Removing obstacles to equal recognition for persons with intellectual disability: Taking exception to the way things are

Anne-Marie Callus

Citation for the published paper

Callus, A.M. (2018). Removing obstacles to equal recognition for persons with intellectual disability: taking exception to the way things are. *Alter: European Journal of Disability Research*. 12 (3), 153-165. DOI: 10.1016/j.alter.2018.03.001.

Removing obstacles to equal recognition for persons with intellectual disability: Taking exception to the way things are

Supprimer les obstacles à la reconnaissance égale pour les personnes ayant un handicap mental: n'être pas d'accord avec le statu quo

Abstract

Article 12 of the Convention on the Rights of Persons with Disabilities challenges the misconception that persons with intellectual disability, among others, are not capable to take decisions for them- selves. This paper first considers the right to equal recognition before the law within the light of the General Comment on Article 12 issued by the Committee on the Rights of Persons with Disabilities which emphasises the need to move away completely from substitute decision-making and to promote supported decision-making. The importance of Article 12 within the context of the Convention as a whole is also considered, together with the limited extent to which supported decision-making has been implemented. The paper argues that, with the exception of some jurisdictions, substitute decision-making is still seen as the best way to respond to the support needs of people with intellectual disability. While there are plenty of examples of supported decision-making practices being used in the daily lives of people with intellectual disability, these remain the exception. Crucially, decisions made in this way are not legally valid. What is needed therefore is a recognition that different people can take decisions using different methods, with or without support, and for these methods to become legally recognised.

Résumé

L'article 12 de la Convention relative aux droits des personnes handicapées conteste l'idée fausse selon laquelle les personnes ayant un handicap mental, entre autres, ne sont pas capables de prendre des décisions pour elles-mêmes. Tout d'abord, cet article propose d'étudier le droit à une reconnaissance juridique égale dans le cadre de l'Observation générale sur l'article 12 publiée par le Comité des Droits des Personnes Handicapées. Celui-ci souligne la nécessité de renoncer aux dispositifs de décisions substitutives et de promouvoir des dispositifs d'aide à la décision. L'importance de l'article 12 dans le contexte de la Convention dans son ensemble est également analysée au regard de la mise en œuvre limitée des mesures d'aide à la décision. L'article montre que, à l'exception de certaines juridictions, la prise de décisions substitutives est toujours considérée comme la meilleure façon de répondre aux besoins de soutien des personnes ayant un handicap mental. Bien qu'il existe de nombreux exemples montrant que des pratiques d'aide à la décision sont utilisées dans la vie quotidienne des personnes ayant un handicap mental, ces pratiques restent l'exception. Fondamentalement, les décisions prises de cette manière ne sont pas juridiquement valables. Il apparaît donc néces- saire de reconnaître que différentes personnes peuvent prendre des décisions en utilisant différentes méthodes, avec ou sans soutien, de telle sorte que celles-ci deviennent légalement reconnues.

1. Introduction

> The difference between Idiots and mad Men [is] that mad Men put wrong Ideas together, and so make wrong Propositions, but argue and reason right from them: but Idiots make very few or no Propositions, but argue and reason scare at all. (John Locke)

This 17th century quotation from John Locke's Essay Concerning Human Understanding may seem quaint, at best, to our 21st century minds. However, while the use of terms like 'idiots' and 'mad Men' in philosophical arguments and the practice of capitalising common nouns in English are things of the past, the idea expressed by Locke, especially in relation to 'Idiots' scarcely being able to argue and reason at all, is still very much alive in the present.

This idea stands in sharp contrast to the proposition found in Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) that 'all persons with disabilities have equal recognition before the law'. The CRPD does not make any distinction between one person with disability and another and therefore assumes that this right belongs to all disabled people, regardless of the nature and severity of their impairment. However, the universal applicability of this right has not been met with universal acceptance, and even less with universal application. In fact, the right of people with intellectual disability to be recognised as equal persons before the law is the subject of many debates, including in much of the literature cited in this paper. The discussion often centres on whether or not people with intellectual disability can exercise their legal capacity, thus being given equal recognition before the law. The fact that this debate exists, and seems to be still going strong a decade after the CRPD came into effect, shows how far people with intellectual disability are from being able to enjoy this right.

2. The focus of this article

The issue of equal recognition before the law affects most directly those who are at risk of having their legal capacity denied, including people with intellectual disability, people with mental health issues, as well as those with profound and multiple disabilities, people with severe brain injury or with advanced dementia, and people in a permanent vegetative state or in a coma. While there are issues that are of common concern for these persons, there are also many divergences. Some divergences are brought about simply by virtue of the fact that no one human being is like any other – the same disability will affect different people in different ways, both physiologically and because of the different social and personal situations that each person lives in. However, there are also issues that have particular resonance for people with similar conditions or types of impairment. This paper focuses on the issues that are of most concern for people with intellectual disability, while attending to the fact that different individuals with intellectual disability have different concerns.

Both supported and substitute decision-making can take many forms. The latter includes inter- diction, incapacitation, plenary or partial guardianship, or any other form of 'court-authorised power to take decisions on behalf of the person' (Fundamental Rights Agency, 2013, p. 9). The former refers to practices where a support person enables a disabled person to take decisions through explaining relevant issues or, if necessary, interpreting the preferences of the individual 'to exercise their legal capacity to the greatest extent possible, by explaining issues and, where necessary, interpreting the preferences of the individual' (p. 9). For the sake of clarity, the terms supported decision-making and substitute decision-making will be used throughout this paper to refer to these two types of practices.

3. The right to recognition

As Dinerstein (2012: 8) comments, the CRPD uses 'deceptively simple' language to assert the right to legal capacity of all disabled persons. Article 12 states that:

> - states parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law;
>
> - states parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

In their General Comment about Article 12, the Committee on the Rights of Persons with Disabilities (2014a) (henceforth referred to as the Committee) affirm equal recognition as a basic right for disabled people, one that is based on the principles of autonomy, independence, and full and effective participation in the community, as set out in Article 3 of the CRPD. The General Comment pulls no punches in asserting the inalienability of the right of disabled persons to exercise their legal capacity in all circumstances and with no exceptions.

The CRPD recognizes that not all disabled people can exercise their legal capacity unsupported in all circumstances. In fact, Article 12.3 obliges States Parties to 'take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity'. And as the General Comment makes it amply clear:

> All forms of support in the exercise of legal capacity, including more intensive forms of support, must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests (Committee on the Rights of Persons with Disabilities, 2014b, p. 7).

In the General Comment, the Committee also calls unreservedly for the abolition of substitute decision-making legislation and practices and for the institution of supported decision-making laws and mechanisms in their stead. However, the Committee notes that not much progress has been made by most States Parties in adopting supported decision-making legislation, in line with the requirements of Article 12.

The reason for this lack of progress can be interpreted in one of two ways. It can be argued that Article 12's right to recognition for all disabled persons is unrealistic. The Committee's position can thus be seen as setting States Parties up to fall short of what will always remain an unattainable ideal. On the other hand, it can be argued that it is misconceptions about the abilities of people with intellectual disability and about the nature of autonomy and of decision-making processes that lead to failure in people with intellectual disability being recognised as persons before the law. At this stage, I feel I should declare myself as agreeing with this second argument. That said, I also feel it is important to understand why legal capacity is not seen as being achievable for all, if one is to find ways of making Article 12 a reality for all disabled persons. The reasons why making this reality happen is important are set out in the next section.

4. Article12 in the wider context of the CRPD

Recognition as persons before the law is fundamental for enabling all disabled persons to enjoy all the rights enshrined in the CRPD. In fact, the General Comment observes that '[l]egal capacity is indispensable for the exercise of civil, political, economic, social and cultural rights' (p. 9). Therefore, disabled people are denied the specific rights embodied in the CRPD itself if they do not enjoy equal recognition before the law. The General Comment also links Article 12 directly with the General Prin- ciples of the CRPD set out in Article 3(a) 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'.

Furthermore, as Mannan, MacLachlan, McVeigh, and the EquitAble Consortium (2012) point out, the first nine Articles of the CRPD, which set out the concepts and principles of the Convention are the basis for the interpretation of the other articles, including of course Article 12. The fundamental principle underlying these articles is that for disabled people to enjoy their rights, to be able to fully participate in an inclusive society, and to enjoy equal opportunities, accessibility and non-discrimination, they need to have their autonomy respected.

Having this respect means that they are free to make their own choices, and act independently. Significantly, Article 3(a) links individual autonomy with the inherent dignity of disabled persons. Even more significantly, the purpose of the whole Convention is 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity' (Article 1), in line with the Universal Declaration of Human Rights (United Nations, 1948) which starts by recognizing that inherent dignity and human rights are 'the foundation of freedom, justice and peace in the world' (p. 1).

As Mladenov (2013) states, the CRPD presents a "new understanding of disabled people's way of being [which]. . . is clearly informed by an emphasis on 'individual autonomy"' (p. 73). This under- standing is evident in several articles throughout the CRPD. Mannan et al. (2012) note that one of the core concepts in the Convention is that of individualised services. As Article 19 states, disabled people's right to live independently and be included in the community comprises their right 'to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement' (Article 19a). Likewise, the follow- ing article does not simply state that disabled people have a right to personal mobility but that they have a right to the facilitation of their mobility 'in the manner and at the time of their choice' [Article 20 (a)].

Furthermore, one finds Article 14 (Liberty and security of the person), Article 21 (Freedom of expression and opinion, and access to information), and Article 22 (Respect for privacy) – three articles which further bolster disabled people's right to self-determination and autonomy. This right they can exercise in their private lives, as seen above, and also in public life especially as asserted in Article 29 (Partici- pation in political and public life) and Article 30 (Participation in cultural life, recreation, leisure and sport). Arstein-Kerslake and

Flynn (2016) also link Article 12 with the right not to be discriminated against (set out in Article 5), the right to marry and to found a family (Article 23), protecting the per- son's integrity (Article 17) and health-related rights (Article 25). Finally, it is important to note that the CRPD also gives disabled people the right to have a say about the implementation and monitoring of the CRPD itself, especially through the obligations it places on States Parties in Articles 4.3 (General obligations) and 33.3 (National implementation and monitoring).

The equal recognition before the law of all disabled people, as asserted in Article 12, can thus be seen as the bedrock of the realisation, at an individual and societal level, of the rights set out in the CRPD. Without equal recognition of legal capacity, a disabled person cannot enjoy these rights fully since they are denied their capacity to act (European Foundation Centre, 2010). And without that capacity, they cannot take for themselves decisions that impact their lives, for example regarding health, work, education, intimate relationships and their place of residence (Glen, 2013; United Nations, 2007).

5. Progressive realisation of equal recognition

The rights that are affirmed in the CRPD are not an end in themselves but a means to an end – that of enabling disabled people to participate fully in society, on an equal basis with others, on their own terms. Thus, the realization of the rights set out in the CRPD can be seen as a process. In fact, the Convention allows for the progressive realisation of economic, social and cultural rights [Article 4 (2) General Obligations], but not for fundamental rights. Furthermore, in the General Comment the Committee asserts that:

> "Progressive realization" (art. 4, para. 2) does not apply to the provisions of Article 12. Upon ratifying the Convention, States parties must immediately begin taking steps towards the realization of the rights provided for in Article 12. (para 30, pp. 7–8)

However, it seems that States Parties are only progressively realising what Article 12 entails, and only a few of them are doing that (European Foundation Centre, 2010). Canada (especially British Columbia) is taken by many as a leader in the enactment of supported decision-making legislation (Devi, 2013). As reported by Boundy and Fleischner (2013), other countries that have adopted such legislation include Sweden, Australia, Germany, Scotland, England and Ireland. In other countries, such as Mexico, 'decision making for people with intellectual disabilities is an emerging topic of discussion' [Inclusion International (2014), p. 10]. There is no one single model of supported decision-making.[1] Lewis (2011) observes that "[t]he term 'supported decision-making' has come to mean that

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[1] For examples of different models of supported decision-making legislation and structures see, among others: Blanck and Martinis (2015); European Foundation Centre (2010); Fundamental Rights Agency (2013); Glen (2015). In their submissions to the Draft General Comment on Article 12, ACT Disability, Aged and Carer Advocacy Service suggest the use of what they term 'subjective decision-making' which is made on behalf of persons in specific circumstances using a will and preferences rather than a best interest approach. The Australian Human Rights Commission suggests a similar approach which they term 'facilitated decision-making'. These two submissions are available at http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx.

which substituted decision-making is not" (p. 704). And, as the same author says further, if the latter 'amounts to civil death, implementation of art. 12 of the CRPD enables civil life' (Lewis, 2011, p. 705).

Civil death is unfortunately still a reality or a potential reality for many people with intellectual disability. There is therefore a pronounced misalignment between the inalienability of the right of universal recognition set out in Article 12 and the General Comment on the one hand, and the lived reality of many people with intellectual disability on the other. In its submission to the Draft Comment, the Australian Human Rights Commission (2014) 'recommends that the Committee include consider- ation of the nature of immediate obligations and the doctrine of progressive realisation, particularly where a State Party is genuinely not able to provide the full supports that are required.' (p. 8, bold in the original). Indeed, as seen in the quotation from the General Comment above, what the Committee itself demands is for States parties 'to begin taking steps towards the realization' of Article 12. But it seems that, with some exceptions, not even these steps are being taken. The current state of affairs is explored further in the next section.

6. States Parties' im(position) on Article 12

Significantly, even those countries, which have supported decision-making legislation in place have retained the possibility of using substitute decision-making for disabled people, imposing their own positions on the matter. In fact, Article 12 is being more often honoured in the breach than in the observance. This situation comes out clearly in the interpretations and reservations made by various governments upon ratification of the CRPD. Taking into account what is stated in these documents is important because, as Mladenov (2013) points out, the Vienna Convention on the Law of Treaties states that the interpretation of the text of treaties should take into consideration related official documentation as well as debates prior to the adoption of the treaty.

In fact, Article 12 was hotly debated even while the text of the CRPD was being negotiated, prior to its adoption in 2006 by the United Nations General Assembly. Several authors attest to the controversy surrounding the insistence of disabled people's organisations that equal recognition before the law should be given to all disabled people. Dinerstein (2012) states that it was Article 12 that gave rise to most debate and most controversy during negotiations, with Lewis (2011) describing legal capacity as having been 'fiercely negotiated by the Ad Hoc Committee' set up by the United Nations to draw up the text of the CRPD (p. 703). For Inclusion International, one of the non-governmental organisations who fought hard not to include a direct reference to substitute decision-making in Article 12, this was one of the most difficult articles to negotiate (Inclusion International, 2014). As seen later, that reference would have made it easier to maintain the status quo and the fact that these organisations had to resist its inclusion is a reflection of how challenging it is to achieve the acceptance of universal recognition of all persons before the law.

Despite the fact that the text for Article 12 was eventually agreed upon and adopted as part of the CRPD, the controversies surrounding this article have persisted with the way it is interpreted (Devi, Bickenbach, & Stucki, 2011; European Foundation Centre, 2010). The biggest debates focus on whether or not Article 12 can be interpreted as allowing substitute decision-making legislation to remain in place (Devi, 2013), and whether it is at all realistic to remove such legislation.[2]

On the Declarations and Reservations webpage of the United Nations Treaty Collection (2017),[3] only Australia, Canada, the Netherlands, and Norway mention supported-decision making in the declarations they made upon ratifying the CRPD. Significantly, all four countries specifically interpret Article 12 as allowing also for substitute decision-making, even if as a last resort. To take one example, Norway's declaration reads as follows:

Norway recognises that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. Norway also recognizes its obligations to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. Furthermore, Norway declares its understanding that the Convention allows for the withdrawal of legal capacity or support in exercising legal capacity, and/or compulsory guardianship, in cases where such measures are necessary, as a last resort and subject to safeguards.

Another six countries (Estonia, France, Georgia, Poland, Singapore and Venezuela) specifically interpret Article 12 as allowing existing substitute-decision making legislation to remain in place. Estonia's declaration is reflective of the others:

> The Republic of Estonia interprets article 12 of the Convention as it does not forbid to restrict a person's active legal capacity, when such need arises from the person's ability to understand and direct his or her actions. In restricting the rights of the persons with restricted active legal capacity the Republic of Estonia acts according to its domestic laws.

Iran, Brunei Darussalam and Kuwai maintain precedence of their respective national laws where there is incompatibility with the CRPD, with Kuwait singling out Article 12 as one of the articles where precedence of the country's own legislation applies. Several countries objected to these declarations, including Mexico, which pointed out the fact that the Vienna Treaty prohibits such stances. On its part, in 2011, the United Kingdom withdrew the reservation it had made regarding putting in place a system for reviewing 'all measures that relate to the exercise of legal capacity' (Article 12.4). Egypt, in its declaration, distinguishes between having the capacity to acquire rights and having the capacity to act, with the former but not the latter being considered universal. The same position is adopted by Iraq and by (pre civil war) Syria (Iraq, 2006).

In March 2017, out of the 172 United Nations Member States which had ratified the CRPD, only the 17 countries mentioned above had made a direct reference to Article 12, and none of them committed themselves to fully replacing substitute with supported-decision making legislation. Of the remaining 155 ratifying Member States, some deal with the issue of supported decision-making in Article 12 in their State reports (Committee 2017). For example, Argentina acknowledges that its substitute decision-making legislation does not meet the required standards, while Austria refers to criticism made by civil society

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[2] See some of the submissions to the Draft General Comment on Article 12 available at http://www.ohchr.org/EN/ HRBodies/CRPD/Pages/DGCArticles12And9.aspx. These submissions are also discussed later in this paper.

[3] The citations and quotations in the rest of this section are taken from this website.

organisations about this type of legislation, and Mexico describes Article 12 as posing ‘challenges which remain to be tackled in the future.’ In its state report, Nepal refers to a draft bill that recognizes the legal capacity of all disabled persons and that invalidates legislation that denies this capacity. In the case of Bulgaria and Latvia, since submitting their reports, they have implemented small-scale projects that promote supported decision-making (Empower people with intellectual dis- abilities, 2017; Zelda, 2017). Inclusion International (2014) also refers to several countries, including the Czech Republic, Colombia, Mexico and Ecuador that are developing supported decision-making. But most countries that have ratified the CRPD seem to be politely ignoring the requirement of repeal- ing substitute decision-making and replacing it with supported decision-making as stipulated clearly by the Committee in its General Comment.

It is no wonder then that the Committee notes that ‘there has been a general failure to understand that the human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making’ (Comment para. 3).

7. The paradigm shift

The need to move from the paradigm of substitute to that of supported decision-making, which is noted by the Committee, is also described in the General Comment as a move from the ‘best interests’ to the ‘will and preferences’ paradigm ‘to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others’ (Comment para. 21).

Several authors speak of the paradigm shift required by the CRPD in general and by Article 12 in particular (Bach & Kerzner, 2010; Bartlett, 2012; European Foundation Centre, 2010; Quinn, 2010, 2011). The human rights lawyer Gerald Quinn (2011) calls Article 12 ‘the lightening (sic) rod for the paradigm shift’ (p. 5) but, as he quips, there have been so many people ‘sprouting platitudes about the “paradigm shift”’ that on hearing it mentioned once again one ‘might be inclined toward random acts of violence!’ (p. 4).

In his paper, Quinn refers to violence of the ideological sort. When contrasting the views of advo- cates of supported and substitute decision-making he speaks of ‘a war of ideas, a clash of creeds’ (p. 4) and of revolutions and counter-revolutions. His call to arms involves a rethinking of our concept of personhood – one that does not de facto exclude those who have an intellectual disability, among others. It also involves repositioning the debate about Article 12 within the larger debate about citizenship rights, arguing that ‘[i]f it continues to be a disability-specific debate it will be dragged down by decades if not centuries of baggage’ (Quinn, 2011, p. 21).

Quinn’s argument is a very valid one and his suggested approach one that should certainly be taken up. However, it needs to be complemented by an understanding of the effect which this centuries-long baggage has had on the way support for people with intellectual disability is seen not as a means of empowerment and of promoting autonomy and self-determination but as a sign of deficit and lack of ability.

8. Of rules and their exceptions

A further effect of that baggage is that it is substitute decision-making and denial of legal capacity rights that are mostly the rule and so an insistence on having only supported decision-making leg- islation and practices in place is a challenge to the status quo, to the way things are, to what is seen as the natural and obvious way of dealing with difficulties in the exercise of one's legal capacity. It is therefore not just a question of substitute decision-making still having the upper hand over supported decision-making. It is that the beliefs and ideas about the nature of intellectual disability on which the former is based are so deeply ingrained that whatever proponents of the supported decision- making paradigm say is always going to be interpreted within the ingrained logic of the substitute decision-making paradigm.

It is as if society functions on two levels: a more or less laissez faire society for most people, including those with physical or sensory impairments, who have the capacity to exercise free will and shape their own destiny (Quinn, 2011); and a hierarchical and strictly determined society for people with intellectual disability, among others, whose lives and life decisions are determined by others because of difficulties to do so by themselves. The existence of these two levels is not, in the eyes of many, seen as a contradiction. Restrictions to legal capacity are assumed to be a necessary, even natural, response when the disabled person is seen as being in need of protection because of an inability of the person to manage their own affairs without support. Thus, Poland's interpretative declaration refers to the application of incapacitation 'when a person suffering from a mental illness, mental disability or other mental disorder is unable to control his or her conduct' (United Nations Treaty Collection, 2017).

As noted earlier, it is Australia, Canada, the Netherlands, and Norway that so far have implemented or come close to implementing supported decision-making but even they speak of exceptions and last resorts. The problem with exceptions is that they leave the door open to the rule (in this case the rule of implementing support decision-making) not being followed. There is a danger that the amount of situations that are deemed as exceptions is so high that using substitute decision-making remains unexceptional, and that it is the supposed rule of supported decision-making that remains the exception. The key point here is that the situation remains so, that substitute decision-making simply retains the status quo as it has been for decades, even centuries. What is presented in these declarations as being treated as exceptional is what is currently unexceptional, because it is legally recognized supported decision-making practices that are still very much the exception. Substitute decision-making mechanisms are the default mode in most countries.

Consequently, advocates of incapacitation, interdiction, guardianship, and other forms of substitute decision-making need only maintain things as they are. These practices are predicated on paternalistic structures that still largely dominate the lives of people of intellectual disability and attitudes that are based on a deficit-model of intellectual disability. The dispositions that arise from these practices and attitudes are then transposed into the interpretations of Article 12 and into the ways in which it is implemented.

9. Taking stock of the way things are

Similarly to substitute decision-making, supported decision-making mechanisms are based on the acknowledgement that some disabled persons, including people with intellectual disability, need sup- port in making choices and taking decisions. This need is in fact also acknowledged in subarticles 3 and 4 of Article 12. Where the two mechanisms part company is the conclusion that they arrive at after making this acknowledgement. Unlike substitute decision-making, supported decision-making does not equate the need for support in making decisions with an inability to take those decisions. More importantly, it does not see this need as a reason for taking away a person's legal capacity, nor does it consider it contradictory for a person to require support in taking decisions and yet retain their autonomy. Needless to say, this is not a position that is endorsed by all and sundry. It is therefore important to take stock of the way things are at different levels. Four levels are being considered here: the supranational, the national, the organisational and the individual.

At a supranational level, everything can be said to be in place. Article 12 grants recognition as persons before the law to all disabled people, regardless of their impairment. The Committee's General Comment reinforces the interpretation of this Article as granting legal capacity to all, thus requiring supported decision-making to be put in place and repealing all substitute decision-making legislation. The Committee's position on this issue is further reinforced by the fact that complaints submitted to it under the Optional Protocol by disabled persons whose right to legal capacity has been removed from them under substitute decision-making legislation in their own country are still considered since the Committee does not recognise the removal of that right.[4]

As seen above, at a national level, we find just a handful of countries with legislation that recognizes supported decision-making or which have declared their commitment towards such legislation. The Representation Agreement Act in British Columbia in Canada is a model of such legislation. However, the jurisdictions, which have adopted, or are considering adopting, supported decision-making legislation remain relatively few. And the possibility of imposing substitute decision-makers in 'exceptional' circumstances is retained. Examples of such circumstances are set out in some of the submissions made in response to the Draft General Comment (Committee on the Rights of Persons with Disabilities, 2014b). Submissions made by the French, German and Danish governments refer to people who are in a coma or a permanent vegetative state, and who have locked-in syndrome, advanced senile dementia, or profound intellectual disability.[5] For the majority of jurisdictions, substitute decision-making legislation remains in place. And, as Clough (2015) argues, this type of legislation is embedded within a medical model view of intellectual disability.

Then, at an organizational level, we find initiatives that promote supported decision-making by developing and promoting practices that enhance the decision-making skills of people with intellectual disability, such as the above-mentioned projects in Eastern Europe and

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[4] See for example the case of the six persons with intellectual disability from Hungary who protested the removal of their right to vote on the grounds of lack of legal capacity. (Available from http://juris.ohchr.org/Search/Details/1988).

[5] Interestingly, Bach (2017) deals with supported decision-making precisely for persons with profound intellectual disability.

Latin America, as well as schemes that provide support in decision-making in some countries, including Germany, Sweden and the United Kingdom, Canada and Australia (Boundy & Fleischner, 2013; Fundamental Rights Agency, 2013). The schemes referred to include practices that directly or indirectly implement the principles of supported decision-making such as circles of support (Etmanski, 2004; Gross, Wallace, Blue-Banning, Summers, & Turnbull, 2012); and person-centred planning (O'Brien & O'Brien, 2004; Ratti et al., 2016). These practices emanate from positions that challenge the assumption of immanent deficits which must be compensated for by practices that exert control over the lives of people with intellectual disability and focus instead on structural barriers that prevent them from exercising such control, and are therefore embedded in the social model of disability (Clough, 2015).

It is interesting to note that, of the 69 organisations that submitted responses to the Draft General Comment, 67 support the retention of legal capacity by all disabled persons and the introduction of legally recognized supported decision-making mechanisms and practices. The focus of these sub- missions is on how such mechanisms should operate and the issues that need to be dealt with. Only two organisations (FUTUPEMA in Spain and the Cambridge Intellectual & Developmental Disabilities Research Group) advocate for the retention of substitute decision-making for people with intellectual disability (Committee on the Rights of Persons with Disabilities, 2014b).

The existence of positions and practices that favour and promote supported decision-making, encouraging as they are, do not tell the whole story. In fact, a focus on these initiatives and the fact that submissions to the Draft Comment were overwhelmingly in favour of supported decision-making can provide a misleadingly positive picture since, at an individual level, there is still very little legal recognition of supported decision-making processes. There may be increasingly more opportunities for people with intellectual disability to make their voices heard and to exercise choice and control in their lives. But these opportunities remain dispersed and limited. Ratti et al. (2016), for example, comment on the limited effectiveness for person-centred planning to bring about change in the lives of people with intellectual disability, while Power (2013) highlights the complexities of working with circles of support. Werner (2012) highlights, among other factors, the need for people with intellectual disability to develop the skills related to taking decisions for themselves. These and other difficulties do not augur well for the enactment of supported decision-making legislation and its enactment in related practices.

For the majority of jurisdictions, substitute decision-

However, the difficulties encountered in making such practices a reality in the daily lives of people with intellectual disability can be overcome by not only seeking to improve the practices themselves but, perhaps more importantly, by addressing external factors that inhibit their success and more widespread use. For example, in their submission to the Draft Comment, Advocacy for Inclusion note that the lack of recognition of legal capacity is not only imposed formally through substitute decision- making legislation but also informally through negative sociocultural constructions of the abilities of disabled persons. Through these constructions, withholding legal capacity is seen as an inevitable outcome of providing safeguards and protection, and the need for support is placed at odds with the retention of legal capacity. Other obstacles arise from a concept of personhood that is directly linked to cognitive functioning which automatically denies the moral (and therefore also legal) status of being a person to those whose difficulties lie precisely in cognitive processes (Flynn & Arstein-Kerslake, 2014). Even worse, such purported protection stems from 'a failure to recognize their humanity and personhood' (Inclusion International, 2014, p. 19).

Thus, positions and practices that focus on the abilities of persons with intellectual disability and are in favour of supported decision-making are still subordinated to positions and practices which are deficit-based, and which take the need for substitute decision-making legislation and practices as a given and actually equates it with the safeguarding of rights. This situation can only be reversed when recognition of legal capacity is enshrined in domestic laws, and therefore at the national level. As seen above, unfortunately this is the level where there seems to be the most resistance to removing sub- stitute decision-making. As Arstein-Kerslake and Flynn (2016) state, 'bring[ing] domestic legislative frameworks into conformity with Article 12 CRPD will inevitably be long and complex' (p. 484).

10. The case for supported decision-making

Arguments for and against supported and substitute decision-making are often bolstered by references to particular individuals whose situation illustrates either the necessity of retaining the safeguards afforded by substitute decision-making or the necessity of removing it not only to ensure the equal recognition of all disabled persons before the law but also to safeguard against abuses that can be perpetrated by those in whom the law invests the power to decide on behalf of a disabled per- son. It is easy to dismiss these arguments as being built on anecdotal evidence of individual situations. After all, exceptions have never made rules. On the other hand, one can argue that it is precisely the individual differences of each situation that needs to be focused on. These differences are inevitable simply because of the multiplicity of factors that impinge on each disabled individual's life: the nature, type and severity of the impairment; the life history of the individual; the amount of support that each person finds in their life; their family background; the social class and ethnic group they belong to; and the history, culture and current situation of the country they live in among other factors.

Substitute decision-making practices do not, and probably cannot, take these differences into account. These practices stem from generic assumptions underlined by the deficit-model of disability and are then applied to individual situations. Supported decision-making, on the other hand, starts with the individual and works with them. Supported decision-making allows for the recognition of the individual differences present in the situations of these persons and for the recognition of the different factors that can help or hinder the ability of a person to exercise their legal capacity. Furthermore, it allows for the recognition that each individual's circumstances are exceptional, simply because no two people are alike and no two situations the same. There can therefore be no generalities, only exceptions.

Each person's situation should be treated as exceptional given that, on a day-to-day basis, persons with intellectual disability find themselves in situations where their legal capacity is recognized and others where it is not. Significantly, the same person can easily experience both types of situation and receive contradictory messages about their own capacity to make choices, express views and take decisions at different levels and in different contexts. Furthermore, a person with intellectual disability can be in a situation where they are not formally placed within the guardianship system but effectively have their life controlled by someone else (Fundamental Rights Agency, 2013). Conversely, a person with intellectual disability may have been formally assigned a guardian who then proceeds to involve the person in decisions and fully respect their will and preferences. These contradictory situations arise from the different responses to the different abilities and support needs experienced by different people with intellectual disability. And those responses are contingent on the disposition of the people who are closely involved in the disabled person's life. Supported decision-making legislation allows for the recognition of these complexities and for the ability to respond to them accordingly. Most importantly, it allows for the legal recognition of decisions taken by the person with intellectual disability in different situations by different means.

Perhaps the single most forceful argument against substitute decision-making is that, once it is imposed on a person, there is no direct recourse for that person under national laws. If they want to appeal the decision, or if they want to take legal action because of abuse perpetrated by their supposed protectors, they cannot take the case themselves to their own country's courts of law, because it is those very courts that have taken away their right to exercise their legal capacity and represent themselves.[6] Having your legal capacity taken away from you and a substitute decision-maker assigned to act on your behalf is one way of crossing the Rubicon – there is no going back from it. On the other hand, supported decision-making, whatever its complexities and imperfections, is a paradigm that allows for adjustments and changes to be made which, crucially, can be directed by the person with intellectual disability themselves.

11. Conclusion: taking exception to the way things are

That supported decision-making practices already exist is clear from, among others, some of the literature cited in this article. But, except in a handful of jurisdictions where supported decision- making is legally recognised, such practices remain private arrangements that are put in place by persons with intellectual disability and those who support them in their daily lives. Bach (2017) points out the value of these practices and the importance of continuing to develop them as a means of challenging the legal status quo where the official recognition of their validity remains the exception rather than the rule. The ad hoc nature and complexity of supported decision-making arrangements should be considered a strength, because these ensure that arrangements made truly suit the support needs of each individual with intellectual disability. Perhaps it is when such practices stop being an exception and become the rule in the everyday lives of people with intellectual disability, when they simply become the way things are done, that the rights enshrined in Article 12 of

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[6] The cause célèbre in this regard is that of Rusi Stanev, the Bulgarian man with mental health issues who, despite having his right to recognition as a person before the law upheld by the European Court of Human Rights, could not demand the court in his country to respect the ECHR's ruling precisely because he was not recognised as a person before his own country's court. National law therefore trumped a ruling taken by a supranational legal body. Perhaps the most tragic aspect of Stanev's story is that he died in 2017 without ever having his guardianship revoked. For more about his case see http://www.mdac.info/en/news/tribute-rusi-stanev.

the CRPD will truly become a reality for people with intellectual disability.

Bartlett (2012) states that moving from substitute to supported decision making legislation would be an ‘extraordinary change... the effects on domestic law would be profound’ (p. 753). A pro- found effect would also be felt by people with intellectual disability, not only because their right to retaining their legal capacity and their right to equal recognition as persons before the law would be upheld, but also because they would gain legal recognition of the methods that they already use to make choices and take decisions. It would mean having legal status conferred on informal supported decision-making arrangements which many persons with intellectual disability and the people who support them in their everyday lives have evolved to suit the needs of each person. And it would also mean that for people with intellectual disability to exercise their legal capacity, they can be supported by adults who take that capacity as a given rather than something that is questioned and needs to be assessed. What matters in the end is that what happens on an individual and daily basis in the life of each and every person with intellectual disability is considered to be valid in the eyes of the law. It is in this way that we can move away not only from using terms like Idiots but also from all the deficit-based misconceptions inherent in the term and its many synonyms.

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