

# CHAPTER 4

## ADVANCE DIRECTIVES IN MENTAL HEALTH: A SOLUTION THAT LEGITIMATISES THE PROBLEM?

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### Summary

*Article 25 of the Convention on the Rights of Persons with Disabilities (CRPD) calls for persons with disabilities to enjoy the highest attainable standard of health without discrimination on the basis of disability. It demands that this right should be rendered on the basis of free and informed consent. Determining whether the patient is competent to give consent has been seen as critical in balancing between respecting patient's autonomy for those capable of making informed decisions and protecting those deemed cognitively impaired. Advance Directives, which provide patient's preferences on treatment in advance at a moment one is considered competent, have advanced among service users and protagonists of patient's rights in mental health. The coming into force of the CRPD with article 12 propagating universal legal capacity, brings the theoretical basis of Advance Directives into question. This article examines whether Advance Directives have the ability to promote the will and preference of the persons with cognitive disabilities specifically in relation to decisions on treatment, to safeguard legal capacity as envisaged by article 12. Advance Directives are reviewed and viewed as discordant with the CRPD in providing equal legal recognition in their current construction. It proposes Advance Directives as construing cognitive disability as the basis of one's loss of ability to decide, thereby, albeit subliminally, thwarting the right to health. It argues that Advance Directives contextually and in practice, legitimise concepts of lack of mental capacity (hence lack of legal capacity) for persons with cognitive disabilities. To promote Advance Directive legislation in the absence of legal framework that recognises legal capacity in the sense / standard as envisaged by the*

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*CRPD, is a recipe for disaster. The paper suggests that Advance Directives can only be CRPD compliant if they are reconceptualised to advance the will and preference of the person with fluidity of universal and equal legal capacity.*

## 1 Introduction

Law and medical ethics require that physicians obtain informed consent from patients before initiating any treatment.<sup>1</sup> It can be rightly argued that, a valid informed consent can only be obtained where there is full disclosure of appropriate information to a 'competent patient' who is to make a choice.<sup>2</sup> The challenge arises where the patient is considered as incompetent thereby lacking mental capacity to decide on one's treatment and without legal capacity one is as toothless as s/he is defenceless. Appelbaum alleges that:

[T]he determination of whether patients are competent is critical in striking a proper balance between respecting the autonomy of patients who are capable of making informed decisions and protecting those with cognitive impairment.<sup>3</sup>

To preserve patients' choice, Advance Directives (ADs) have been put forward among service users in mental health. The United Nations Convention on the Rights of Persons with Disabilities (CRPD), under article 12, establishes universal legal capacity and makes it clear that there is no stage at which one loses legal capacity.<sup>4</sup> The presumption is that 'all persons with impairments, regardless of their functioning, can exercise legal capacity'.<sup>5</sup> It is from this background that this article examines whether ADs restore legal capacity which historically has been denied for persons with psychosocial/cognitive disabilities or has the ability to promote the will and preference of the persons with disability specifically in relation to decisions on treatment. It construes ADs as the acceptance of the social construction of psychosocial disability as the basis of one's loss of ability to decide. This may act as a return to the view of disability (psychosocial disability), 'as an aspect of social security and welfare legislation, health law or guardianship',<sup>6</sup> which has been the traditional

1 JW Berg et al *Informed consent: Legal theory and clinical practice* (2001) 12.

2 PS Appelbaum 'Assessment of patients' competence to consent to treatment' (2007) 357 *The New England Journal of Medicine* 1834.

3 As above.

4 United Nations Committee on the Rights of Persons with Disabilities, General Comment 1: Article 12: Equal recognition before the law, 19 May 2014, UN Doc CRPD/C/CG1 (2014) para 14 <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no-1-article-12-equal-recognition-1> (accessed 24 January 2019).

5 T Degener 'Challenges and compliance of the UN CRPD' Working Paper of the Academy of European Law (2013) 4.

6 R Kayess & P French 'Out of the darkness into the light? Introduction to the Convention on the Rights of Persons with Disabilities' (2008) 8 *Human Rights Law Review* 1 at 14.

way of viewing disability in practice and legislation. The article argues that instead of empowering persons with psychosocial disabilities, if not properly construed, introduced and monitored, ADs legitimise denial of legal capacity to persons with psychosocial disabilities.

## 2 Legal capacity under the CRPD

In modern times, disability advocates have advanced beyond advocating for equal protection of the law to the need for equal recognition before the law (a fruit of ‘decades of activism by the disability community’).<sup>7</sup> Legal capacity refers to ‘an individual’s status and authority within a given legal system’.<sup>8</sup> It describes the rights and status of a person separate from cognitive competence.<sup>9</sup> Such encompasses ‘persons’ power or possibility to act within the framework of a legal system’.<sup>10</sup> Thus two elements intersect: legal standing as the state of viewing a person as a subject before the law and legal agency which is the ability to act within the legal system.<sup>11</sup>

Where one is viewed as lacking legal standing, personhood at law is lost and such extinction results in civil death, that is, inexistence at law, which has been the story of persons with psychosocial disabilities.<sup>12</sup> As such, legal capacity is a medium through which persons exercise the right to make decisions and have those decisions respected by others.<sup>13</sup> Legal capacity thus preserves personal autonomy.

It has been argued that the removal of the footnote to article 12(2) which restricted legal capacity in three of the six official United Nations (UN) languages to mean ‘capacity for rights’,<sup>14</sup> reaffirmed state parties’

7 SKB Glen ‘Changing Paradigms: Mental capacity, legal capacity, guardianship and beyond’ (2012) 44 *Columbia Human Rights Law Review* 123.

8 T Minkowitz ‘The United Nations Convention on the Rights of Persons with Disabilities and the right to be free from non-consensual psychiatric Interventions’ (2007) 34 *Syracuse Journal of International Law and Commerce* 405.

9 B Carter ‘Supported decision-making’ Background Discussion Paper, Ministry of Justice, Australia [https://healthsciences.unimelb.edu.au/\\_\\_data/assets/pdf\\_file/0010/3391696/Supported-decision-making.pdf](https://healthsciences.unimelb.edu.au/__data/assets/pdf_file/0010/3391696/Supported-decision-making.pdf) (accessed 25 July 2020).

10 Council of Europe Commissioner for Human Rights ‘The right of people with disabilities to live independently and be included in the Community’ <https://wcd.coe.int/viewDoc.jsp?id=1917847> (accessed 30 August 2022).

11 B McSherry & K Wilson ‘The concept of capacity in Australian mental health law reform: Going the wrong direction?’ (2015) 40 *International Journal of Law and Psychiatry* 62.

12 As above.

13 G Quinn et al ‘Restoring the “human” in “human rights”’: Personhood and doctrinal innovation in the UN Disability Convention’ in C Gearty & C Douzinas (eds) *The Cambridge companion to human rights law* (2012) 36-55.

14 United Nations Economic, Social & Cultural Rights Council, Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, UN Doc A/AC.265/2006/L.6 (14-25 August 2006).

intention to guarantee legal capacity universally and without limitations.<sup>15</sup> Grounded in the social model, which views disability as an interaction between the individual and the environment, it divorces legal capacity from mental capacity. It emphasises addressing barriers and environmental adaptations and not fixing or curing the individual.<sup>16</sup> Such is a human rights approach which recognises legal capacity of every human being without considering individual capacities.<sup>17</sup> This ensures that persons with disabilities have the decision-making power and recognition before the law on a par with people without disabilities. In this way, capacity is ever existent in the being in her/his entire existence whether mental capacity fluctuates or not.

## 2.1 Mental capacity conception

The United Nations Committee on the Convention on the Rights of Persons with Disabilities (CRPD Committee) defines mental capacity as the 'decision-making skills of a person'.<sup>18</sup> Assessments of decision-making skills have traditionally focused on a person's cognitive abilities.<sup>19</sup> Methodologically, assessment tests consider a person unable to make a decision where one is said to be unable to understand or retain information, unable to use and weigh information in the process of decision-making and unable to communicate one's decision.<sup>20</sup> From these variables, it is clear that there is a recognition of the fluctuation of mental capacity and that its assessment is in relation to a particular decision at a specified time. 'This approach is flawed in that firstly, it is discriminatorily applied to people with disabilities'.<sup>21</sup> Secondly,

'it presumes to be able to accurately assess the inner-workings of the human mind and, when the person does not pass the assessment, it then denies him or her a core human right – the right to equal recognition before the law'.<sup>22</sup>

Series alludes to the fact that 'a person is accorded legal rights and responsibilities only as far as they are found to be competent and their decisions are authentically theirs'.<sup>23</sup> Does an 'unwise' decision entail lack of capacity to decide? 'It is irrelevant that the decision is considered unwise in the eyes of the majority, as long as it is broadly consistent with the

15 Minkowitz (n 8) 411.

16 L Series 'Relationships, autonomy and legal capacity: Mental capacity and support paradigms' (2015) 40 *International Journal of Law and Psychiatry* 80.

17 As above.

18 General Comment 1(n 4) para 12.

19 McSherry & Wilson (n 11) 64.

20 Mental Capacity Act 2005.

21 General Comment 1 (n 4) para 15.

22 As above.

23 Series (n 16) 81.

individual's own value system'.<sup>24</sup> Regrettably, empirical research indicate that in mental capacity assessments, the assessors struggle to distinguish between 'incapacious' and 'unwise' decisions.<sup>25</sup>

## 2.2 Legal and mental capacity interface

Mental capacity has been and remains closely linked to legal capacity. It is an essential ingredient of individual autonomy that demarcates decisions that are legally effective from those that are ineffective.<sup>26</sup> Persons perceived to have mental capacity are said to have legal capacity as such their decisions are respected at law (and in general). On the other hand, those deemed lacking mental capacity will be judged to lack legal capacity hence their decisions are invalid.

Just as there are variances of decision-making skills among persons without disabilities, how well-developed decision-making skills are among persons with disabilities, differ. But this does not necessitate different treatment for those without disabilities but with 'poor decision-making skills'. The CRPD Committee opposes the use of mental capacity as the basis for restriction to equal participation of persons with disabilities in civil law.<sup>27</sup> The fact that there is a requirement for establishing mental capacity in order for an AD to be considered binding or informative, reveals its social camouflage. Determining compliance with article 12 requires assessing whether legal capacity is denied to persons with disabilities on an equal basis with persons who do not have disabilities. Essentially, the requirement to evaluate whether the denial of legal capacity is discriminatory on the basis of disability in purpose or effect, is applicable to ADs. Normally, inspections of mental capacity do not arise when persons without disabilities execute a directive. As such its applicability on persons with psychosocial disability is discriminatory hence contrary to the spirit of article 12.

Mental health laws are directed at restricting freedom and self-determination as they are premised on 'an equation of psychosocial disability to legal incapacity, and legal incapacitation is the primary way in which the law deals with persons with psychosocial disabilities'.<sup>28</sup> It is only through a guarantee of legal capacity on an equal basis with others in all aspects of life, not ADs, that will result in the elimination of such legal regimes. As Minkowitz rightly argues, 'disability is not a loss of physical

24 C Emmett et al 'Homeward bound or bound for a home? Assessing the capacity of dementia patients to make decisions about hospital discharge: Comparing practice with legal standards' (2012) 36 *International Journal of Law and Psychiatry* 73.

25 As above.

26 G Richardson 'Mental capacity in the shadow of suicide: What can the law do?' (2013) 9 *International Journal of Law in Context* 87.

27 General Comment 1 (n 4) para 12.

28 Minkowitz (n 8) 408.

or mental integrity, but a situation in which people possess their own physical and mental integrity that deserves respect equally with other'.<sup>29</sup> Do ADs restore, to persons with disabilities, the historically denied right to legal capacity?

### **3 Advance directives and universal legal capacity dichotomy**

ADs are instruments that enable competent persons to dictate medical treatment choices in anticipation of future periods of incapacity.<sup>30</sup> Their intention is to establish one's preferences on treatment should the person become incompetent or incapable of communicating those preferences.<sup>31</sup> In mental health, ADs stipulate treatment preferences for times 'when a consumer of mental health services has a mental health crisis and is unable to communicate those preferences'.<sup>32</sup> ADs are considered by many as a vehicle for the recognition of consumer rights in mental health law.<sup>33</sup> Weller asserts that ADs are a practical step towards a broader 'culture of supported decision-making' in the mental health context.<sup>34</sup> ADs act as instruments to support clients in reaching decisions and facilitate collaborative partnership between doctors and patients, particularly due to the fact that it takes into account that mental capacity may fluctuate over the course of mental illness.<sup>35</sup> A conceptual analysis of ADs in relation to article 12 of CRPD would suggest that the tool may be essential in the advancement of supported decision-making as opposed to as a tool for decision-making. As Fiona Morrissey observes, ADs are an important supported decision-making tool.<sup>36</sup> Ireland is one country that has attempted to embrace ADs.

#### **3.1 Assisted Decision Making (Capacity) Act 2015**

In an effort to advance respect for choices of persons with psychosocial disabilities, Ireland legalised advance health directives through the adoption of the Assisted Decision Making (Capacity) Act. Whereas the intention was good, the outcome was retrogressive not only in that the

29 Minkowitz (n 8) 412.

30 P Weller 'Psychiatric advance directives and human rights' (2010) 17 *Psychiatry, Psychology and Law* 218.

31 DS Srebnik et al 'Advance directives for mental health treatment' (1999) 50 *Psychiatric Services* 919.

32 As above.

33 Weller (n 30) 219.

34 As above.

35 S Pathare et al 'Supported decision-making for persons with mental illness: A review' (2012) 34 *Public Health Reviews* 25.

36 FE Morrissey 'The introduction of a legal framework for advance directives in the UN CRPD era: The views of Irish service users and consultant psychiatrists, Ethics, Medicine and Public Health' (2015) 326.

advanced directives are still not binding in Ireland but also that this law retains the mental capacity standard. For instance, the advance health directive has been defined as:

[A]n advance expression made by the person, in accordance with section 84, of his or her will and preferences concerning treatment decisions that may arise in respect of him or her if he or she subsequently lacks capacity.<sup>37</sup>

Further, the Act provides that an advanced health directive can be made by a person who is not less than 18 years old and has capacity.<sup>38</sup> It is the argument of this paper that the emphasis being made on capacity for a validity of ADs is contrary to the aspirations of CRPD but reveals the true face of ADs. And so, the Assisted Decision-Making Act adoption of ADs is a huge step in the wrong direction, as far as article 12 of the CRPD is concerned.

ADs are not tools that universally assist service users in general; rather, they are specifically useful to those who fear that they may be denied the right to choose their course of treatment. In practice, ADs don't serve as the ultimate decision-making supportive tool on treatment, but provide an opportunity for preferences for treatment. ADs are highly promoted by psychiatry professionals. This alone raises red flags as to how tailored they are to the needs and protection of service users as well as survivor organisations.<sup>39</sup> It is an argument of this paper that while preference on what kind of treatment (drugs or form) is to be administered to a patient is part of the right enshrined under article 12 of the CRPD, the principle right lies in the freedom to decide on whether treatment should be administered as a preamble determination. Choices on the kind of treatment arises where one has already agreed to treatment. Further, reviews of ADs in practice seem not to support advanced decisions to refute treatment as it 'faces opposition from the majority of psychiatrists'<sup>40</sup> at enforcement stage.

The origin and progression of ADs in psychiatry emanates from the premise that one can lose mental capacity. For this reason, the validity of an AD depends on it being executed when the executor had mental capacity. And the non-reversible nature once effected during 'crisis' is based on the conviction that a decision made while having mental capacity cannot be reversed when one has lost mental capacity (or while one is under a mental capacity fluctuation). It is the position of this paper that:

37 Section 82(1) of the Assisted Decision Making (Capacity) Act 2015.

38 Section 84 of the Assisted Decision Making (Capacity) Act 2015.

39 Reference is made to article 4.3 of the CRPD (requiring close consultation with organisations of persons with disabilities on all implementation matters) and 8 (awareness-raising obligations).

40 Morrissey (n 36) 326.

[T]he point at which an AD enters into force (and ceases to have effect) should be decided by the person and included in the text of the directive; it should not be based on an assessment that the person lacks mental capacity.<sup>41</sup>

Gooding and Flynn argues that ‘introducing mental capacity as grounds for interference (involuntary admissions) would fail to stem disability-based discrimination; instead, it would cement it’.<sup>42</sup> Similarly, embracing ADs which incorporate mental capacity assessments would not advance realisation of legal capacity (will and preferences) of persons with psychosocial disabilities. On the contrary, it will cement societal/cultural prejudices against universal legal capacity.

Although ADs are a creature brought forward as a clear solution to human rights deficits in mental health laws, they not only have limited impact in practice,<sup>43</sup> but further act as a fertile ground for prejudices against decision-making abilities of persons with disabilities. Further, as a Survey conducted in Ireland unveils, the use of ADs to refuse all treatment led to negativity to their acceptability.<sup>44</sup> This demonstrates how in practice ADs are not tools to advance decision-making but rather (largely) to promote treatment choices. This does not ignore the use of ADs to appoint the proxy, but rather requires that even then, in circumstances of purported crisis, the proxy should aim at establishing the person’s will and preference in the present. Essentially, ADs are a tool for those that have agreed to treatment but refuse certain treatments.<sup>45</sup> ADs are, therefore, very limited in their scope and impact to incite decision-making and even as a tool for supported decision-making.

Conceptually, the genesis of ADs is flawed as far as legal capacity, as conceptualised by the CRPD, is concerned. It largely develops from the concession of the fact that at a certain stage of mental illness, called ‘health crisis’, one loses mental capacity hence legal capacity to determine one’s mental treatment is lost. This should be scrutinised from the understanding that ‘a person is accorded legal rights and responsibilities only in so far as they are found to be competent and their decisions are authentically theirs’.<sup>46</sup> In this regard, ADs have the potential to inadvertently cast doubt upon the legal capacity of persons with disabilities, categorically labelling them incompetent. It entrenches the assumptions that surround treatment of persons with psychosocial disabilities – that they lack the capacity to make valid medical decisions.<sup>47</sup> In fact, the CRPD has moved away from

41 General Comment 1 (n 4) para 17.

42 P Gooding et al ‘Querying the call to introduce mental capacity testing to mental health law: Does the Doctrine of Necessity Provide an Alternative?’ Centre for Disability Law and Policy, National University of Ireland, Galway, Ireland (2015) 247.

43 Weller (n 30) 219.

44 Morrissey (n 36) 329.

45 Morrissey (n 36) 330.

46 Series (n 16) 81.

47 PJ Weller ‘“Lost in translation: Human rights and mental health law’ in B McSherry & P Weller (eds) *Rethinking rights-based mental health laws* (2010) 51-72 at 63



the mental capacity-based model. This raises the question: what disability-neutral criteria would be used in preferring a person's decision at one time over another (the case of ADs)?<sup>48</sup> This is an area fertile for further discussion, as a depth conversation is beyond the reach of this paper.

Ireland has zealously moved away from institutionalisation in favour of community reintegration, without comprehensively restoring legal capacity. To return this population to their communities while denying them full legal capacity – the right to control their own lives - amounts to a denial of existence at law. Where one doesn't exist in law, they cannot enjoy any rights, and the purpose for which ADs aim to achieve, thus returning autonomy to the person, is challenged by the mechanism itself. In the absence of legal capacity, one cannot enjoy any rights, and so to de-institutionalise without returning respect for legal capacity is to institutionalise within society/community. It can hence be argued that the paternalistic approach of ADs restores the social barrier to decision-making of persons with disabilities, which is contrary to the aspirations of the CRPD.

## 4 A theoretical analysis of advanced directives

The social model of disability construes disability as a result of societal barriers that stand in the way of persons with impairments in their equal participation in everyday life. Whereas the medical model sees the problem being in the individual and needing treatment, the social model considers the individuals' environment and circumstances. In this paper, ADs are interpreted as a product of the medical model view of disability, whereas their implementation to advance the CRPD's aspirations is challenged as they are unmasked as the social barrier legitimising prejudices that have historically treated persons with psychosocial disabilities as incompetent.

### 4.1 The medical model

The medical model regards disability as impairment requiring treatment.<sup>49</sup> Psychosocial disability in this case is considered a deviation from the normal health status; a state where one is incompetent and unable to comprehend. Exclusion of persons with psychosocial disabilities from society is regarded as a result of their individual complexities and problems and the reasons for exclusion are 'clearly' in their impairment which prevent them from realising the consequences of their decisions. Such is what the social model theorist Michael Oliver conceptualises as,

<sup>48</sup> Series (n 16) 866.

<sup>49</sup> T Degener 'Challenges and compliance of the UN CRPD' Working Paper of the Academy of European Law (2013) 5.

'ideological construction of disability through individualism and medicalisation, the politics of disablement'.<sup>50</sup> This is where the theoretical critique of the ADs arises. ADs genesis and construction arise from the acceptance or 'realisation' that at a certain state of mental illness, persons with psychosocial disability lose their capability to decide, that is mental capacity is lost. The fact that the condition of making a valid AD lies in the proof of existence of capacity at the point of its execution, supports this thought.<sup>51</sup> But further, the very justification of ADs is that one should make their will and preferences known while they are able to, otherwise once in crisis, they are mentally incapable. Persons with mental impairments need a shelter, a social protection for cases where they have lost legal capacity, and that is what necessitates making decisions in advance.

The medicalisation of disability in ADs lies in the fact that by their nature, they are construed as a treatment preference as opposed to a decision-making tool. That is, refusal of total treatment would rarely be seen as the purpose for which ADs are created. It would be naive to argue that ADs are worse than forced treatment or treatment without consent. Yet it is more dangerous to conclude that 'staged consent' or a choice without the option to refuse would amount to advancement of the aspirations of the CRPD. But more importantly, where ADs are implemented within a pathologising approach, this leads to retrogression. On the other hand, ADs might be tools aimed at breaking social barriers, so as to advance the wishes and will of persons with psychosocial disability (breaking social bearers), thereby advancing the social model of disability.

## 4.2 The social model

The social model of disability stems from the text of Fundamental Principles of Disability arguing that disability is not as a result of impairments but results from the disabling barriers that persons with disabilities face in society.<sup>52</sup> This model focuses on society as opposed to the individual and explains disability as a social construct through discrimination and oppression.<sup>53</sup> It distinguishes an impairment from disability. Disability is regarded as a mere difference within the continuum of human variations.<sup>54</sup> Of great importance here is the deviation of the social model from the consideration of disability as a condition of body or mind of the individual (medical model), into considering disability as a result of the way environment and society responds to impairment.<sup>55</sup>

50 M Oliver *The politics of disablement* (1990) 96.

51 Section 84(1) of the Assisted Decision Making (Capacity) Act 2015.

52 M Oliver 'The social model of disability: Thirty years on' (2013) 28 *Disability & Society* 1024.

53 Degener (n 5) 5.

54 As above.

55 As above.

The above understanding of the social model is helpful in critiquing ADs in their implementation. First and foremost, ADs approach to decision making, is hanged on competence. The very requirement of its execution requiring that the executor to be competent, is evidence to it. On the other hand, the decision is largely on choices of treatment as opposed to the ultimate or primary decision on consent or refusal of treatment. The attitude is: let the patient get treatment and be healed from this impairment that is preventing him or her from being able to exercise mental capacity. Such shows a clear medicalisation of disability in the ADs, to which the social model has advanced to move away from.

Secondly, while recognising that ADs are tools that hypothetically intend to break the social barrier of decision-making for persons with psychosocial disabilities so that even in their perceived crisis state their preferences are followed and adhered to, ADs' impact on social prejudices cannot be left unaddressed. To begin with, ADs legitimatise prejudice against individuals with psychosocial disabilities through applying a mental capacity standard, such that only an instrument executed while they had capacity can be trusted. 'To legitimize the very practices the CRPD sought to eradicate'<sup>56</sup> is a dangerous path to take. Again, as ADs tilt towards accepting at least a particular treatment as opposed to total refusal, they are a premeditated decision to (in some cases, involuntarily) treat persons with disabilities masquerading as tools to preserve autonomy. This is not to argue that persons with psychosocial disabilities will always refuse treatment, rather is to say in a system that has not embraced a 'No to treatment' as a competent decision, the effect of blind endorsement of ADs becomes worrisome. The proxy approach may be raised here, but still the issue is that even that does not show confidence in the choices of the 'patient', but rather hinges trust on the person one chose while he/she had mental capacity. General Comment 1 urges that an outside decision-maker should make a decision based on their 'best interpretation' of the person's will and preferences at the time the decision is made.<sup>57</sup> As this paper is limited in scope to address all issues, to conclude this discussion on the social model, in a society that is yet to accept decisions of persons as valid once diagnosed with mental illness, ADs will legitimatise the prejudices and in jurisdictions where they are legally binding and common, an absence of an AD in an individual case will automatically oust one's 'choice'. Will and preference are dynamic concepts, which is why ADs cannot be regarded as promoting will and preferences of the executor unless such is proven static or the interpretation of ADs is dynamic in consideration to the person's present wishes. Usually, when faced with a patient, clinicians are underpinned and prejudiced by the patient's best interests concept from which their clinical responsibility and practice emanates. It is the argument of this paper that without a guarantee of equal

56 Series (n 16) 80.

57 General Comment 1 (n 4) para 2.

legal capacity to persons with disabilities, ADs can offer little, if any, guarantee to respect of persons' will and preferences to/on treatment.

As discussed, the medical model has been seen as the basis for considering persons with psychosocial disabilities as lacking mental as well as legal capacity and necessitating treatment on the persons. The social model would strongly pose the lack of legal capacity as a social construction which bars the decision making of persons with psychosocial disabilities. ADs embrace the medical model by acceptance of the over-emphasis on the need to treat psychosocial disabilities. Consistent with the medical model, ADs further emphasise the need for assessment and proof of legal capacity before society can respect such decision(s) when made. The ADs while adopting the social model approach in respect for the user's decision, retain elements of the medical model by (whether directly/indirectly or knowingly/unknowingly) concluding that psychosocial disabilities result in loss of mental capacity. This is a frightening state of affairs for it comes as an empowerment tool yet legitimises the stereotypes that disempower persons with psychosocial disabilities as having no legal capacity. This is ironic and yet a thin line distinction to the extent that the negative impact of ADs can go unnoticed, yet its impact is and will be disastrous. As Kerslake and Flynn observe:

Historically, people with disabilities have been denied legal personhood and agency on a differential basis. This has fostered inequality in legal capacity law that has permeated legal and social systems. The starting point for change is dismantling these unequal systems. It is not recreating structures that perpetuate a different legal status of people with disabilities.<sup>58</sup>

Similarly, the whole adoption of the ADs as an empowering tool for persons with disabilities without breaking the barriers that have been upheld for ages in their denial to decision-making, is regressive to realisation of article 12 of the CRPD. ADs arise from the acceptance of considering a person as having autonomy before the law based on their capability to decide. For persons with disabilities, they are or have been historically considered unable to make a decision, lacking mental capability, as such ADs are tools to return this legal capacity. This legitimises the dehumanisation of persons with psychosocial disabilities as they lose their legal capacity when in 'serious mental' breakdown.

58 A Arstein-Kerslake & E Flynn 'The General Comment on article 12 of the Convention on the Rights of Persons with Disabilities: A roadmap for equality before the law' (2016) 20 *The International Journal of Human Rights* 471 at 485.

## 5 Examining redemability of advance directives under the lens of the CRPD

An AD understood as ‘a written declaration that a patient can use to accept or refuse future medical treatment’<sup>59</sup> is facially a tool to advance autonomy of patients even in the most difficult times. Patients use advance directives to communicate to health providers their preferences as regards future health care decisions. As a form of reliable and accurate reflection of a patient’s desires as regards treatment decisions, ‘ADs are extremely useful as direct and reliable expressions of a patient’s wishes’.<sup>60</sup> Without a doubt, the preceding discussion highlights a distinction of ADs in general as to how they are applicable and conceptualised in mental health services.

It has been posited that ‘ADs were originally developed to allow decisions regarding end-of-life care’.<sup>61</sup> These instruments also known as ‘living wills’ were later introduced or extended to the mental health context, for purposes of advancing possibilities of mental health patients to express their treatment choices in advance before incapacity.<sup>62</sup> There is therefore no denial that ADs have for ages been recognised and accepted as ‘strategies for giving people with mental disorders more say in the management of their treatment and their lives’.<sup>63</sup> ADs are a tool aimed at advancing autonomy. Thus, ADs meet the general legal requirement of consent to medical treatment. In the absence of ADs, patients deemed incapable of giving consent are nevertheless treated in their ‘best interests’.<sup>64</sup>

Now, as a transition of progress to the realisation of rights of persons with cognitive disabilities, ADs should be applauded and safeguarded for they addressed a number of issues that dominated the era of institutionalisation in mental health. Thus, ADs in mental health have been important in many ways. First, ADs advance adherence to treatment as one is involved in the process of choice, hence beneficial therapeutically. Another advantage of ADs is that they reduce involuntary detention and treatment. This has facilitated de-institutionalisation and has been revolutionary to mental health services. Further, ADs advance

59 MO Tyminski ‘The current state of advance directive law in Ohio: More protective of provider liability than patients rights’ (2005) 19 *Journal of Law and Health* 411 at 414.

60 Tyminski (n 59) 416.

61 RL O’Reilly ‘The capacity to execute an advance directive for psychiatric treatment’ (2008) 31 *International Journal of Law and Psychiatry* 66.

62 F Morrissey ‘Advance directives in mental health care: Hearing the voice of the mentally ill’ (2010) 16 *Medico-Legal Journal of Ireland* 21 at 22.

63 Department of Health, ACT, Australia, Department of Health ‘Review of the ACT Mental Health (Treatment and Care) Act 1994: Options Paper’ (2007) 20.

64 Morrissey (n 36).

collaborative decision-making thereby harnessing patient expertise which leads to quality healthcare services.<sup>65</sup> For this reason, ADs have an economic benefit in that there is a reduction in the readmission rates thereby easing the pressure on mental health services demand.<sup>66</sup> And finally, ADs advance patient preferences even where the patient is deemed incapable of making a choice or expressing such a choice. Unfortunately, despite all these positives well documented in health services discourse, the introduction and adoption of the CRPD, changes the narrative entirely. With article 12 advancing universal legal capacity in its quest for equality before the law at all times, ADs in the state in which they are conceptualised, fail to pass the human rights model test. Perhaps this is the pinnacle of acclaimed paradigm shift brought by the adoption of the CRPD.

General Comment 1 addresses the challenge well as it states:

For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their *will and preferences* which should be followed at a time when they may not be in a position to communicate their wishes to others. All persons with disabilities have the right to engage in advance planning and should be given the opportunity to do so on an equal basis with others. States parties can provide various forms of advance planning mechanisms to accommodate various preferences, but all the options should be non-discriminatory. Support should be provided to a person, where desired, to complete an advance planning process. The point at which an advance directive enters into force (and ceases to have effect) should be decided by the person and included in the text of the directive; it should not be based on an assessment that the person lacks mental capacity.<sup>67</sup>

To cement the substantive argument above, it goes further to say:

The type and intensity of support to be provided will vary significantly from one person to another owing to the diversity of persons with disabilities. This is in accordance with article 3 (d), which sets out ‘respect for difference and acceptance of persons with disabilities as part of human diversity and humanity’ as a general principle of the Convention. *At all times, including in crisis situations*, the individual autonomy and capacity of persons with disabilities to make decisions must be respected.<sup>68</sup>

From the above, it is clear that there is a conceptual titanic confrontation between ADs and article 12, which cannot be ignored. The autonomy of a person with mental disabilities, through the CRPD paradigm shift, is never lost even during mental capacity variance levels of crisis. And so as long as one’s capacity to decide is denied or suspended or pended on the basis of

65 DL Ambrosini & AG Crocker ‘Psychiatric advance directives and the right to refuse treatment in Canada’ (2007) 52 *Canadian Journal of Psychiatry* 398.

66 E O’Shea & B Kennelly *The economics of mental health care in Ireland* (2008) 71.

67 General Comment 1 (n 4) para 17 (emphasis added).

68 As above.

mental capacity, ADs fail to adhere to the spirit of the CRPD. Nevertheless, ADs, can be reconceptualised in mental health to align to the CRPD by subjecting their validity and relevance to the will and preference of the persons with mental disabilities, and realigning its legitimacy guidelines to article 12. That is, as long as ADs are the most effective and clear way of establishing the will and preference of the person, without undermining in anyway universal legal capacity, ADs are redeemable.

## 6 Conclusion

As alluded to in the preamble of this paper, law and ethics demand that free and informed consent is sought from the patient before any treatment. The CRPD enforces this by

requiring health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed by, *inter alia*, raising awareness of human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.<sup>69</sup>

The recognition of legal capacity for persons with disabilities needs to be pursued with all effort and without shortcuts. This will not be easy and patience will be needed more especially in third world countries, like Malawi, where the concept of rights is already considered foreign and a challenge to state sovereignty. But even in countries like Ireland with long traditional norms of paternalism, the challenge is equally tasking. It is essential that the granting of legal capacity should not be conditional. As ADs in the state they are in contextually legitimise concepts of lack of mental capacity as resulting in lack of legal capacity for persons with psychosocial disabilities, they can be construed as exacerbating the problem they aim to solve. This essay has raised doubts as to ADs' ability to promote effective participation by persons with psychosocial disabilities in decisions concerning treatment that affect their lives. In order for ADs to align to the aspirations of the CRPD, there will be a need to modify their operation so as to exist as living documents that do not end up binding people against their will and preference where such has changed. Further, their validity should not be conditional on existence of mental capacity.

Additionally, it is important to consider the relative utility of ADs in different global contexts. ADs seemed to have been very useful for America and (especially) Europe, given the comparatively well-developed healthcare service infrastructure and the challenges of institutionalisation. Such is not the case for Africa and specifically Malawi, where the challenge starts from the lack of services themselves, such that a choice of treatment is not an urgent conversation, as yet. Thus, as advocates push for

69 Article 25 of the Convention on the Rights of Persons with Disabilities.

availability of mental health services, ADs in the state they are conceptualised might not be the way forward for Africa and/or Malawi. Generally, to promote AD legislation in the absence of legal framework that recognises legal capacity in the sense/standard of the CRPD, is a recipe for disaster. ADs have 'a limited scope when they are merely a reaction to the coercive power of rights-based legalism'.<sup>70</sup> Elimination of the social barriers of prejudices against persons with psychosocial disabilities remains critical. A solution that legitimatises the problem becomes the problem requiring a solution; the story of ADs.

70 Weller (n 30) 219.