹¹⁴ *Law v Canada (Minister of Employment and Immigration)* 1999, 1 SCR 497 at para 53. quoted in Caivano, N., *Conceptualizing Capacity* (2014), *op. cit.*, p21
- ¹¹⁵ *Clark v. Clark*, 1982 CanLII 2253 (ON SC), <<http://canlii.ca/t/g120z>>, retrieved on 2017-06-22
- ¹¹⁶ *Koch (Re)*, 1997 CanLII 12138 (ON SC), <<http://canlii.ca/t/1vv7q>>, retrieved on 2017-06-22
- ¹¹⁷ *GUARDIANSHIP OF ADULTS BILL 2016* (NT, Australia), Part 1 (4), (5) (c); *Consent to Medical Treatment and Palliative Care Act 1995*, (SA), Part 2A
- ¹¹⁸ *Guardianship and Administration Bill 2014* (Vic), Part 7
- ¹¹⁹ *Guardianship and Management Act 1991* (ACT); *Disability service and guardianship act 1987* (NSW); *Guardianship and Administration Act 1986*, (Vic); *Guardianship and Administration Act 1993* and *Consent to Medical Treatment and Palliative Care Act 1995* (SA); *Guardianship and Administration Act 1990* (WA); *Guardianship and Administration Act 1995* (Tas); *Guardianship and Administration Act 2000* (Qld)
- ¹²⁰ *Consent to Medical Treatment and Palliative Care Act 1995* (SA) [CMTPC 1995 (SA)], Part 3, Division 1, 15; However, *Mental Health Act 2015* (ACT) provides that information should be given to the patient, see *Mental Health Act 2015* (ACT), Chapter 3, part 3.1
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- ¹²² See *infra* Part II A 2), p43
- ¹²³ See eg., *Family Law Act 1997* (WA), [FLA 1997 (WA)], Part 5, Division 7, Subdivision 4 and Part 1 (5)
- ¹²⁴ *Children and Young People Act 2008* (ACT), Part 1-3, Division 1.3.2 (15); *FLA 1997* (WA), Part 5, Division 11, Subdivision 4, Section 199 and Section 69ZA; *CMTPC 1995* (SA), Division 4 (12); *EDUCATION ACT 2016* (NT), Preliminary matters (7); *Guardianship and Administration Act 1995* (Tas), Part 6
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- ¹²⁷ *GUARDIANSHIP OF ADULTS ACT 2016* (NT), Act No. 15 of 2016 [GOA 2016 (NT)]
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- ¹³³ *Ibid*, Chapter 2 (5)
- ¹³⁴ OPA SA Vic/ ALRC (2014) *op. cit.*, p11
- ¹³⁵ *GOA 2016* (NT), Section 8
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- ¹⁴² Hoffman, S.; Sritharan, L.; Tejpar, A., *CRPD Impacting Mental Health Laws and Policies* (2016), *op. cit.*, p3
- ¹⁴³ *Capacity Act 2015* (Ireland), Part 1 (3)

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- ¹⁴⁶ Dinerstein R., *Implementing Legal Capacity* (2012) *op. cit.*
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¹⁶⁸ Mental Health Commission, *A quality mental health service that is founded on the provision of recovery-based care, dignity and autonomy for service users*, [Ireland Mental Health Commission], Assisted Decision-Making

¹⁶⁹ CRPD (2006), Preamble (e)

¹⁷⁰ Comprehensive information about the *Assisted Decision-Making (Capacity) Act 2015* can be found at [http://justice.ie/en/JELR/Pages/Assisted_Decision-Making_\(Capacity\)_Act_2015](http://justice.ie/en/JELR/Pages/Assisted_Decision-Making_(Capacity)_Act_2015)

¹⁷¹ Comprehensive information about Director of the Decision Support Service can be found at http://www.mhcirl.ie/DSS/dir_dss/

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¹⁷⁴ Ibid

¹⁷⁵ *Capacity Act 2015* (Ireland), Part 1, Section 3, (1)(3)(5)(6)

¹⁷⁶ Ibid, Part 1, Section 3, (2)

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¹⁷⁸ Comprehensive information about the Irish Family Planning Association can be found at <https://www.ifpa.ie/Sexual-Health-Services/FAQ>

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¹⁹⁵ Comprehensive information about Nidus can be found at http://www.nidus.ca/?page_id=240

¹⁹⁶ OPA SA Vic/ ALRC (2014) *op. cit.*, p18

¹⁹⁷ Victoria Office of the Public Advocate, (2015). *Supported Decision Making Pilot Project*, ASID SDM Symposium, p23

¹⁹⁸ House of Lords, *MCA 2005* (2014), paragraph 70

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- ²²³ ADACAS, *SDM*, (2013), p5
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