The Universal Right to Legal Capacity-Clearing the Haze

Peer-reviewed author version

OPGENHAFFEN, Tim (2022) The Universal Right to Legal Capacity-Clearing the Haze. In: Human rights law review, 22 (3) (Art N° ngac021).

DOI: 10.1093/hrlr/ngac021
Handle: http://hdl.handle.net/1942/38134

The universal right to legal capacity. Clearing the haze

Tim Opgenhaffen

Institute for Social Law, KU Leuven, Leuven, Belgium

CORe, Hasselt University, Hasselt, Belgium

ABSTRACT

The right to legal capacity (Article 12 CRPD) is the most contested realisation of the UN Convention on the Rights of Persons with Disabilities. If implemented, it would revolutionise the position of persons with psychosocial disabilities, intellectual disabilities and other cognitive conditions. Yet its implementation has been hindered by conceptual misunderstandings and by a lack of distinction between the key questions in the debate. This contribution first demonstrates that advocates and opponents apply 'substitute decision-making' and 'legal capacity' differently, leading to different expectations. Second, it substantiates that once all the concepts are understood correctly, three distinct questions underpin the interpretation of article 12 CRPD: [1] what makes a person's will reliable? [2] What is good support? And [3] how can such a reliable will be diverged from, given other interests? Instead of giving *the* answers, this contribution brings consistency to the debate and proposes a structured pathways for a future approach to legal capacity.

KEYWORDS: legal capacity, psychosocial disability, intellectual disability, CRPD, substitute decision-making

1. INTRODUCTION

The universal right to legal capacity (article 12 CRPD) is the most important and most contested realisation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). According to the Committee on the Rights of Persons with Disabilities (CCRPD), mental incapacity is no reason for legal incapacity, best interests are not a valid standard and substitute decision-making is prohibited. If fully implemented, this would revolutionise the legal position of persons with psychosocial disabilities, intellectual disabilities and other cognitive conditions (hereinafter: disabilities). Even more: since legal capacity should be considered universal, it will have an impact on every person, with and without disabilities.[1]

However, its implementation has been questioned. The one-sided focus on positive action without any possibility to interfere is considered unachievable and even if it could be achieved, undesirable. Despite all the efforts to bring about a so-called 'paradigm shift', its implementation has stagnated or led to only minor legal changes that reflect the old paradigm, rather than the new one.

A haze of ambiguity hinders the debate on article 12 CRPD and ultimately renders its implementation impossible. The current contribution substantiates that this haze has a double cause. First, there is a language barrier between the traditional approach and the CRPD approach to legal capacity. To some extent both approaches use the same words to say something different. Second, conceptually different aspects of the universal right to legal capacity are tackled simultaneously, leading to false expectations.

[1] Dhanda, 'Universal Legal Capacity as a Universal Human Right' in Dudley, Silove and Gale (eds), *Mental Health and Human Rights. Vision, Courage and Practice* (2012).

This contribution aims to clear the haze by first demonstrating that the opposition between a traditional approach and CRPD approach distracts from a shared goal and that to a certain extent terminological misunderstandings lie at the basis of it. If understood correctly, the universal right to legal capacity is not far-fetched but feels familiar: if a person's will is reliable, best interests are not an argument to put this aside only because of a disability. However, that it is not far-fetched does not mean that the right to universal legal capacity is not controversial. Second, this contribution substantiates that once all the concepts are understood correctly, future research should strive for a sound answer to three distinct (though interrelated) questions: [1] What makes a person's will reliable (and how do we determine that reliable will in a disability-neutral way)? [2] What is good support (and how do we offer it in a disability-neutral way)? And [3] how can such a reliable will be diverged from, given other interests (and how do we do so in a disability-neutral way)? Instead of giving *the* answers, this contribution brings consistency to the debate and proposes a structured pathways for a future approach to legal capacity.

2. OPPOSITION OR LANGUAGE BARRIER?

A. Two seemingly opposed approaches

For a long time, legal incapacity, guardianship and substitute decision-making — as well as *parens patriae* interventions such as involuntary commitment — were considered appropriate responses to a disability.[2] Persons with disabilities as well as others had the

[2] Lewis, 'Legal Capacity in Human Rights Law' (PhD diss, Leiden University, 2015) at 44; Devi, Bickenbach, and Stucki, 'Moving Towards Substituted or Supported Decision Making? Article 12 of the Convention on the Rights of Persons with Disabilities', *European Journal of Disability Research* 5, no. 4 (2011) at 257-58.

right to be protected against the adverse consequences of a disability.[3] However, attention has gradually started to be paid to the restricting nature of these responses, as they are not merely protective measures. They constitute potentially unjustifiable interference in the private life of a person with a disability. Legal incapacitation based on a disability (rather than on what a person is able to do) and plenary guardianship (rather than a tailor-made approach) have been questioned. For example, in Europe, one breakthrough is recommendation number R(99)4, in which the Committee of Ministers of the Council of Europe set out four key principles:

(1) Legal incapacity is a restriction of freedom *and* a protection against unjustified interference by third parties.
(2) Legal incapacity is justified if it is based on a lack of mental capacity.
(3) Mental capacity refers to cognitive competencies that are assessed as specifically and gradually as possible.
(4) Legal incapacity shall be as short as possible and shall be aimed at self-fulfilment.

These four key principles in Recommendation R(99)4 are exemplary for what in this contribution will be called the traditional human rights approach to legal capacity. As it stands today, in this approach any judgement by a third party that results in the loss of legal capacity constitutes an interference with the right to private life and therefore needs

[3] European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) on Moldova, 12 January 2012, CPT/Inf(2012)3, at para 159; CPT on Turkey, 28 May 2009, CPT/Inf(2009)17, at para 80; Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment on Mission to Ghana, 5 March 2014, A/HRC/25/60/Add.1, at para 79; ECtHR on *Stanev v Bulgaria* Application No 36760/06, Merits and Just Satisfaction, 17 January 2012, at para 240; Human Rights Committee (HRC) in *Fijalkowska v Poland* (1061/2002), Views, CCPR/C/84/D/1061/2002, at para 8.3; See also HRC, Concluding observations regarding the Czech Republic, 9 August 2007, CCPR/C/CZE/CO/2, at para 14.

to be justifiable. It should however be noted that the margin of appreciation remains wide and that, in practice, an interference is often easily justified. The quality of the procedure and legal remedies seem to be more predominant assessment criteria in this respect. Consequently, the traditional human rights approach to legal incapacity, guardianship, substitute decision-making and *parens patriae* interventions is pragmatic. It starts off from the *need* to protect some persons with disabilities and others from the consequences of lacking the ability to make certain decisions. The extent to which a person is able to understand and appreciate the consequences of such decisions is relevant.[4]

This approach is under pressure from the right to equal recognition before the law in article 12 CRPD, which requires member states to support and safeguard legal capacity. Persons with disabilities are recognised by law (first paragraph) and have and can exercise the same rights in all aspects of life on an equal basis with others (second and fifth paragraphs). A disability does not justify legal incapacity. In addition, the member states should offer protection against abuse by third parties (fourth paragraph) and should provide access to support (third paragraph).

At first glance, this might suggest that the CRPD adds a layer to the already existing human rights approach. However, the CCRPD suggests something radically new. It questions the link between mental and legal capacity, rejects that a person's best

[4] ECtHR in *Shtukaturov v Russia* Application No 44009/05, Merits, 27 March 2008, at para 95; *Lashin v Russia* Application No 33117/02, Merits and Just Satisfaction, 22 January 2003, at para 97; *H.F. v Slovakia* Application No. 54797/00, Merits and Just Satisfaction, 8 November 2005, at para 39-41; *Stanev v Bulgaria* Application No 36760/06, Merits and Just Satisfaction, 17 January 2012, at para 244; *A.M. v Finland* Application No 53251/13, Merits and Just Satisfaction, 27 March 2017, at para 88; *Sýkora v Czech Republic* Application No 23419/07, Merits and Just Satisfaction, 22 November 2012, at para 102; Commissioner for Human Rights of the Council of Europe (Comm.DH) in Issue Paper, 20 October 2008, CommDH/IssuePaper(2008)2, at para 11; Also see CPT on Republic of Macedonia, 25 January 2012, CPT/Inf(2012)4, at para 146.

interests could overrule their will and preferences, and is opposed to all substitute decision-making.

(1) Legal capacity must not be denied on the basis of mental capacity. It is not only discriminatory to deny legal capacity directly because of a disability (status approach), but also because of a lack of mental capacity (functional approach).[5]

(2) The will and preferences are imperative to decision-making. Since mental capacity is a discriminatory criterion, an alternative approach is required. This approach should focus on the rights, the will and the preferences.[6] To make a valid decision, it is sufficient to have a will and preferences. These will and preferences cannot be deviated from for protection's sake.[7]

(3) All substitute decision-making must be replaced by supported decision-making. Since a lack of mental capacity should not impact a person's legal capacity and since autonomy prevails, substitute decision-making is no longer allowed.[8] To remedy the lack of mental capacity, persons with disabilities should have the right — not the duty — to be supported.[9]

---

[5] CCRPD, General Comment No.1: Equal recognition before the law (art. 12), 19 May 2014, at para 15.

[6] Ibid., at para 16-17; CCRPD, Concluding observations regarding Azerbaijan, 12 May 2014, CRPD/C/AZE/CO/1, at para 27; CCRPD, Concluding observations regarding New Zealand, 31 October 2014, CRPD/C/NZL/CO/1, at para 22; CCRPD, Concluding observations regarding Argentina, 8 October 2012, CRPD/C/ARG/CO/1, at para 19; also by Independent Expert on the Enjoyment of All Human Rights by Older Persons, 24 July 2014, A/HRC/27/46, at para 36.

[7] CCRPD, General Comment No.1: Equal recognition before the law (art. 12), 19 May 2014, at para 14.

[8] Ibid., at para 7 and 16; and CCRPD, Concluding observations regarding Belgium, 28 October 2014, CRPD/C/BEL/CO/1, at para 23; CCPRD concluding observations regarding Croatia, 15 May 2015, CRPD/C/HRV/CO/1, at para 17; Before General Comment No.1 substituted decision making was still deemed justifiable in exceptional cases. See for example Richardson, 'Mental Disabilities and the Law. From Substituted to Supported Decision-Making' (2012) 65 *Current Legal Problems*, 333.

[9] CCRPD, General Comment No.1: Equal recognition before the law (art. 12), 19 May 2014, at para 16.

Although radical, the approach of the CCRPD has not appeared out of the blue, but is closely linked to the social model of disability.[10] In this model, a disability is not an impairment that can be medically assessed and responded to, but results from the inability of society to adapt to it. The social model aims to remove barriers that stand in the way of societal participation. Applied to legal incapacity, not being allowed to make decisions because of a medical condition is thus a societal barrier that should be removed. Accordingly, article 12 CRPD is considered the gateway to social participation.[11]

B. A Babel-like confusion

The interpretation of the CCRPD has received mixed responses.[12] The CCRPD has been accused of deconstructing current legal systems without offering guidelines for their reconstruction.[13] It is hard to see how the principles could be put into effect in practice, what the consequences would be, and when or how a decision could still be substituted to protect a person.[14] As a consequence, the approach of the CCRPD is downplayed by

---

[10] Ibid., at para 5; Council of Europe Committee of Ministers, Recommendation (2014)2 on the Promotion of Human Rights of Older Persons, 19 February 2014, para 12-3 and Council of Europe Parliamentary Assembly, Resolution 1642 (2009) on the Rights for People with Disabilities and their Full and Active Participation in Society, 29 January 2009, at para 7.1.

[11] Arstein-Kerslake and Flynn, 'The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality Before the Law' (2016) 20 *The International Journal of Human Rights* 471, at 485.

[12] Idem. at 473.

[13] Appelbaum, 'Protecting the Rights of Persons With Disabilities: An International Convention and Its Problems' (2016) 67 *Law & Psychiatry* 366, at 367; Freeman et al., 'Reversing Hard Won Victories in the Name of Human Rights. A Critique of the General Comment on Article 12 of the UN Convention of the Rights of Persons with Disabilities' (2015) 2 *Lancet Psychiatry*, 844.

[14] See Comm.DH, *Who Gets to Decide? Right to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities* (2012), at 10; Szmukler, Daw and Callard, 'Mental Health Law and the UN Convention of the Rights of Persons with Disabilities' (2014) 37 *International Journal of Law and Psychiatry*, 245.

many as counterproductive.[15] In addition, the lack of clarity leaves member states unwilling to implement article 12 CRPD.[16] Other human rights bodies do not always follow the committee either. For example, the country reports of the Human Rights Committee and the UN Committee against Torture continue to adopt a more traditional, protection-based approach[17] and the European Court of Human Rights (ECtHR) interprets the CRPD in a narrower way.[18] Even strong supporters of the CRPD, such as the European Commissioner for Human Rights and the Special Rapporteurs at the United Nations, are not always consistent with the CCRPD.[19] However, it often goes unnoticed

[15] Szmukler, 'UN CRPD: equal recognition before the law' (2015) 2 *The Lancet Psychiatry* e29; Freeman et al., supra n 13; Dufour, Hastings and O'Reilly, 'Canada should retain its reservation on the United Nation's Convention on the Rights of Persons with Disabilities' (2018), *The Canadian Journal of Psychiatry* 1.

[16] Stavert, 'Paradigm Shift or Paradigm Paralysis? National Mental Health and Capacity Law and Implementing the CRPD in Scotland' (2018) 7 *Laws* 26.

[17] HRC, Concluding observations regarding the Czech Republic, 9 August 2007, CCPR/C/CZE/CO/2, at para 17; HRC, Concluding observations regarding Lithuania, 31 August 2012, CCPR/C/LTU/CO/3, at para 14; HRC, Concluding observations regarding Bulgaria, 19 August 2011, CCPR/C/BGR/CO/3, at para 17; Also see Subcommittee on prevention of torture, 'The Rights of Persons Institutionalized and Treated Medically without Informed Consent', 26 January 2016, CAT/OP/27/2; Lewis, supra n 2 at 53-55.

[18] For example ECtHR in *R.P. et al.. v United Kingdom* Application No 38245/08, Merits and Just Satisfaction, 9 October 2014 at para 66-67; *Lashin v Russia* Application No. 33117/02, Merits and Just Satisfaction, 22 January 2013, at para 97; *Hadžimejlić et al.. v Bosnia and Herzegovina* Application No's 3427/13, 74569/13 and 7157/14, Merits and Just Satisfaction, 3 November 2015, at para 50.

[19] For example Comm.DH, Visit to Denmark, 24 March 2014, CommDH(2014)4, at para 124; Comm.DH, Visit to the Czech Republic, 21 February 2013, CommDH(2013)1, at para 108; Comm.DH, Visit to Hungary', 16 December 2014, CommDH(2014)21, at para 127; Comm.DH, Visit to Romania, 8 July 2014, CommDH(2014)14 at para 54; Also see Independent Expert on the Enjoyment of All Human Rights by Older Persons, 24 July 2014, A/HRC/27/46, at para 36 and Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, 1 February 2013, A/HRC/22/53, at para 66.

that the debate on legal capacity has to put up with Babel-like confusion.[20] In particular, 'substitute decision-making' and 'legal capacity' are misapprehended.

According to the CCRPD, 'support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making'.[21] When, however, do we speak of a substitute decision? Traditionally, this is the case when a decision is taken by a third party, regardless of whether this corresponds to what the person would have wanted. This is not what is meant by the CCRPD if it aims to abolish all substitute decision-making regimes.[22] According to the CCRPD, a substitute decision-making regime is a system where:

> (i) legal capacity is removed from a person, even if this is in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against their will; and (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective 'best interests' of the person concerned, as opposed to being based on the person's own will and preferences.[23]

In other words, there is *no* substitute decision if the third-party intervention in the sense of article 12 § 4 CRPD corresponds with what the person wants and if the third party makes the same decision the person would have made. The CCRPD only opposes 'unwanted' interventions. For example, the CRPD may not be called on to leave a person in a vegetative state to their own fate, unless they would have wanted this. To go further, that decisions are taken by someone else, in accordance with a person's will and preferences, makes these interventions a form of 'support', rather than 'substitution'.

---

[20] Also suggested in Szmukler, Daw and Callard, supra n 14 at 251.

[21] CCRPD, General Comment No.1: Equal recognition before the law (art. 12), 19 May 2014, at para 17.

[22] Ibid., at para 28.

[23] Ibid., at para 27.

The different usage of the words 'support' and 'substitution' has an impact on what is meant by 'legal capacity'. Although the CCRPD definition of legal capacity is conventional – it is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency)[24] – according to the CCRPD a person still exercises their rights and duties if their will and preferences are voiced by someone else. As a consequence, if for example a medical decision needs to be taken and the person in question is unable to express their will, someone else may make a decision on the basis of the person's previously expressed will and preferences, or on the basis of the best interpretation of what the person in question would have wanted. This does not leave the person in question legally incapacitated. A person is still legally capable of taking decisions if their will and preferences are voiced by someone else. Legal incapacity only arises if a person's will and preferences are not respected.

C. Not far-fetched, though controversial

If a person retains their legal capacity as long as their will and preferences are respected, irrespective of whether the actual decision is voiced by the person or by a third party, a universal right to legal capacity is not far-fetched. It fits the traditional principle of autonomy and extends it to persons with disabilities; a tendency that is also followed by other human rights bodies. [25]

---

[24] Ibid., at para 13.

[25] Council of Europe Committee of Ministers, Recommendation (2006) 5, Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015, 5 April 2006, action lines 9 and 12; Council of Europe Committee of Ministers, Recommendation (2011) 14 on the Participation of Persons with Disabilities in Political and Public Life, 16 November 2011, at para 3-4; and Council of Europe Committee of Ministers, Recommendation (2014) 2 on the Promotion of Human Rights of Older Persons, 19 February 2014.

In essence, irrespective of whether a person is termed 'legally incapacitated' and a decision is called 'substitute', both the adherents of the traditional approach and the adherents of the CRPD could (or at least: should) agree on the logic applied: best interests are not an argument to put aside a reliable will simply because a person has a disability. For the CRPD, this is an implication of the social model of disability. Persons with disabilities are in need of full citizenship,[26] and it is wrong to consider that what they think and feel is irrelevant.[27] However, from a more traditional viewpoint this also should be (and is[28]) a shared concern.

3. THREE DISTINCT BUT INTERRELATED QUESTIONS

In addition to terminological disparity, a second problem arises: the three main questions in the debate are insufficiently distinguished. These questions are: [1] What makes a person's will reliable (and how do we determine that reliable will in a disability-neutral way)? [2] What is good support (and how do we offer it in a disability-neutral way)? And [3] how can such a reliable will be diverged from, given other interests (and how do we do so in a disability-neutral way)? In the answer to each of these questions, the search for a disability-neutral approach plays a central role. After all, the problem with our current protective mechanisms is that they are designed for persons with disabilities. What the

[26] CCRPD, General Comment No.1: Equal recognition before the law (art. 12), 19 May 2014, at para 4; Comm.DH, supra n 14 at 31.

[27] Dhanda, supra n 1 at 184.

[28] Supra, n 25; Council of Europe Parliamentary Assembly, Resolution 1642 (2009) on the Rights for People with Disabilities and their Full and Active Participation in Society, 29 January 2009, at para 7; Comm.DH, supra n 14 at 18; Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, 1 February 2013, A/HRC/22/53, para 65; Independent Expert on the Enjoyment of All Human Rights by Older Persons, 24 July 2014, A/HRC/27/46, at para 36.

CRPD is calling for is a universal system that applies to everyone, and that makes no (in)direct distinction on the grounds of disability.

There is a logical sequence in dealing with these questions. First, it is necessary to conceptually determine the basis on which past or present expressions should be considered a reliable will. Second, we should know how, in practice, we can help a person to shape what we consider to be a reliable will, either alone or with support. Third, when a will is reliable, then – and only then – we may consider how to diverge from it, given that there are other interests. There is a fallacy involved in dealing with the third question without answering the others: an essential problem with the current approach to mental capacity testing is precisely that current preferences are no longer taken into account in the quest for a reliable will once a person is deemed to lack the capacity to make a decision.

A. To what extent is a current expression a reliable will? The quest for the Holy Grail

It is a misconception that under the CRPD, every impulse – verbal or non-verbal – must be followed blindly.[29] As in a traditional approach, a person's will must be reliable. This stems from the terminology applied by the CPRD itself. A person's 'will' and 'preferences' are essential in the CRPD approach and may not be substituted for the sake of protection. While the (C)CRPD does not give a clear-cut definition for either, 'will' seems to refer to 'a person's deeply held, reasonably stable and coherent personal beliefs, values and commitments and conception of the good', while 'preferences' refer to wishes

[29] Slobogin, 'Eliminating Mental Disability as a Legal Criterion in Deprivation of Liberty Cases. The Impact of the Convention of the Rights of Persons With Disabilities on the Insanity Defense, Civil Commitment, and Competency Law' (2015) 40 *International Journal of Law and Psychiatry* 36, at 40.

or inclinations.[30] As both do not necessarily coincide, in case of a conflict they must be atoned. Even though not everyone will agree with the terminological distinction between will and preferences and the consequences attached to it, most (if not all) will agree that not every current inclination necessarily coincides with what a person truly wants or prefers. Discussing hard cases on self-harm, Flynn and Arstein-Kerslake, two important proponents of a more radical CRPD-interpretation, for example state that 'a verbal expression in one instance may not necessarily represent the true will and preferences of an individual'.[31] They 'highlight the importance of exerting great efforts to discover the true will and preference'.[32] Comparably, although not that explicit, CCRPD itself states that 'if it is not practicable to determine the will and preferences of an individual, the "best interpretation of will and preferences" must replace the "best interests" determinations'.[33]

If one agrees that will and preferences do not necessarily coincide, or alternatively a true will and preference exists, it would be against the spirit of the CRPD to only look for the reliable will (alternatively the true will and preference), if there are no inclinations at all or if the consequences of the inclinations are deemed to be undesirable. Instead, a logical assumption at least on a conceptual level is that every legally valid decision – irrespective of whether it is taken by a person with or without disabilities – should reflect a reliable will and that this reliable will does not necessarily coincide with current inclinations. Additionally, the reliable will is also a frame of reference needed for

---

[30] Szmukler, '"Capacity", "best interests", "will and preferences" and the UN Convention on the Rights of Persons with Disabilities' (2019) 18 *World Psychiatry* 34, at 38.

[31] Flynn and Arstein-Kerslake, 'Legislating personhood: Realising the right to support in exercising legal capacity' (2014) 10 *International Journal of Law in Context* 81, at 98.

[32] Ibid. at 99.

[33] CCRPD, General Comment No.1: Equal recognition before the law (art. 12), 19 May 2014, at para 21.

supported decision making. Consequently a decision should only be considered substituted if a person's reliable will is set aside. Only then legal incapacity is put in place.

However, what is a reliable will and how to establish it in a non-discriminatory way, is a quest for the Holy Grail. Since (almost) everyone is capable of verbal and non-verbal communication, current expressions are an important starting point. To what extent do these expressions reflect a reliable will?

Traditionally, there are three standards to determine whether a current expression reflects reliable will.[34] The first is status based; certain characteristics – for example an impairment or disease – predetermine that the preferences of a person are too unreliable to lead to a valid decision.[35] The second is outcome based; whether a current expression reliably reflects a person's will depends on whether it leads to desirable consequences.[36] The third is function based; a current expression reflects reliable will if the person who expresses it has the mental capacity to understand and appreciate both the situation and the consequences of their expressed preference.[37] As mentioned, the traditional human

---

[34] Ibid., at para 15; Comm.DH, supra n 14 at 13; For an overview see Dhanda, 'Legal Capacity in the Disability Rights Convention. Stranglehold of the Past or Lodestar for the Future' (2006-07) 34 *Syracuse Journal of International Law and Commerce* 429, at 431-33; Booth Glen, 'Changing Paradigms. Mental Capacity, Legal Capacity, Guardianship and Beyond' (2012-13) 44 *Columbia Human Rights Law Review* 93, at 94-5.

[35] Comm.DH, 'Visit to Norway', 18 May 2015, CommDH(2015)9; at para 10; Report of the Independent Expert on the enjoyment of all human rights by older persons, 13 August 2015, A/HRC/30/43 at para 45.

[36] For example Winick, 'The Side Effects of Incompetency Labeling and the Implications for Mental Health Law' (1995) 1 *Psychology, Public Policy and the Law* 6, at 29; Buchanan, 'Mental Capacity and Legal Competence to Consent to Treatment' (2004) 97, *Journal of the Royal Society of Medicine* 415; White, *Competence to Consent* (1994), at 67.

[37] Grisso and Appelbaum, 'Comparison of Standards for Assessing Patients' Capacities to Make Treatment Decisions', *The American Journal of Psychiatry* 152 (1995) at 1033; Moye and Marson, 'Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research', *Journal of Gerontology* 62, No. 1 (2007) at 5; For an application see Moye et al., 'Capacity to Consent to Treatment:

rights approach gives weight to this third, functional standard, as do most current laws.[38] Status is disregarded, as it leads to unnecessary interference and is deemed discriminatory.[39] The CCRPD in turn does not only disregard judgements based on status and on outcome; for two reasons the functional standard is also rejected.

First, even if the reliability of a preference is assessed functionally, an element of status is often present: as mental capacity is presumed, mental incapacity is often only tested *because* a person has an impairment.[40] This creates a model in which having an impairment (status) gives rise to mental capacity testing and subsequently legal incapacity. According to the ECtHR, the element of status involved is insufficient to consider this approach to be discriminatory.[41] This has to be critically assessed in the light of article 12 (2) CRPD. After all, the (refutable) presumption of mental incapacity that arises is based on the stigma associated with disability.[42]

Empirical Comparison of Three Instruments in Older Adults With and Without Dementia", *The Gerontologist* (2004) at 166-75.

[38] HRC, Concluding observations regarding the Czech Republic, 9 August 2007, CCPR/C/CZE/CO/2, at para 12; Council of Europe Committee of Ministers, Recommendation (99) 4 on principles concerning the legal protection of incapable adults, 23 February 1999, at principle 1.1; Lewis, supra n 2 at 63.

[39] ECtHR in *Shtukaturov v Russia* Application No 44009/05, Merits, 27 March 2008, at para 90; *Lashin v Russia* Application No 33117/02, Merits and Just Satisfaction, 22 January 2003, at para 90.

[40] See equally Szmukler, supra n 15; Council of Europe Committee of Ministers, Recommendation (99) 4 on principles concerning the legal protection of incapable adults, 23 February 1999, at principle 1.2.

[41] ECtHR in *Kocherov and Sergeyeva v Russia*, Appication No 16899/13, Merits and Just Satisfaction 29 March 2016, at para 122-23: ECtHR in *Shtukaturov v Russia* Application No 44009/05, Merits, 27 March 2008, at para 134; *Mikhaylenko v Ukraine*, Application No 49069/11, Merits and Just Satisfaction, 30 May 2013 at para 42.

[42] See Comm.DH, 'Visit to the Slovak Republic', 13 October 2015, CommDH(2015)21, at para 127; See as well the concurring opinion in ECtHR in *Kocherov and Sergeyeva v Russia*, Appication No 16899/13, Merits and Just Satisfaction 29 March 2016; Council of Europe Committee of Ministers, Recommendation (2011) 14 on the Participation of Persons with Disabilities in Political and Public Life, 16 November 2011, at para 4; CCRPD, Concluding Observations regarding El Salvador, 5 October 2013, CRPD/C/SLV/CO/1, at para 27; Freeman et al., n 13 at 846; Flynn and Arstein-Kerslake, 'The Support

Second, even if one were to filter the status aspect out of the functional approach by moving away from the presumption of mental capacity and by systematically assessing everyone, mental capacity testing is still said to have a discriminatory effect, as it disproportionately affects persons with disabilities.[43] Persons with (certain types) of Disabilities are more likely not to meet the functional standard. This viewpoint may not be dissociated from one of the premises of the social model of disability: every impulse – no matter how subtle – is *potentially* relevant (though not necessarily reliable).[44] The CRPD challenges intuitions, as it rejects any a priori assumption that there is no reliable expression of will if a person fails the mental capacity test (for example understanding, appreciation, reasoning or expressing a choice in the MacCAT).[45]

Nevertheless, and as explained earlier, the fact that the functional standard is no longer a quality characteristic for current expressions does not mean that every current expression constitutes a reliable will. For example a person with dementia (as well as any other person) may communicate a preference and may subsequently act against it.[46] This

---

Model of Legal Capacity. Fact, Fiction, or Fantasy?' (2014) 32, *Berkeley Journal of International Law* 124 at 130-31; Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, 1 February 2013, A/HRC/22/53, at para 65.

[43] CCRPD, Concluding observations regarding the Republic of Korea, 29 October 2014, CRPD/C/KOR/CO/1, at para 21; Also see HRC, Concluding observations regarding the Russian Federation, 21 November 2009, CCPR/C/RUS/CO/6, at para 19 and Council of Europe Committee of Ministers, Recommendation (2011) 14 on the Participation of Persons with Disabilities in Political and Public Life, 16 November 2011, at para 3. The latter refers to the principle of non-discrimination. However, it is unclear whether the functional approach is excluded by it; see Lewis, supra n 2 at 34-36.

[44] Comm.DH, supra n 14 at 23; CCRPD, Concluding observations regarding China, 15 October 2012, CRPD/C/CHN/CO/1, at para 22; Flynn and Arstein-Kerslake, supra n 42 at 131; Keeling, 'Supported Decision Making. The Rights of People with Dementia' (2014) 30, *Nursing Standard* 38, at 40.

[45] Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, 1 February 2013, A/HRC/22/53, at para 27.

[46] Arstein-Kerslake and Flynn, supra n 11 at 483-484.

has prompted scholars to develop new disability-neutral ways to assess the reliability of a person's preferences. An often-cited alternative approach was developed by Bach and Kerzner, who subject preferences to a quality test based on a person's life story.[47] The fact that a person can no longer reconstruct their life story may result in a situation in which their preferences conflict with their (more stable) will. [48] For example, a person with dementia (as well as any other person) may refuse a vaccine due to a fear of needles, while their life story may show a will for a healthy life and vaccinations have not been a problem in the past. It is the duty of the person who knows the life story to point out this discrepancy in order to reconcile the contradictory will and preferences.[49]

The approach of Bach and Kerzner demonstrates that there are alternatives to mental capacity testing. However, the CCRPD's problem of indirect discrimination is not solved. A judgement that a preference does not correspond with a life story remains an interference, similar to a judgement that a person lacks mental capacity. First, such an approach can only be disability-neutral if an implicit element of status is avoided and everyone's current expressions are systematically evaluated (i.e. there is no presumption that a current expression matches a person's life story). Second, even if that would be the case, there is a very high chance that the persons (with certain) disabilities are more likely

---

[47] Bach and Kernzer, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* (2010); also see Devi, 'Supported Decision-Making and Personal Autonomy for Persons with Intellectual Disabilities. Article 12 of the Convention of the Rights of Persons with Disabilities' (2013) 41, *Journal of Law, Medicine and Ethics* 792, at 796.

[48] Bach and Kernzer, supra n 47 at 84-90.

[49] Ibid., at 84-90; Arstein-Kerslake and Flynn, supra 11 at 484; Szmukler and Bach, 'Mental Health Disabilities and Human Rights Protections' (2015) 2, *Global Mental Health* e20, at 7.

than others to express preferences that do not correspond to their life story and are therefore more affected.[50]

In essence, there is no solution for this so-called problem of indirect discrimination: every model to assess preferences will always have a greater effect on persons with disabilities. Claiming the need for a model that has no impact is naïve, utopianist and even dangerous. It overlooks the consequences of an impairment and a person's subsequent needs.[51] As the United Nations Subcommittee on Prevention of Torture – in general, an adherent of the CCRPD approach – establishes, new inequalities arise if a person who is unable to assess a situation or to communicate effectively is left to their own devices.[52] Such a 'hands-off' approach is not what the CRPD had in mind: the text of Article 12(4) CRPD clearly states that protective measures with respect to the exercise of legal capacity must not only respect the 'will and preferences' of a person, but also their 'rights'.[53]

Third-party observations on whether current expressions reflect a reliable will are inevitable. Yet therein lies the breaking point. It is up to future research to find a mode of operation that is able to overcome the inherent risk that this approach is only applied to persons with disabilities (instead all must be approached in the same way). However, it

---

[50] Burch, 'Autonomy, Respect and The Rights of Persons with Disabilities in Crisis' (2017) 34, *Journal of Applied Philosophy* 389, at 391 and 397.

[51] Dawson, 'A Realistic Approach to Assessing Mental Health Laws' Compliance with the UNCRPD' (2015) 40, *International Journal of Law and Psychiatry* 70, at 73-5; Parker, 'Getting the Balance Right. Conceptual Considerations Concerning Legal Capacity and Supported Decision Making' (2016) 13, *Journal of Bioethical Enquiry* 381, at 389-91; Slobogin, supra n 29 at 37.

[52] Subcommittee on prevention of torture, supra n 17 at para 14.

[53] Martin et al., *Achieving CRPD Compliance. Is the Mental Capacity Act of England and Wales Compatible With the UN Convention of the Rights of Persons With Disabilities? If Not, What Next?* (Position Paper Essex Autonomy Project, 2014) at 13, 23 and further.

must be critically questioned that if the approach applies to everyone, it is problematic that persons with disabilities are affected more often than others, especially if the result is not legal incapacity and a substitute decision, but an impetus for more support towards a decision that does reflect a person's will.

In this respect, one might even ask whether - as the CCRPD suggests[54] - we should really abandon mental capacity testing altogether. Clearly, the way mental capacity is used in the legal capacity debate today is problematic; usually only persons with disabilities are assessed and the finding that a person lacks mental capacity is a cut-off point in the assessment. What a person thinks, feels or believes is deemed irrelevant and little attention is paid to reliable will *beyond* mental incapacity. However, the relationship between mental and legal capacity could be adapted in a way many could agree on, and while the alternative based on a person's life story has the same limitations in terms of a discriminatory effect. As the Commissioner for Human Rights of the Council of Europe (yet another human rights body that generally supports the CCRPD) suggests,[55] the functional standard might still play a role when assessing preferences, provided that — in the case of mental incapacity — it is not legal incapacity (in a traditional sense) but support (in a CRPD sense) that is decided on.[56] In that case, a person's life story will still play an important role as a means to interpret current preferences in the case of mental incapacity. At the same time - and this is in favour of the position of the CCRPD - one may wonder whether a paradigm shift can be built partly on a concept that led to the call for that shift and whether established practices can be so easily abandoned.

---

[54] CCRPD, General Comment No.1: Equal recognition before the law (art. 12), 19 May 2014, at para14 and 29(i).

[55] Comm.DH, supra n 14 at 13 and 28-9.

[56] Ibid. at 13.

To conclude, what is a reliable will and to what extent is a current expression a reflection of a reliable will is a first question. Too often the search for the will stops at the point where mental incapacity is observed. This first question opens a first field of research. The life story as a touchstone for current expressions offers a promising pathways in this field, but still leaves many questions unanswered. For example, about how specific an episode from the life story must be to serve as a touchstone, how to be disability-neutral in practice, how (and by whom) such a test is carried out without best-interest interference. Legal researchers can give indications here, but ultimately it will be up to other fields of research (nursing studies, anthropology, psychology, etc.) to provide CRPD-compliant tools for legal scholars to work with.

B. What is adequate support? A broad range of means, including representation

The acceptance of 'universal legal capacity' must not lead to a person being left to their own devices. The ultimate goal is that reliable will is determined for everyone, either alone or with the (potentially far-reaching) help of others. Doing so in a disability neutral way would make legal capacity universal.

At the core is the duty of governments to recognise and offer a broad range of support to allow persons with disabilities and others to move towards a situation of having a will that is reliable. People should be able to appoint others to support them, have access to information and to advance care planning, and be acknowledged if their communication is nonverbal.[57] Once what makes a will reliable has been determined, support mechanisms can be established to help persons towards that real will. There is

[57] CCRPD, General Comment No.1: Equal recognition before the law (art. 12), 19 May 2014, at para 17; Lewis, supra n 2 at 42-44; for an application Devi, supra n 47 at 795.

plenty of care research on dealing with expressions, preferences and will in a non-cognitive way that can be introduced into legal reasoning. For example, participatory art activities in dementia care might offer a frame for decision making through fiction.[58] In the same way anthropological research that considers the will to be something we do, rather than have, might offer clues by explaining how 'daily wanting' (i.e. current expressions) can be turned into 'willing' in how we interact with others.[59]

It is a misconception that legal representation should be excluded from the list of support mechanisms. For some, far-reaching support is inevitable. As a will should be still reliable, and as not every expression of a preference corresponds with this, article 12 CRPD does not mark the end of representation models; it calls for a shift of them. At the core of that shift is the role of third parties as interpreters of a person's will and preferences: they interpret preferences in order to ascertain what constitutes reliable will, without substituting it.[60]

Representation may not automatically result in a person no longer being able to exercise their rights themselves.[61] This principle is already present in the traditional approach,[62] though in practice, treaty interpretations make little effort to define the role of the person concerned once they have been legally incapacitated (in a traditional sense).

---

[58] See Opgenhaffen et al., 'Care Planning and the Lived Experience of Dementia: Establishing Real Will and Preferences beyond Mental Capacity' in Vandenbulcke, Dröes, and Schokkaert (eds), *Dementia and Society* (2022) 211.

[59] See the inspiring paper of Driessen, 'Sociomaterial Will-Work: Aligning Daily Wanting in Dutch Dementia Care', in Krause and Boldt (eds), *Care in Healthcare* (2018) 111.

[60] Flynn and Arstein-Kerslake, supra n 42 at 131; Gooding, 'Navigating the Flashing Amber Lights of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns' (2015) 15, *Human Rights Law Review* 45, at 52-55.

[61] ECtHR in *X v Croatia*, Application No 11223/04, Merits and Just Satisfaction, 17 July 2008, at para 53.

[62] ECtHR in *Ivinović v Croatia*, Application No 13006/13, Merits and Just Satisfaction, 18 September 2014, at para 44.

Although R(99)4 calls for a system of representation that promotes autonomy, the approach adopted consists primarily of delineating a field of competence that is as narrow as possible. Once this field has been delineated, little attention is paid to the involvement of the person in question.[63] Starting from the CRPD, there is a need to refine this; the prior appointment of a representative does not necessarily mean that a person may no longer make decisions. As a consequence, the representative is a back-up, not the first contact. The starting point is that any expression, regardless of how subtle, reflects or may lead to constituting a person's reliable will. The role of the representative is to interpret a person's expressions and to provide support where necessary.[64] This support could even go as far as what would be traditionally called a substituted decision, as long as this decision reflects what the person would have wanted.[65]

Third parties are interpreters and spokespersons. Again, this is not entirely new; in the traditional approach as it stands today, the task of a representative is (at least on paper) also to rely as much as possible on the wishes of the person concerned.[66] According to the CCRPD this means, at the very least, that an advance directive must be

---

[63] Council of Europe Committee of Ministers, Explanatory Memorandum of Recommendation (2014) 2 on the Promotion of Human Rights of Older Persons, 19 February 2014, at para 60: although the CM applies the logic of the CRPD, a margin of appreciation is awarded to the members states and best interests are still a justified ground for interference.

[64] CCRPD, Concluding observations regarding the Republic of Korea, 29 October 2014, CRPD/C/KOR/CO/1, at para 21; Comm.DH, Visit to Denmark, 24 March 2014, CommDH(2014)4, at para 126; and Comm.DH, Visit to Norway, 18 May 2015, CommDH(2015)9, at para 15; Council of Europe Committee of Ministers, Recommendation (2006) 5, Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015, 5 April 2006, action line 9.

[65] Gooding, supra n 60 at 52-55.

[66] ECtHR in *Mihailovs v Latvia*, Application No 35939/10, Merits and Just Satisfaction, 22 January 2013, at para 145; Council of Europe Committee of Ministers, Recommendation (2003) 24 on the Organisation of Palliative Care, 12 November 2003, at number IIX.

respected in so far as it is relevant in the current context.[67] However, it is less clear on what basis a decision must be taken if there is no clear prior will and the current expression is unreliable. Traditionally, there has been little guarantee that contextual preferences and a person's life story will be respected when another outcome is objectively in the better interests of the represented person.[68] This could be solved through procedural requirements. Yet today the ECtHR for example recognises that to combat potential conflicts[69] and to oppose a representative's misinterpretation,[70] persons with disabilities should be able to address a court independently.[71] This would, however, not be sufficient to safeguard the substantive requirement raised by the CRPD: it is most likely that a more active monitoring system is required in order to ensure that an expression of will, however subtle it may be, is an element to be taken into account in order to arrive at a decision that is as close as possible to a person's will and preferences.

To conclude, the issue of adequate and disability-neutral support raises a second series of questions. It makes little sense to deal with them first, as we will then not know

---

[67] CCRPD, General Comment No.1: Equal recognition before the law (art. 12), 19 May 2014, at para 19(d).

[68] For example ECtHR in *R.P. et al.. v United Kingdom* Application No 38245/08, Merits and Just Satisfaction, 9 October 2014 at para 75-76; HRC, Concluding observations regarding the Czech Republic, 9 August 2007, CCPR/C/CZE/CO/2, at para 14; CAT, Concluding Observations regarding Bulgaria, 14 December 2011, CAT/C/BGR/CO/4-5, at para 19; SPT, visit to Kyrgyzstan, 28 February 2014, CAT/OP/KGZ/1, at para 112; For a critique Comm.DH, supra n 14 at 14; Lewis, n. 2 at 35; For a critique on *best interests* see Wall, 'Being and Being Lost', in Foster, Herring,, Doron (eds.), *The Law and Ethics of Dementia*, ed. D. Foster, J. Herring and I. Doron (2014) 327, at 333-35.

[69] ECtHR in *D.D. v Lithuania*, Application No 13469/06, Merits and Just Satisfaction, 14 February 2012, at para 118.

[70] ECtHR in *Stanev v Bulgaria*, Application No 36760/06, Merits and Just Satisfaction, 17 January 2012; *D.D. v Lithuania*, Application No 13469/06, Merits and Just Satisfaction, 14 February 2012, at para 150; *Mihailovs v Latvia*, Application No 35939/10, Merits and Just Satisfaction, 22 January 2013 at para 143; *Nikolyan v Armenia*, Application No 74438/14, Merits and Just Satisfaction, 3 October 2019, at para 95.

[71] CAT, Concluding Observations regarding Bulgaria, 14 December 2011, CAT/C/BGR/CO/4-5, at para 19.

where support leads to. So only after we determined what we consider to be a reliable will (the first question), adequate support raises a second domain for further research. Legal research can play a leading role in this field (for example dealing with the question when is support justifiable from the CRPD-viewpoint), but not without close contact with other research disciplines. Much research on 'alternative sources' of support remains untouched by legal scholars today.

C. How to diverge from a reliable will? Towards universal paternalism

Once a reliable will has been established, the question arises whether we may diverge from it and how we can do so in a disability-neutral way. When answering this question it is important to localise the problem raised by article 12 CRPD. For all, with or without disabilities, there could be reasons to diverge from a reliable will. It is untrue that because of article 12 CRPD anything goes. A will that is reliable may not necessarily be realistic: someone cannot ask for the moon. The basic principle should be that a disability may not have a direct or indirect effect on legal capacity. This does not mean that a person's legal capacity cannot be limited on other grounds, for example a person's status as a prisoner or the fact that their will conflicts with the rights and interests of others, as long as it counts for all. Moreover, equal recognition of a person's will and preferences does not mean that they have to be respected simply because they are reliable: laws can still impose restrictions based on the content of a decision, again, as long as they count for all. For example, the equal recognition of the reliable will to die does not include the right to euthanasia. As long a prohibition applies to everyone, with or without disabilities, this is not a restriction concerning the right to legal capacity, but a (potentially justified) restriction on other rights.

Article 12 CRPD is not at stake if the reason why a reliable will is diverged from counts for all. The problem however is that persons with disabilities are more likely to

face unwanted interventions (interventions that diverge from their reliable will) based on a paternalist rationale. These could be based on disability-specific legislation (most involuntary commitment laws) or on laws that affect persons with disabilities to a greater extent than others (such as most guardianship laws).[72] Their acceptability is rejected by the CRPD and the broader disability movement.[73] Steered by the principle of the right to equal recognition before the law, they require unwanted interventions to be 'disability-neutral'. General comments number one and number five by the CRPD committee make it clear that in case of interventions, 'disability-neutral' has to be understood broadly and deals with both direct and indirect discrimination. Not only disability-specific legislation, but also functional and outcome based laws with a disproportionate impact on persons with disabilities are considered a problem. The threshold for what is disproportional is low. That unwanted interventions should be disability-neutral on paper and in practice has an enormous impact. It is agreed by many that involuntary commitment laws — as well as best interest considerations in guardianship laws — are not in accordance with the CRPD[74], although many also consider that the CPRD is going too far in this respect.[75]

The fact that best interests are thrown overboard has been criticised by some, all the more because in doing so, the CCRPD attaches an absolute value to the 'will and

---

[72] Flynn and Arstein-Kerslake, 'State intervention in the lives of people with disabilities: the case for a disability-neutral framework' (2017) 13, *International Journal of Law in Context* 39.

[73] Davidson et al., 'An international comparison of legal frameworks for supported and substitute decision-making in mental health services' (2016) 40, *International Journal of Law and Psychiatry* 30.

[74] Perlin, 'Striking for the Guardians and Protectors of the Mind: The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law' (2013) 117, *Penn State Law Review* 1159, at 1189-90; CCRPD, General Comment No.1: Equal recognition before the law (art. 12), 19 May 2014, at para 21 and 29(b); Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, 1 February 2013, A/HRC/22/53, at para 61.

[75] Freeman et al., supra n 13; Dufour, Hastings and O'Reilly, supra n 15.

preferences' of a person, where the treaty speaks of the 'rights, will and preferences'.[76] When the CCRPD defines the concept of rights, it limits this to the right to make mistakes.[77] In the light of all of a person's rights, it can sometimes be more proportionate to go against their will and preferences.[78] This could be all the more justified as their vulnerability makes them unequal, and when proclaiming equality, this vulnerability will only increase.[79] This criticism would be accurate if respect for a person's 'will and preferences' were to imply that every impulse should be respected. As substantiated earlier, however, under the CRPD this is not the case. Reliable will should first be established, either with or without support. Once this has been accomplished, according to the CRPD, a person with a disability is no different from anyone else. Therefore, if others are not protected against the potential consequences of their reliable will, why should persons with disabilities be? Indeed, there is no reason to treat their reliable will differently.

Once split up into three distinct questions, it becomes self-evident why unwanted interventions must be disability-neutral and must apply to all. However, in this regard it is unclear what criteria an intervention should meet in order to be disability-neutral, and how these criteria could be met. First, with regard to the criteria, while there is agreement according to the CRPD on what is *not* disability-neutral (for example mental capacity testing), there is little knowledge about what criteria interventions should meet in order to be disability-neutral. This knowledge is of course essential to develop alternatives. Second, if there were criteria, it is not clear how they could be met. Relevant literature

---

[76] Martin et al., supra n 53 at 39-44.

[77] For example CCRPD, General Comment No.1: Equal recognition before the law (art. 12), 19 May 2014, at para 22.

[78] Martin et al., supra n 53 at 40-41.

[79] Comparable in Subcommittee on prevention of torture, supra n 17 at para 14.

predominantly focuses on what is obviously not disability-neutral. It pinpoints unlinking legal from mental capacity and concentrates on supported decision-making. Referring to the three questions, literature mainly deals with how to determine whether a will is reliable in a disability-neutral way and how to support someone in reliably expressing their will. It is true that this reduces the number of unwanted interventions; however, the core question of how to diverge from a reliable will is ignored. Nevertheless, even the strongest advocates of the CRPD approach agree that interventions may be necessary. They suggest relying on the criterion of necessity in order to tackle this problem.[80] 'Necessity' is a general justification to intervene that already exists as a reaction to (imminent) risk of harm. Necessity is a general (often unwritten) basis that renders specific laws inoperative so as to safeguard other interests. While some suggest necessity could be appropriate, whether and how this may be the case — as well as how to prevent disproportional effects — has not yet been investigated thoroughly.[81] Avoiding these effects should either lead to less paternalism for persons with disabilities or to more paternalism for everyone.

To conclude, the third question on how to counteract a reliable will in a way that is disability-neutral has meaning only if it is preceded by the search for a reliable will. This third question opens up a third field of research. In addition to the issue of what good disability-neutral criteria are, there is the normative issue of when we consider coercion to be acceptable (for all).

---

[80] Gooding and Flynn, 'Querying the call to introduce mental capacity testing to mental health law: Does the doctrine of necessity provide an alternative?' (2015) 4, *Laws* 245; Flynn and Arstein-Kerslake, supra n 72 at 39-57; De Bhailís and Flynn, 'Recognising legal capacity: commentary and analysis of Article 12 CRPD' (2017) 13, *International Journal of Law in Context* 6, at 15-17.

[81] Steele, 'Temporality, disability and institutional violence: revisiting In re F' (2017) 26, *Griffith Law Review* 378, at 379-82.

4. CONCLUSION

The universal right to legal capacity raises many normative and practical questions. Some of them are pertinent. However, as this contribution substantiates, many of them arise from terminological misunderstandings and from a lack of distinction between the essential questions in the debate. With regard to the former, substitute decision-making is applied differently in the traditional and in the CRPD approach. While traditionally a decision has been 'substitute' when taken by someone else, irrespective of what a person would have wanted, the CRPD only applies 'substitute' to decisions a person would not have wanted. This equally results in a different usage of 'legal capacity'. Under the CRPD, a person still has legal capacity if their will is voiced by someone else. As a consequence, if for example a medical decision is to be taken and the person in question is unable to express their will, someone else may make a decision on the basis of a person's previously expressed will and preferences, or on the basis of their best interpretation of what the person in question would have wanted. This does not leave the person in question legally incapacitated. A person is still legally capable of making decisions if their will and preferences are voiced by someone else. Legal incapacity only arises if a person's will and preferences are not respected.

With regard to the latter issue of the lack of distinction, three questions arise when the concepts are isolated. The first is the normative question of what constitutes a reliable will. The second refers to what support is sufficient in order to reach this reliable will. The third question concerns how to counteract a reliable will. It is essential to answer each of these questions in a disability-neutral way, so a new approach to legal capacity inevitably applies to everyone.

To avoid false expectations, it is important to distinguish the issues. For example, if a will is not reliable, there is no sense in dealing with the third question. At that point

one should instead be concerned about the second question and how to reach a reliable will.

This contribution aimed to bring consistency to the debate by exposing a language barrier and by raising questions for future research. Doing so makes it clear that the concept of universal legal capacity is not that far-fetched. However, this is not to say that the concept of universal legal capacity does not present controversial normative issues for (preferably interdisciplinary) research to deal with. In particular, the reliability of a will — including the role of unavoidable third party observation — and ways to counteract a reliable will in a disability-neutral way, warrant normative discussion. Moreover, future change requires a willingness to accept that a new perspective on the legal capacity for persons with disabilities inevitably impacts persons without disabilities.