Addressing Barriers to CRPD Compatibility for Advance Planning Provisions: An Empirical Study

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Abstract:

This thesis identifies and addresses main barriers to compatibility with the Convention on the Rights of Persons with Disabilities (hereafter referred to as the CRPD) for advance planning provisions in England and Wales. The CRPD reimagines current mental capacity and mental health law, focusing on supporting the individual and respecting individual will and preference. Advance planning is one such explicit form of support. There are two potential uses for advance plans under the CRPD. These are to provide documented will and preference to be used when an individual has lost the ability to communicate, and to self-bind some decisions to overrule future will and preference during a mental health experience. The latter is by far the most contested. Despite ratification in 2009, we are yet to see meaningful legislative attempts at CRPD-compatible advance planning in England and Wales. Attempts are stifled by the retention of mental capacity assessments, their reliance on true self conceptions, and the tension between safeguarding vulnerable adults and the CRPD's right to take risks and make mistakes. This thesis outlines these barriers to CRPD-compatibility and asks whether and how these barriers resonate with people who have experience of mental health difference. It also considers how identified barriers may be overcome to achieve greater compatibility while achieving the desired support.

People with various mental health differences were invited to provide responses to these questions. 6 focus groups and 6 individual interviews were conducted, involving a total of 25 participants. Participants had a range of first and second-hand mental health experiences, including psychosis, PTSD, bipolar, schizophrenia, personality disorder, OCD, anxiety, depression, memory loss, dementia and Alzheimer's. Main findings provide insight into self with mental health and how this offers a challenge to the true self conception often used to justify advance planning and restrictions to legal capacity. It supports existing research findings demonstrating a desire for self-binding by individuals who experience drastic changes in self and decision making during a mental health experience.[1] Findings also indicate that the nature of mental health and how it impacts

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[1] T. Gergel and others, 'Reasons For Endorsing Or Rejecting Self-Binding Directives In Bipolar Disorder: A Qualitative Study Of Survey Responses From UK Service Users' (2021) 8 The Lancet Psychiatry.
L. A. Stephenson and others, 'Advance Decision Making In Bipolar: A Systematic Review' (2020) 11

self influence participant opinions on self-binding, specifically whether self-binding should be available to all individuals and the scope of decisions an individual could be permitted to self-bind. Currently advance planning works the same for everyone, however these findings suggest a divergent approach may be more appropriate. Findings also indicate support for a non-absolutist adherence to will and preference when this adherence would lead to serious, direct self-harm leading to loss of life.[2] New thinking is explored in relation to advance planning as a potential user-led alternative to mental capacity assessments and a way to opt into state intervention.

A Note on Terminology

Throughout this thesis, the phrase 'mental health difference' or 'mental health experience' is used. Participants were asked prior to interview whether they had a preferred term of reference. Many did not like being referred to as 'disabled' as they did not think this label applied to them. There are also conceptual problems with using the phrase 'mental illness' or 'mental health diagnosis/condition' because of negative connotations based on 'illness' or 'lack' and because not everyone has a diagnosis or agrees with the diagnosis they are given. The term 'disabled person' also does not accurately describe the focus within this thesis on mental health as opposed to somatic conditions, despite often overlap between the two. One participant, Jessie, suggested 'mental health difference' because she believes it acts as an equalizer and does not carry with it negative connotations. Everyone has some level of mental health difference given mental health ebbs and flows, but some have greater difference compared with the general population.

Mental health difference or mental health experience is therefore the preferred terminology of this thesis to reflect these sentiments and because of the unsuitability of other phrases.

Frontiers in Psychiatry.

[2] E. Flynn and A. 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.
M. Bach and L. Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' (2010) prepared for the Law Commission of Ontario. Available <https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf> Accessed 26th January 2021.

Abbreviations

Abbreviation	Explanation
OCD	Obsessive Compulsive Disorder
PTSD	Post-traumatic Stress Disorder
WHO	World Health Organization
FTD	Fronto-Temporal Lobe Dementia

Introduction

It is fitting to begin this thesis with a tale from Homers Odyssey. This tale concerns Ulysses who is on a voyage with his crew after the Trojan War. During his travels Ulysses is warned of the Sirens, whose enchanting song would surely lead him to a watery grave. But Ulysses, so wanting to hear them, says to his crew: "take me and bind me to the crosspiece halfway up the mast…to the mast itself. If I beg and pray you to set me free, then bind me more tightly still…"[3] Ulysses blocks the ears of this crew with wax and they bind his hands and feet to the mast."[The Sirens] sang…words most musically, and as I longed to hear them further I made signs by frowning at my men that they should set me free; but they … bound me with still stronger bonds til we got out of hearing of the Siren's voices. Then my men took the wax from their ears and unbound me."[4]

While hearing the Sirens song, Ulysses experienced a 'temporary insanity' during which he wanted to make a harmful decision, namely to be untied from the mast and swim to the Sirens. Ulysses instead was able to avoid this fate with the help of his crew, by being bound to the mast and remaining bound even when he had changed his mind. This kind of decision is referred to as self-binding or a 'Ulysses contract.'[5] It is when an individual makes a decision to be applied at a future point in time when they are unable to make that decision for themselves. The purpose of these decisions is to protect self from harm.

In modern day mental health care, these decisions come in the form of advance plans. In the same way the Siren's song caused 'temporary insanity,' so too can some mental

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[3] Homer and Samuel Butler, *The Iliad And The Odyssey* (Barnes and Noble Inc) Book 12 (XII) 576.

[4] Ibid 577.

[5] Derek Morgan, 'Odysseus And The Binding Directive: Only A Cautionary Tale?' (1994) 14 Legal Studies. The story of Ulysses (Odysseus in Greek) was the basis of an influential article by Derek Morgan on the positive and negative implications of advance directives in medical care.

health experiences. A parallel is therefore drawn between the Siren's song and mental health difference. These come in the form of advance refusals of medical treatment, Lasting Power of Attorney, recovery plans, and advance care plans. In England and Wales these are currently regulated by the Mental Capacity Act 2005.

Advance planning provisions are deserving of closer attention following the introduction of the United Nations Convention on the Rights of Persons with Disabilities. The CRPD was ratified by the UK in 2009 and is the first UN treaty to award rights specifically to disabled people. It is termed a 'paradigm shift' in that it shifts the rights of disabled people from a medical model to support model approach. The support model believes 'disability' should be perceived not as individual shortcoming nor something to be cured, but as barriers within society which disable meaningful participation. These barriers, be they physical, policy related or legal, should therefore be removed to ensure equal rights for disabled people.

Article 12 of the CRPD titled 'Equal Recognition Before the Law' introduces the concept of universal legal capacity. Essentially this awards persons with perceived and actual deficits in mental capacity the right to equal recognition before the law, meaning they retain the ability to make decisions and have those decisions recognized by law. Rather than restricting some decisions, will and preference is to be adhered to at all times and an individual is to be supported in their decision making. This challenges a fundamental concept within many legal systems- that there exist some scenarios in which an individual may be unable to make legally enforceable decisions because of mental impairment.

If we apply this to Ulysses, there seems to be no justification under a strict reading of the CRPD to privilege Ulysses' previous self over his self now on the grounds that he lacks the capacity to make this decision. Therefore, while his crew can provide support by deterring him from a decision to be unbound, ultimately his will and preference should be respected. This essentially renders any form of self-binding seemingly redundant when a contrary wish is expressed.[6]

This becomes particularly problematic in the context of harmful decisions- including decisions which are out of character, based on delusion or the side effects of medication- and raises the question of what to do when support is refused or fails to deter the individual from harm.

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[6] M Scholten et al, 'Psychiatric Advance Directives Under The Convention On The Rights Of Persons With Disabilities: Why Advance Instructions Should Be Able To Override Current Preferences' (2019) 10 Psychiatry.

Based on these unanswered questions, many academics and policy makers have abandoned ship when it comes to full CRPD compatibility. Concerns relate to whether full compatibility is possible while providing the appropriate level of support and safeguarding for persons with mental health difference.

While CRPD compatibility is at the forefront of academic literature, less has been done to consider in depth the implications of the CRPD for advance planning provisions and how they could be reformed to achieve CRPD compatibility.[7] Advance plans pose a set of related but separate questions to CRPD compatibility more broadly, thus allowing this thesis to focus on one aspect of compatibility which is more manageable given time and word constraints. In addressing some of the barriers to compatibility for advance plans, this will likely provide insight into how compatibility may be achieved in other areas.

This thesis therefore attempts to generate new thinking on how advance plans can be made compatible with the CRPD. This includes identifying main barriers to compatibility and gathering participant responses on how they wish to use advance planning as a method of support under the CRPD, with the aim of creating new thinking on how barriers can be overcome. This is in the hopes of providing some practical recommendations on how to create CRPD compatible advance plans whilst retaining their utility in situations where they could be of most use to people with mental health difference.

A Roadmap of this Thesis

This thesis contains 7 Chapters. Chapter 1 provides an overview of advance planning and juxtaposes the way advance planning provisions work under the Mental Capacity Act with how they appear to work under the CRPD. As we shall see there is a lack of clarity on how advance planning works under the CRPD, particularly concerning self-binding provisions. This Chapter also explores will and preference and the different weight incapacitous will and preference is given under the Mental Capacity Act and Mental Health Act versus the CRPD. This involves reflection of which will and preference count as an expression of 'legal agency' and are therefore protected by Article 12.

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[7] This is with the exception of P. Weller, *New Law And Ethics In Mental Health Advance Directives* (1st edn, Routledge 2015)

Chapter 2 outlines a conceptual and fundamental barrier to CRPD compatibility for advance plans under the Mental Capacity Act. Namely, that concepts of self with mental health need to be reconceptualized to achieve CRPD compatibility and envisage a universal self who, regardless of deficits to mental capacity, is awarded full legal capacity. It is argued that many social and philosophical theories on self and personhood create a divide line between a 'healthy' and 'ill' self, where that divide is drawn based on the presence of mental health difference. This divide has influenced mental capacity law which seeks to divide the healthy autonomous self from the ill non-autonomous self. Indeed, the purpose of advance planning is to protect the wishes of the autonomous self for as long as possible. In mental capacity law this divide is also made based on the 'presence of a disturbance in the functioning of the mind or brain' which disproportionately targets those with mental health difference.[8] It is argued the CRPD would not maintain a divide in selves based on mental health difference, and instead promotes a universal concept of self.

Chapter 3 describes the methodology of this thesis, including recruitment, data analysis and research design including the three data collection methods- an interactive activity on self, case studies and semi-structured questions.

Chapter 4 uses data from the elements of self interactive activity to reflect on participants conceptions of self with mental health. This includes whether and how self changes during a mental health experience. It uses thematic analysis to outline key themes of how self changes to see whether participants responses reflect the characteristics of an 'ill' social legal theory self and therefore whether this conceptual divide between selves is warranted. Findings from this chapter call into question the validity of a 'true' self conception and the divide line discussed in Chapter 2. The question of whose wishes we are upholding with advance planning and why, is therefore firmly brought into question.

Chapter 5 explores whether there are limits to will and preference adherence when adherence would result in harm, and how this has been interpreted by UN treaty bodies and academics. This is to explore whether self-binding may be permitted under the CRPD to protect self and others from harm. The Chapter uses participants responses to case studies to explore whether, based on experience, participants would want to self-bind some decisions during a mental health experience. In the case studies participants are asked to reflect on whether to uphold or overrule wishes made during a mental health experience which are contrary to those previously expressed in an advance plan.

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[8] Mental Capacity Act 2005 s2(1).

Specifically, discussion focuses on how responses are influenced by harm and how mental health impacts self.

Chapter 6 highlights how mental capacity assessments pose one of the greatest barriers to CRPD compatibility, in their use to trigger advance plans. It reflects on participants experiences of mental capacity assessments to locate areas for potential improvement and presents an alternative trigger for self-binding provisions under the CRPD- a user led statement on change in self caused by mental health difference. This alternative is by no means an attempt at legislative reform, but instead is used to create new thinking on this area and frame data. The chapter highlights how this alternative makes some marked improvements on mental capacity assessments and in achieving CRPD compatibility. Participant responses to this alternative are discussed and suggestions are made on how this approach could be further developed. This approach however is not without its problems and creates a whole new set of questions which require further research.

Chapter 7 concludes by summarizing the main arguments of the thesis and provides practical suggestions on how to achieve greater CRPD compatibility for advance planning provisions. The chapter also offers concluding observations on the future of advance planning under the CRPD.

Chapter 1: Advance Planning under the Convention on the Rights of Persons with Disabilities

An Introduction to Advance Planning

Advance planning provisions allow an individual to record wishes and decisions to be used at a future point in time when they are assessed as no longer having the mental capacity to make those decisions.[9] They come in many forms including advance decisions (also referred to as a living will, advance directive or psychiatric advance directive,) which involve treatment refusals, and advance care plans which includes treatment refusal as well as more positive decisions. They allow an individual to have greater control over their care and treatment decisions. In a sense they act as a form of

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[9] Different terms are used to describe advance planning provisions, all of which have the same method of providing support but are discussed differently in terms of which decisions they can contain.

substitute decision making, as they allow a prior capable decision to 'substitute' a latter incapacitous decision.[10] Conceptually their purpose is to extend and protect the wishes of the autonomous self for as long as possible.[11] Historically advance planning provisions have been used in a general health context and for somatic conditions.[12] These provisions were first applied to a mental health context by Thomas Szasz in the 1980's as part of the anti-psychiatry movement and were largely understood as a way of lawfully refusing unwanted medical treatment.[13] They were recognized as a mechanism to help balance the contradiction between patient choice and autonomy versus clinical power and compulsory treatment. They do this by creating legal obligations on clinicians and care providers to respect patient choice, although the extent to which this is effective in practice in England and Wales is discussed in the next section. Despite attention focusing on advance plans as a way of refusing treatment, they have since been recognized as tools to grant positive rights, privilege patient choice and respect patient right to health. They are recognized as a part of the movement toward privileging patient involvement as the new standard for best practice in mental health care. They have therefore been extended beyond treatment refusals to document financial and welfare decisions, care and treatment preferences, and are utilized in crisis planning and recovery focused care.[14] Arguments are also developing regarding the benefits of allowing people to use advance plans to consent to treatment in advance.[15]

Research on advance planning provisions demonstrated their potential to reduce compulsory admissions and treatment. Henderson and Flood et al conducted a single blind randomized control trial on the effects of joint crisis planning on compulsory treatment.[16] The crisis plan was formed jointly with the individual, care coordinator, psychiatrist and project worker and contained, amongst other information, an advance statement of preferences for care in the event of future relapse. Those who used joint crisis planning were subject to significantly less compulsion under the Mental Health Act

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[10] P. Weller, *New Law And Ethics In Mental Health Advance Directives* (1st edn, Routledge 2015) 9.
[11] E. L. Saks, *Refusing Care* (1st edn, University of Chicago Press 2002).
[12] G.S. Owen and others, 'Advance Decision-Making In Mental Health – Suggestions For Legal Reform In England And Wales' (2019) 64 International Journal of Law and Psychiatry, 163.
[13] T. S. Szasz, 'The Psychiatric Will: A New Mechanism For Protecting Persons Against "Psychosis" And Psychiatry.' (1982) 37 American Psychologist.
[14] A. M. Scheyett and others, 'Psychiatric Advance Directives: A Tool For Consumer Empowerment And Recovery.' (2007) 31(1) Psychiatric Rehabilitation Journal.
[15] G. Widdershoven and R. Berghmans, 'Advance Directives In Psychiatric Care: A Narrative Approach' (2001) 27 Journal of Medical Ethics; R. J. Bonnie, 'Advance Directives: A Tool For Reducing Coercion' (2012) 63 Psychiatric Services; Department of Health and Social Care, Reforming the Mental Health Act (Cm 355, 2021) 69-70.
[16] C. Henderson and others, 'Effect Of Joint Crisis Plans On Use Of Compulsory Treatment In Psychiatry: Single Blind Randomised Controlled Trial' (2004) 329 BMJ.

(13%) compared with those in the control group (27%) and experiences fewer hospital admissions (30% compared with 44%).[17] Swanson et al compared a sample of people (147) who had completed a facilitated psychiatric advance directive with those who had not (97) at 6, 12 and 24 month intervals to compare the frequency of coercive interventions. Findings reveal that those who completed a facilitated advance directive were almost half as likely to experience some form of coercion (6.5%) compared with the control group (19.7%).

Perceived benefits of advance planning included increased patient control over care and treatment decisions. In Henderson and Flood et al's study, 71% of participants immediately after creating the crisis plan and 56% at the 15 month follow-up, felt they had more control over their care and treatment, and would recommend crisis planning to others (90% at immediate and 82% at follow-up).[18] Increased empowerment, patient control and enhanced rights was also the main perceived benefit of advance planning according to O'Connell and Stein's research involving 272 stakeholders involved in the psychiatric advance directive process.[19] Other benefits include assisting professionals and family members with treatment decisions, facilitating and/or improving treatment and communication,[20] helping to facilitate a more therapeutic and collaborative relationship between professionals and patients,[21] increasing the likelihood that treatment preferences would be followed and increasing patient compliance with treatment.[22]

Overall, attitudes of people with mental health difference towards advance plans are positive. Of the 496 with bipolar who responded to this question in Bartlett and Mudigonda et al's quantitative questionnaire, 82.3% thought it very important to be able to make plans in advance about personal welfare.[23] Likewise a survey of 1,011 psychiatric outpatients in the United States found that between 66-77% of people

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[17] Ibid 138.

[18] C. Henderson and others, 'Views Of Service Users And Providers On Joint Crisis Plans' (2009) 44 Soc Psychiatry Psychiatr Epidemiol, 373.

[19] M. J. O'Connell and C. H. Stein, 'Psychiatric Advance Directives: Perspectives Of Community Stakeholders' (2005) 32 Administration and Policy in Mental Health, 261.

[20] Ibid.

[21] E. Peck, P. Gulliver and D. Towel, 'Information, Consultation Or Control: User Involvement In Mental Health Services In England At The Turn Of The Century' (2002) 11 Journal of Mental Health, 448.

[22] C. M. Wilder and others, 'Medication Preferences And Adherence Among Individuals With Severe Mental Illness And Psychiatric Advance Directives' (2010) 61 Psychiatric Services.

[23] P. Bartlett and others, 'Planning For Incapacity By People With Bipolar Disorder Under The Mental Capacity Act 2005' (2016) 38 Journal of Social Welfare and Family Law, 271.

wanted to complete an advance plan if given assistance.[24] Similar high rates of approval are also demonstrated in Ireland,[25] New Zealand[26] and India.[27]

Despite this high approval however, uptake of advance plans in practice remains low. Of the 549 service users surveyed in Bartlett and Mudigonda et al's study, only 44.1% had engaged in any form of advance planning covered by the survey.[28] 28% of this was limited to non-binding informal conversations on property and affairs.[29] In O'Connell and Stein research, 55% of the 272 stakeholders surveyed said they had never heard of a psychiatric advance directive,[30] and only seven out of 104 people with schizophrenia reported having a psychiatric advance directive.[31] In the US study only 4-13% of individuals had completed an advance directive despite 66-77% wanting to.[32]

Reasons identified for this lack of uptake include a lack of patient knowledge,[33] a lack of information,[34] problems recording and accessing advance plans,[35] concerns that advance plans would have no impact on treatment,[36] and that informal statements in recovery planning means that formal legal provisions are being sidelined.[37]Despite a low completion rate, Australia, Belgium, Canada, Germany, Ireland, India, Scotland, England and Wales, The Netherlands and a number of states in the United States have explicit

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[24] J. Swanson et al. "Psychiatric Advance Directives Among Public Mental Health Consumers in Five U.S. Cities: Prevalence, Demand, and Correlates." The journal of the American Academy of Psychiatry and the Law (2006) 34(1) 43–57.
[25] B. O'Donoghue and others, 'Patient Attitudes Towards Compulsory Community Treatment Orders And Advance Directives' (2010) 27 Irish Journal of Psychological Medicine.
[26] K. Thom, A. J. O'Brien and J. J. Tellez, 'Service User And Clinical Perspectives Of Psychiatric Advance Directives In New Zealand' (2015) 24 International Journal of Mental Health Nursing.
[27] G. S. Gowda and others, 'Factors Influencing Advance Directives Among Psychiatric Inpatients In India' (2018) 56 International Journal of Law and Psychiatry.
[28] P. Bartlett and others, 'Planning For Incapacity By People With Bipolar Disorder Under The Mental Capacity Act 2005' (2016) 38 Journal of Social Welfare and Family Law, 271.
[29] Ibid.
[30] M. J. O'Connell and C. H. Stein, 'Psychiatric Advance Directives: Perspectives Of Community Stakeholders' (2005) 32 Administration and Policy in Mental Health, 249.
[31] Ibid 242.
[32] J. Swanson et al. "Psychiatric Advance Directives Among Public Mental Health Consumers in Five U.S. Cities: Prevalence, Demand, and Correlates." The journal of the American Academy of Psychiatry and the Law (2006) 34(1).
[33] P. Bartlett and others, 'Planning For Incapacity By People With Bipolar Disorder Under The Mental Capacity Act 2005' (2016) 38 Journal of Social Welfare and Family Law, 272.
[34] M. J. O'Connell and C. H. Stein, 'Psychiatric Advance Directives: Perspectives Of Community Stakeholders' (2005) 32 Administration and Policy in Mental Health, 242.
[35] P. Bartlett and others, 'Planning For Incapacity By People With Bipolar Disorder Under The Mental Capacity Act 2005' (2016) 38 Journal of Social Welfare and Family Law, 273.
[36] M. J. O'Connell and C. H. Stein, 'Psychiatric Advance Directives: Perspectives Of Community Stakeholders' (2005) 32 Administration and Policy in Mental Health, 242.
[37] P. Bartlett and others, 'Planning For Incapacity By People With Bipolar Disorder Under The Mental Capacity Act 2005' (2016) 38 Journal of Social Welfare and Family Law, 274, 275.

legal provisions recognizing advance planning. With the exception of the U.S, all have ratified the CRPD. It is therefore important to examine the current scope and function of advance planning provisions, to better appreciate the possible challenges and potential introduced in seeking compliance with the CRPD. This will be done in relation to advance planning provisions in England and Wales.

Advance Planning under the Mental Capacity Act 2005

Advance planning in England and Wales is legally recognized by the 2005 Mental Capacity Act. Formal legally binding provisions include advance directives to refuse treatment and lasting powers of attorney.

Prior to the Mental Capacity Act 'living wills' were already being utilized, notably in response to the HIV/AIDS crisis in the 1980's and 1990's, to allow people to refuse treatment in certain circumstances.[38] It was in the 1990's that courts began to consider the legal nature of advance plans, first in the case of *Re T*- which was in many ways a false start since damages for non-compliance were nominal;[39] and more notably in *Re C (Adult: refusal of medical treatment).* [40] This case involved a man with paranoid-schizophrenia who had developed gangrene in his leg. If the leg was not amputated below the knee his predicted chance of survival was only 15%. The man continuously refused to consent to the amputation, and despite his capacity to make the decision being affected by his mental health, it was held that his refusal was to carry over and act as an advance statement of wishes during any future periods of incapacity. This ruling had more judicial effect than *Re T* since Justice Thorpe issued an injunction prohibiting future treatment which was incompatible with advance, competent wishes.[41] This provided future similar cases with a remedy by which any party acting incompatibly- by overruling an advance statement concerning medical treatment- would be held in contempt of court.

These rulings in advance decisions were part of` a common law interlude prior to the 2005 act, which attempted to answer questions on how to define mental incapacity, when and who could make decisions on another's behalf and how to determine best

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[38] The Terrence Higgins Trust and King's College London, 'Living will' (1992) London.
[39] *Re T* [1992] 4 ALL ER 649, pg. 665, 669.
[40] *Re C* (Adult: refusal of medical treatment) [1994] 1 ALL ER
[41] Ibid 819, 825.

interests.[42] This interlude led to a series of rulings beginning with *Re F (mental patient: sterilisation)* in 1989,[43] and followed by *Re S (hospital patient court's jurisdiction)*[44] *R (adult medical treatment)*[45] and *Re TF (an adult residence)*[46] which proved "doctrinally unsatisfactory."[47] This case law together with case law on advance plans, highlighted many unanswered questions and prompted the Law Society's 1989 publication "Decision Making and Mental Incapacity: A Discussion Document." This proved the impetus for the series of Law Commission reports and draft bills which would eventually become the Mental Capacity Act 2005.[48]

The legally binding nature of advance refusals, alongside lasting powers of attorney, was therefore enshrined in the 2005 act in sections 24-26 and 9-14 respectively. The act is also the first to enshrine a mental capacity assessment which is used to trigger an advance plan and is discussed shortly.

Advance directives (also called living wills or advance refusals,) allow a person to refuse medical treatment- including life sustaining medical treatment- in advance. [49] Lasting power of attorney allow an individual to appoint a substitute decision maker or 'donee,' to make decisions on that individuals behalf at a time when they lack capacity.[50] There are two forms of lasting power of attorney which differ based on the types of decisions the donee is permitted to make. The first allows a donee to make decisions concerning the individual's welfare,[51] the second for decisions about property and affairs.[52]

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[42] Peter Bartlett, *Blackstone's Guide To The Mental Capacity Act 2005* (2nd edn, Oxford University Press 2008).

[43] *Re F (mental patient: sterilisation)* [1990] 2 AC 1.

[44] *Re S (hospital patient court's jurisdiction)* [1996] Fam 1 (CA).

[45]*Re R (adult medical treatment)* [1996] 2 FLR 99.

[46] *Re TF (an adult residence)* [2000] 1 MHLR 120.

[47] Peter Bartlett, *Blackstone's Guide To The Mental Capacity Act 2005* (2nd edn, Oxford University Press 2008) 26.

[48] Law Commission, 'Mentally Incapacitated Adults And Decision Making: An Overview' (Consultation Paper 119, Law Commission 1991). Law Commission, 'Mentally incapacitated adults and decision making: a new jurisdiction' (Consultation Paper 128 1993). Law Commission 'Mentally incapacitated adults and decision making: Medical treatment and research' (Consultation Paper 130 1993). Law Commission 'Mentally incapacitated adults and decision making: Mental incapacity' (Consultation Paper 231 1995). Lord Chancellors Department, 'Who Decides? Making decisions on behalf of mentally incapacitated adults' cm 3803 (1997). Lord Chancellors department 'Making Decisions: the government's proposals for making decisions on behalf of mentally incapacitated adults' cm 4465 (1999).

[49] Mental Capacity Act s24(1).

[50] Ibid s9.

[51] Ibid s9(1)(A).

[52] Ibid s9(1)(B).

Informal advance planning provisions have also emerged outside the law in a non-clinical context.[53] These provisions are advisory and include advance care plans which focus on end-of-life care, recovery plans and joint crisis plans.[54] The creation of recovery plans is being regularly facilitated by mental health facilities and the plans themselves can include contact information of support persons, who not to contact, any identified triggers, a crisis plan including details of when a supporter needs to step in, and a wellness maintenance plan.[55] Moreover, when asking participants about advance planning during interviews/focus groups many referred to recovery plans.[56] Crisis plans were originally founded in the Survivor Movement to document support arrangements in times of crisis, and joint crisis plans involve an independent facilitator who mediates between the individual and the relevant clinician and care team to generate the advance plan together.[57]

There are currently no formal legal provisions which allow a person to consent to treatment in advance, nor a provision which an individual can use to go beyond treatment refusal to request specific care or treatment.[58] There are many reasons for this, including fear that advance directives would be used to request assisted dying, resource constraints - for example demanding a treatment which is no longer available, and because clinicians cannot be made to provide treatment that is clinically unnecessary, futile or not appropriate for the patient’s condition.[59] A concern with advance consent and requesting specific treatments expressed in the Law Commission Consultation on Medical Treatment and Research is that an individual may find it hard to adequately appreciate future circumstances and the evolution of treatment options.[60] A tension which exists throughout the report, and which is addressed by only permitting

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[53] G.S. Owen and others, 'Advance Decision-Making In Mental Health – Suggestions For Legal Reform In England And Wales' (2019) 64 International Journal of Law and Psychiatry, 165-166.
[54] 'Planning Now For Your Future – Advance Care Planning - Dementia UK' (*Dementia UK*, 2021) <https://www.dementiauk.org/get-support/legal-and-financial-information/advance-care-planning/> accessed 14 January 2021.
[55] An example of a recovery plan includes 'Wellness Recovery Action Plan (WRAP)' (*CWP*, 2021) <https://www.cwp.nhs.uk/about-us/our-campaigns/person-centred-framework/recovery-toolbox/wellness-recovery-action-plan-wrap/> accessed 14 January 2021.z
[56] This is reflective of findings in Bartlett et al’s study: P. Bartlett and others, 'Planning For Incapacity By People With Bipolar Disorder Under The Mental Capacity Act 2005' (2016) 38 Journal of Social Welfare and Family Law, 274, 275.
[57] G.S. Owen and others, 'Advance Decision-Making In Mental Health – Suggestions For Legal Reform In England And Wales' (2019) 64 International Journal of Law and Psychiatry, 166.
[58] Office of the Public Guardian, 'Mental Capacity Act Code Of Practice' (2007) 5.44 available: https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice
[59] Ibid 9.6, 5.44
Law Commission, *Mentally Incapacitated Adults and Decision-Making Medical Treatment and Research* (Law Comm No 129, 1993) paras 1.8-1.9
[60] Ibid para 3.12

legally binding refusals, is to strike an appropriate balance between patient wishes and the autonomy of medical professionals to judge what is in the best interests of the patient at that time.[61]All aforementioned forms of advance planning play some role in guiding best interest decisions under the Mental Capacity Act. Under section 4 of the Act, where a person is assessed as lacking mental capacity an appointed decision maker may make decisions on that individual's behalf which they consider to be in their best interest. In making a best interest ruling, the decision maker must consider, as far as is reasonable to ascertainable "the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity)."[62] Advance plans are therefore to be considered under a best interest's assessment. However, these are but one of many considerations for the representative decision maker, meaning that plans which are only advisory in nature- including recovery plans and advance care plans, can be easily overruled. Valid powers of attorney and advance directives on the other hand are intended to be legally enforceable in and of themselves.

Valid advance directives are to be treated as though they were the individual's current capacitous decision under s26(1) MCA. This is with the exception of persons detained under part 4 of the 1983 Mental Health Act, which permits a valid advance directive to be overruled where treatment is needed to treat 'mental disorder'[63] and its ancillary,[64] with the exception of electroconvulsive therapy.[65]

In order to be valid, an advance directive must be made by a competent individual who has mental capacity;[66] reasonable information about the decision and its consequences; and it must be strictly applicable to the scenario in which it is to be applied.[67] The burden of proof on the validity and applicability of the advance refusal is on the individual creating the directive[68] and the older the refusal is the more heavily it is scrutinized.[69] The directive will not be valid if any circumstances specified in the advance decision are absent or new unanticipated circumstances have arisen which would likely have affected the decision had P anticipated them;[70] if the directive has been withdrawn[71] or if P has

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[61] Ibid para 1.8
[62]Mental Capacity Act 2005, s 4(6)(a).
[63] Mental Capacity Act s28.
[64] *Tameside and Glossop Acute Services Trust v. CH* (1996) 1 F.L.R. 762.
[65] Mental Capacity Act s28(1A).
[66] Ibid s24(1)(b).
[67] Ibid s25(1), s25(4)(a).
[68] S. Muzaffar, "To Treat Or Not To Treat'. Kerrie Wooltorton, Lessons To Learn' (2011) 28 Emerg Med J, 742.
[69] Office of the Public Guardian, 'Mental Capacity Act Code Of Practice' (2007) 9.29–9.30, available: https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice
[70] Mental Capacity Act s25(4)(b, c).
[71] Ibid s25 (2)(a, b).

done anything else clearly inconsistent with the advance decision remaining their fixed decision.[72]

An advance directive refusing general treatment (as opposed to life sustaining treatment,) can be oral according to the code of practice.[73] There may arise practical problems however with this approach as medical professionals may not wish to rely on 'he said she said' statements when making treatment decisions. There likely exists some tension therefore between how advance directives for general treatment can be formatted according to guidelines- orally, compared with how they are formatted in practice to be most effective- in writing. Morgan comments on the benefits of written advance plans, including that it helps establish (though not conclusively) that the wishes documented are truly the individuals own and not a result of undue influence and facilitates decisions being documented in more specific as opposed to general terms to better fulfill the validity criteria in the MCA.[74]

Advance directives refusing life sustaining treatment need to be in writing, signed by the individual and witnessed by at least one other person according to s25(6)a of the Act. They may come under more scrutiny if they are witnessed by a family member for fear of undue influence and do not include words along the lines of 'even if this refusal of treatment were to shorten my life.'[75] The level of evidence must be scrutinised with special care where life is at risk and any doubts around validity fall on the side of life preservation.[76] Medical professionals can reject an advance directive if they are not satisfied these criteria have been met, meaning that advance directives for both general treatment and life sustaining treatment are inherently revocable.[77] There exists no statutory requirement that this revocation be objectively reasonable.[78]

In order for a lasting power of attorney to be valid, the grantor must be an individual who has reached 18 and who had capacity to execute it.[79] The attorney(s) appointed

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[72] Ibid s25(2)(c).

[73] Office of the Public Guardian, 'Mental Capacity Act Code Of Practice' (2007) 9.22–9.23, available: https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice

[74] Derek Morgan, 'Odysseus And The Binding Directive: Only A Cautionary Tale?' (1994) 14 Legal Studies, 429.

[75] Based on comments made by Celia Kitzinger at the Birmingham Law School Advance Decisions Workshop, during a talk titled "Supporting People Who Want to Refuse Treatment in Advance of Losing Capacity: Report from the Coalface".

[76] *HE v A Hospital NHS Trust* [2003] EWHC 1017 (Fam), para 43.

[77] Ibid para 37.

[78] S. Muzaffar, ''To Treat Or Not To Treat'. Kerrie Wooltorton, Lessons To Learn' (2011) 28 Emerg Med J, 742.

[79] Mental Capacity Act s9(2)(c).

must also be 18 years old[80] and can be a trust corporation for decisions concerning property and affairs.[81] Any lasting power of attorney must comply with section 10 of the Mental Capacity Act and be registered in accordance with the requirements laid out in schedule 1. In terms of their creation, lasting powers of attorney must be written, signed by the donor, the proposed donee(s), one impartial witness, and the certificate provider- either someone who has known the donor for at least two years or a relevant professional i.e. a healthcare professional or solicitor.[82]

Both lasting powers of attorney and advance directives are triggered by a finding of mental incapacity.

The Mental Capacity Act is the first in England and Wales to codify a mental capacity assessment to determine when an individual is thought no longer capable of making decisions for themself. According to section 2(1) of the act, a person lacks mental capacity '*... if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.'*[83] Considerable weight is given therefore to cognitive functioning and the ability to make decisions. According to s3(1) a person is unable to make a decision if they cannot understand, use, weigh and retain relevant information to a decision, and are not able to communicate that decision through whatever form, to others. The assessment is therefore decision specific. It was designed by drafters to be accessible so that as many people as possible can use it.

The Mental Capacity Act adopts a functional approach to capacity founded in the Council of Europe's Recommendation No. R (99)4 on Principles Concerning the Protection of Legally Incapable Adults, which states that "[f]or the purpose of the principles, incapacity is a functional concept relating to decision-making."[84] This means decision making ability is assessed and decisions are denied accordingly. Therefore, if a person is assessed as

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[80] Ibid s10(1)(a).

[81] Ibid s10(1)(b).

[82] 'LP12 Make And Register Your Lasting Power Of Attorney: A Guide (Web Version)' (*GOV.UK*, 2020) <https://www.gov.uk/government/publications/make-a-lasting-power-of-attorney/lp12-make-and-register-your-lasting-power-of-attorney-a-guide-web-version> accessed 16 January 2021.

[83] Note that 'mind' which seems here to refer to impairment caused by mental health difference, is conflated with 'brain' which seems to refer to somatic conditions, for example head injury. There exist some interesting questions here, beyond the scope of this thesis, on whether the two ought to be conflated or whether mental capacity assessments ought to apply differently for mental health difference and somatic conditions.

[84] Council of Europe Committee of Ministers Explanatory Memorandum Recommendation No.R (99) 4 Principles Concerning the Protection of Legally Incapable Adults [1999] 16

lacking mental capacity, their decision lacks legal enforceability meaning it will not be adhered to at law.

Conceptually then, the aim of advance plans is to extend the wishes of a competent self to a future point in time when they lack mental capacity. They therefore extend the wishes of the unimpaired self to future periods of incapacity.

Advance directives and lasting powers of attorney therefore provide some scope for self-binding. Self binding also referred to as a 'Ulysses Contract,' allows one version of self with mental capacity to make decisions on behalf of a future self who is assessed as lacking capacity. One version of self is therefore allowed to bind the decisions of a future self on the basis of mental impairment. The very draw of advance planning for some may be to overrule some decisions during a mental health experience to protect themselves and others from harm. Support for this can be found in *Briggs v Briggs* in which Mr Justice Charles describes advance directives and lasting powers of attorney as 'enabling conditions' which clearly demonstrate a legislative intention for one version of self to bind another.[85] This is so even if that later self is "very different and have very different perspectives on a whole range of issues including the quality of their life."[86]

Saks argues in favor of self-binding because they represent the interests of the 'true self' capable of making capacitous decisions. She states: "[i]mpairments are limitations and, all else being equal, it is better not to suffer limitations."[87] They are also seen as documenting long-standing wishes, the longevity of which is taken to mean they are more genuine than contrary wishes expressed during a mental health experience. [88] Dworkin discusses this in terms of documenting 'critical interests'- long held wishes and beliefs, which he believes should overrule 'experimental interests' -short term things people do for the enjoyment of doing them. [89]

While self-binding therefore is inherently protectionist it may be conceptually preferential to other forms of substitute decision making as decision making remains with the individual, albeit a version of that person at an earlier point in time.[90]

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[85] [2016] EWCOP 53, [2017] COPLR 42

[86] Ibid, para 28.

[87] E. R. Saks, *Refusing Care* (1st edn, University of Chicago Press 2002) 204-205.

[88] J. Savulescu and D. Dickenson, 'The Time Frame Of Preferences, Dispositions, And The Validity Of Advance Directives For The Mentally Ill' (1998) 5 Medicine and Health 229.

[89] R. Dworkin, *Life's Dominion: An Argument About Abortion, Euthanasia and Individual Freedom* (Harper Collins, London, 1993) 211, 228-229.

[90] E. R. Saks, *Refusing Care* (1st edn, University of Chicago Press 2002) 205.

As mentioned however, advance planning provisions are not without their practical and conceptual problems.

As mentioned, uptake of advance plans is low. Of those advance directives which are completed- despite their legally binding nature, there are instances in which medical professionals are hesitant to uphold an advance refusal- especially when that directive refuses life sustaining medical treatment. Life preservation is a well-documented phenomenon in case law surrounding advance directives, and there exists a tension between the legal enforceability of advance directives under the Mental Capacity Act versus in practice[91]

Bonner and colleagues - all practicing medical professionals- use a case study to discuss their hesitancy on following an advance refusal of life sustaining treatment following an overdose.[92] This is for several reasons, but ultimately boils down to their fear that the individual may change their mind, or that more could be done to help them. They also talk about the additional harm that could be done while trying to establish an advance directive as valid and applicable to the circumstances.

The concern that an individual may change their mind when confronted with a future unfamiliar situation, for which they could not accurately predict what they may want, forms one of the dominant conceptual concerns for self-binding. The classic example of this is Dworkin’s theoretical Margo case. This case involves a woman- Margo, who has permanent and progressive Alzheimer’s and would now be considered to have lost mental capacity.[93] Margo is regularly visited by a medical student, Firlik, who comments that “despite her illness or maybe somehow because of it, Margo is undeniably one of the happiest people I have ever known.”[94] Margo presently demonstrates a desire to live. Dworkin then asks us to imagine that Margo, when competent, created an advance refusal stating that she wished to refuse life sustaining treatment. Instead “she should be killed as soon and as painlessly as possible.”[95] Dworkin asks, in the event Margo becomes ill and needs lifesaving treatment, do we honor the directive or her current will and preference? In other words, which version of self do we listen to?

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[91] See for example *Re E* [2012] EWHC 1639 (COP) para 140; *HE v A Hospital NHS Trust* [2003] EWHC 1017 (Fam) para 46; *Bland* [1993] AC 789.

[92] S. Bonner, M. Tremlett and D. Bell, 'Are Advance Directives Legally Binding Or Simply The Starting Point For Discussion On Patients’ Best Interests?' (2009) 339 BMJ.

[93] R. Dworkin, *Life’s Dominion: An Argument About Abortion, Euthanasia and Individual Freedom* (Harper Collins, London, 1993) 220-221.

[94] Ibid 221.

[95] Ibid 226.

Dresser applies Parfit’s theory of personal identity to argue that there exists no continuity between the two selves, meaning Margo is now a different person and should no longer be bound by the directive.[96] Morgan also comments on this problematic idea that the creator may have changed to such a degree that we can no longer feasibly be talking about the same person.[97] As stated by Buchanan “the very process that renders the individual incompetent and brings the advance directive into play can and indeed often does - destroy the conditions necessary for her personal identity and thereby undercut entirely the moral authority of the directive.’[98] Studies have shown that people can adjust their quality of life, and what they once considered a life not worth living may change.[99] This echoes Dresser’s comment that people should be supported to achieve a kind of ‘good life’ within their capacities, as opposed to this being compared to their quality of life pre-mental health difference.[100]

This kind of legally enforceable self-binding is therefore problematic in circumstances such as Margo’s. While the Mental Capacity Act directs best interest decision makers to have regard for present wishes and feelings, no further guidance is provided as to what should happen if past and present wishes conflict. Under s24(2)(c) of the act, an advance directive is invalid if the individual has done something “clearly inconsistent with the advance decision remaining [their] fixed decision.” However it is unclear whether the individual must have acted with mental capacity or whether this could include incapacitous wishes contrary to the advance directive.[101] There is then the added question of whether this would be interpreted more generously in practice, or the person would be considered to have mental capacity, if the contrary decision they were expressing aligned with the relevant clinicians. The CRPD on the other hand makes it clear that regardless of capacity, individual will and preference is to be respected. This would seem to preclude any form of self-binding when a contrary wish is expressed, even if that wish is expressed during a mental health experience. Therefore by far the biggest

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[96] R Dresser, 'Life, Death And Incompetent Patients: Conceptual Infirmities And Hidden Values In The Law' (1986) 28 Ariz. L. Rev. 373, 380-381.

[97] D. Morgan, 'Odysseus And The Binding Directive: Only A Cautionary Tale?' (1994) 14 Legal Studies, 433.

[98] A. Buchanan, 'Advance Directives And The Personal Identity Problem' (1988) 17 Philosophy & Public Affairs, 280.

[99] See for example J. N. Morris, S. Suissa, S. Sherwood, S. M Wright, D. Greer, 'Last Days: A Study Of The Quality Of Life Of Terminally Ill Cancer Patients' (1986) 39 Journal of Chronic Diseases 47.

[100] R. Dresser, 'Life, Death And Incompetent Patients: Conceptual Infirmities And Hidden Values In The Law' (1986) 28 Ariz. L. Rev. 373, 384.

[101] A. Ruck Keene, R. Cooper and T. Hobbes, 'When Past And Present Wishes Collide: The Theory, The Practice And The Future' [2017] Eld LJ, 132, 133. <https://www.mentalcapacitylawandpolicy.org.uk/wp-content/uploads/2017/11/When-wishes-and-feelings-collide.pdf> accessed 14 January 2021.

conceptual hurdle for advance planning provisions is how they are to be conceived under the CRPD.

Advance Planning under the Convention on the Rights of Persons with Disabilities

The CRPD was ratified by the United Kingdom in June 2009, and the optional protocol was ratified in August that same year. Because the UK is a dualist state which requires treaties to be incorporated into domestic legislation, the CRPD is not binding on courts, but serves as a source of 'persuasive authority' in interpreting domestic law.[102]

This convention is the first piece of international legislation to recognise rights specifically for disabled people. The three key international human rights law treaties- the United Nations Declaration on Human Rights (adopted 1948,) the International Covenant on Civil and Political Rights (adopted 1966) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) (also adopted in 1966,) do not list disability as a protected characteristic. Instead it is encompassed under the scope of 'all' or 'other status.'[103] Between 1996 and 2003 only 17 disability related complaints were made under UN mechanisms- 13 of which were deemed inadmissible.[104]

In light of this gap, the UN published a series of declarations including the 1971 Declaration of the Rights of Mentally Retarded Persons[105] and the 1975 Declaration of the Rights of Disabled Persons.[106] These declarations however made it clear that disabled people were still different, with the 1971 declaration stating that 'the mentally retarded person has, *to the maximum degree of feasibility,* the same rights as other human beings'[107] [emphasis added.] The 1975 declaration also perpetuated a medical model

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[102] L. Series, 'Role Of The CRPD In Domestic Law In The United Kingdom' <https://thesmallplaces.wordpress.com/resources-on-legal-capacity-and-the-united-nations-convention-on-the-rights-of-persons-with-disabilities/> accessed 14 January 2021.

[103] "all": United Nations Declaration on Human Rights, Article 7. "other status": International Covenant on Civil and Political Rights Article 26. International Covenant on Economic, Social and Cultural Rights Article 2(2).

[104] M. A. Stein and Janet E. Lord, 'Future Prospects For The United Nations Convention On The Rights Of Persons With Disabilities', *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian perspectives* (Martinus Nijhoff Publishers 2009) 18.

[105] General Assembly, 'Declaration on the Rights of Mentally Retarded Persons: Resolution 2856 (XXVI)' (20 December 1971).

[106] General Assembly, 'Declaration on the Rights of Disabled Persons Resolution 3447 (XXX)' (9 December 1975).

[107] General Assembly, 'Declaration On The Rights Of Mentally Retarded Persons Resolution 2856 (XXVI)' (20 December 1971) 1.

concept of disability.[108] During the 1980's there was an influx of awareness around disability rights and in 1983 a World Programme of Action Concerning Disabled Persons was established, from which came a series of general assembly resolutions on disability.[109] This period culminated in the ICESCR committee general comment no.5 in 1994 which formally recognised that disability fell within its scope since 'other status' "clearly applies to discrimination on the grounds of disability."[110] This recognition came eighteen years after the treaty came into effect in 1976. These resolutions however lack legal enforceability[111] and in 2001 the UN General Assembly established an Ad Hoc Committee to consider a disability based human rights instrument.[112] This group produced the foundational text which after negotiations and amendments,[113] would become the CRPD in 2006.[114]

The CRPD has been considered revolutionary. This is in terms of its 'paradigm shift' in the way disability is conceived, for its specific conveyance of anti-discrimination rights to disabled people, and in its formation- being the first UN convention to ever involve non-governmental organisations (NGOs) throughout the conventions drafting. Many of these NGOs- including for example Disabled Peoples' International and the World Federation of the Deafblind, are run largely *by* disabled people, and the stamp of this inclusion can be summarized in the convention's slogan 'nothing about us, without us.'[115]

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[108] For example the definition of disability is 'any person *unable* to ensure *by himself or herself*, wholly or partly, the necessities of a *normal* individual and/or social life, *as a result of deficiency,'* [emphasis added] which is very individual focused and focused on what an individual can't do as a result of disability rather than wider social barriers.

[109] Including the General Assembly 'Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care' (1991). and General Assembly 'United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities' (1993).

[110] International Covenant on Economic, Social and Cultural Rights Committee, 'General comment No. 5: Persons with disabilities' pg 111, para 5.

[111] I acknowledge here the debate around whether IHR treaties are legally enforceable in the sense that it is difficult to enforce state compliance.

[112] Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities, G.A. Res. 56/168, U.N GAOR, 56th Sess., Supp. No. 168, U.N. Doc. A/RES/56/168 (Dec. 19, 2001).

[113] 8 sessions total including a working group run by the Ad Hoc committee from 2002-2006, all can be found and read here: https://www.un.org/esa/socdev/enable/rights/adhoccom.htm

[114] Working Group to the Ad Hoc Committee, 'Ad Hoc Comm. on a Comprehensive and Integral International Convention on the Prot. & Promotion of the Rights & Dignity of Pers. with Disabilities,' (U.N. Doc. A/AC.265/2004/WG.1 Jan 27 2004) para1.

[115] A list of NGOs involved in the working group for the CRPD are listed here: https://www.un.org/esa/socdev/enable/rights/ahcwg.htm

The CRPD adopts a social model approach to disability- a model popularized by Michael Oliver in his 1990 publication 'The Politics of Disablement' during the disability movement.[116] This model alters the perspective of disabled people from 'objects' to be cared for to 'subjects' capable of being full rights bearers.[117] This model therefore moves away from a medical model- which focuses on the individual, their impairment and how it can be 'fixed,' and instead focuses on social barriers and how they can be alleviated to better promote the rights of disabled people to achieve equality. Therefore emphasis within the convention is placed on supporting disabled people in achieving equality. Advance planning is one such explicit method of support mentioned in the CRPD Committee's general comment no.1.[118]

This general comment provides authoritative interpretations of Article 12 of the convention titled 'Equal Recognition before the Law.' Article 12 has the greatest implication for advance planning and is therefore the focus of this thesis.

Article 12 introduces the concept of universal legal capacity. It states:

> "1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
>
> 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

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[116] M. Oliver, *The Politics Of Disablement* (Macmillan 1990).

[117] C. de Bhailis and E. Flynn, 'Recognising Legal Capacity: Commentary And Analysis Of Article 12 CRPD' (2017) 13 International Journal of Law in Context, 6, 9.
Note that Michael Oliver never provided a definition of who is, and how someone accrues the status of, a 'legal subject.' This is particularly relevant when considering the next Chapter on 'self' in law, and further cements the importance of a re-exploration of the capabilities needed to hold and exercise legal personhood.

[118] United Nations Commission, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 17.

> 3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
>
> 4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
>
> 5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.*"*

This right to equal legal capacity is expanded on in the general comment which defines legal capacity as *"the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency)."*[119] There is no set definition of legal agency under the CRPD, but it is described in paragraph 14 of the general comment as 'the ability to act on rights accrued from legal standing, and to have those actions recognized by the law.' 'Recognized by law' has been interpreted to mean that decisions made by persons with disabilities be legally enforceable,[120] although there is some disagreement on *which* decisions constitute an exercise of legal agency, discussed more in Chapter 5. [121]

Legal capacity is a distinct concept from mental capacity which is defined as *"the decision-making skills of a person, which naturally vary from one person to another and*

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[119] Ibid para 13.

[120] A. Arstein-Kerslake and E. Flynn, 'The Right To Legal Agency: Domination, Disability And The Protections Of Article 12 Of The Convention On The Rights Of Persons With Disabilities' (2017) 13 International Journal of Law in Context, 23.

[121] Ibid; T. Minkowitz, 'CRPD And Transformative Equality' (2017) 13 International Journal of Law in Context, 77, 79.

may be different for a given person depending on many factors, including environmental and social factors."[122]

The Committee explains that:

> "…the concepts of mental and legal capacity have been conflated so that where a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed. This is decided simply on the basis of the diagnosis of an impairment (status approach), or where a person makes a decision that is considered to have negative consequences (outcome approach), or where a person's decision-making skills are considered to be deficient (functional approach). The functional approach attempts to assess mental capacity and deny legal capacity accordingly. It is often based on whether a person can understand the nature and consequences of a decision and/or whether he or she can use or weigh the relevant information. This approach is flawed for two key reasons: (a) it is discriminatorily applied to people with disabilities; and (b) 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. In all of those approaches, a person's disability and/or decision making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but, rather, requires that support be provided in the exercise of legal capacity*."*[123]

They continue:

> ""[U]nsoundedness of mind" and other discriminatory labels are not legitimate reasons for the denial of legal capacity (both legal standing and legal agency).

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[122] United Nations Commission, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 13.
[123] Ibid para 15.

> Under article 12 of the Convention, *perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity*"[124] [emphasis added].

In short, the CRPD calls for a removal of the functional approach and mental capacity assessments. Instead the will and preference of the individual is to be adhered to, and support should be provided in order to assist the individual in constructing and communicating their will and preference to others, to uphold their legal capacity.

Some reliance on cognition has therefore been retained via 'will and preference.' This is because come reasoning is needed in order to form a preference, even where that reasoning is very basic, for example to avoid pain. However cognition is relied upon to a much lesser extent compared with mental capacity assessments as the level of cognition required to form a preference is much lower than the standard needed for capacity assessments- to 'understand, use, weigh and retain relevant information.'

Individual will and preference is to be recognised at law, even if that will and preference is made during a period of mental incapacity, for example, during a mental health experience.

In terms of support, the Committee state that "[s]upport 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."[125] It is also worth noting that individuals have the rights to refuse support and terminate their support relationship at any time.[126]
One method of support explicitly acknowledged by the Committee is Advance Planning:

> "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-

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[124] Ibid para 13.
[125] Ibid para 17.
[126] Ibid para 19, 29(g).

> discriminatory. Support should be provided to a person, where desired, to complete an advance planning process."[127]

Given support should never constitute substitute decision making, the Committee provides the following characteristics of substitute decision making, which advance plans should avoid if they are to be considered a method of support. These include where:

> "
>
> (a) legal capacity is removed from a person, even if this is in respect of a single decision;
>
> (b) a substitute decision maker can be appointed by someone other than the person concerned, and this can be done against his or her will; **or**
>
> (c) 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."[128] [emphasis added]
>
> …..
>
> "Where, after significant efforts have been made, 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."[129]

Thinking back to the Mental Capacity Act then, its use of best interest assessments and how best interests could overrule an advance plan or incapacitious will and preference when the person is assessed as lacking capacity, seems to be prohibited under the CRPD. They make it clear that respecting individual will and preference is of paramount importance.

Initial observations on how the CRPD is likely to impact advance planning under the Mental Capacity Act therefore, is as follows. It seems unlikely that advance directives

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[127] Ibid para 17.

[128] Ibid para 27. As amended by the corrigendum found here: 1https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1/Corr.1&Lang=en

[129] United Nations Commission, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 21.

would remain inherently revocable without a requirement for reasonability under the CRPD, given they convey will and preference and given the CRPDs move away from a medical model towards a model of support. This would also seemingly apply to section 4 of the Mental Health Act and its ability to overrule valid advance directives to treat mental disorders and their ancillary. If a method of support can be so easily overruled it is not such of a support at all. This also seems to be driven home in the Committee's statement that "[a]t all times, including in crisis situations, the individual autonomy and capacity of persons with disabilities to make decisions must be respected."[130] This would likely include any wishes communicated by a valid advance directive. This sentiment has already been evoked to some extent in the Wessley report[131] and proceeding government white paper titled 'Reforming the Mental Health Act,' by their introduction of Advance Choice Documents.[132] These provide more scope to request and refuse treatment and should be followed if created when the individual had capacity. While the Mental Health Act retains the power to overrule advance choice documents, they seek to set a higher standard for overruling will and preference, and to make that process more transparent.[133]

Advance directives and other advance planning provisions are also likely to carry much greater weight under the CRPD compared with the Mental Capacity Act. This is because they contain will and preference which is privileged by the Committee, given their prohibition of substitute decision making, and given decisions made when an individual is unable to communicate are to be based on a best interpretation of will and preference as opposed to what's in the persons best interests. This is discussed in more detail in the next section. It is possible that existing provisions could be more strictly enforced to give greater effect to will and preference in practice. It is also likely that efforts are made to ensure more wide-spread, routine and rigorous advance planning to both increase the volume and applicability of advance plans. Indeed efforts are already being made by the government to offer greater assistance in the completion of valid lasting powers of attorney in the context of an ageing population by developing online forms and the 'track my LPA' service.[134]

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[130] Ibid para 18.
[131] S. Wessley, 'Modernising The Mental Health Act Increasing Choice, Reducing Compulsion Final Report Of The Independent Review Of The Mental Health Act 1983' (2018)
[132] Department of Health and Social Care, Reforming the Mental Health Act (Cm 355, 2021)
[133] S. Wessley, 'Modernising The Mental Health Act Increasing Choice, Reducing Compulsion Final Report Of The Independent Review Of The Mental Health Act 1983' (2018) <https://www.gov.uk/government/groups/independent-review-of-the-mental-health-act#governance> accessed 14 January 2021, 21-22.
[134] N. Goodwin, 'We'Ve Launched The New 'Use A Lasting Power Of Attorney' Service. - Office Of The Public Guardian' (*Publicguardian.blog.gov.uk*, 2021)

This expansion of advance planning could also lead to an increase in the types of decisions included in an advance plan beyond advance refusals, financial and welfare decisions, or an increase in the subset of these decisions to include more detail. This could include an increase in more positive rights being awarded greater legal weight than they currently hold (advisory.)[135] How far this scope may extend is unknown but is likely people may be encouraged to include a wider scope of more subjective will and preference for a wider range of decisions, to guide any future support person. It is for this reason that advance planning is explored in this thesis as an umbrella term, as opposed to limiting discussion to one existing provision which is open to change. This will also enable exploration of how different types of decisions in different scenarios create different barriers to compatibility.

In terms of how advance plans could apply, there exists one definite and one potential use for advance planning under the CRPD. The first is the more straight forward and involves advance plans being used to communicate will and preference when the individual is unable to make any communication with support, also termed 'facilitated decision making.'[136] An example of this would be where a person is unconscious or in a coma and the advance plan is used to determine the persons will and preference. This would either help avoid a 'best interpretation' of will and preference seen as the persons will and preference is documented, or could form the basis of a 'best interpretation' decision. This is a widely accepted use of advance planning under the CRPD and is therefore the basis for CRPD compatible reform.

The second potential use of advance planning is more controversial, as it involves the use of self-binding to prevent harm by requesting support despite verbally refusing and allowing others to take over for certain decisions. Therefore despite the CRPD Committee's insistence that will and preference should be privileged, this would involve overruling some decisions made by self during a mental health experience and having this be a form of support. This would allow individuals to avoid some harmful decision

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<https://publicguardian.blog.gov.uk/2020/07/17/weve-launched-the-new-use-a-lasting-power-of-attorney-service/> accessed 15 September 2021.

[135] Office of the Public Guardian, 'Mental Capacity Act Code Of Practice' (2007) < Office of the Public Guardian, 'Mental Capacity Act Code Of Practice' (2007)> accessed 15 January 2021.

[136] M. Bach and L. Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' (2010) prepared for the Law Commission of Ontario. Available <https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf> Accessed 26th January 2021.

making during a mental health experience, in a similar way to Ulysses. This more controversial potential function for advance plans is the one explored in this thesis.

There is an ongoing debate as to whether overruling legal capacity via substitute decision making is justified. Some academics heavily involved in the drafting of the CRPD feel support is sufficient and there exists no scenario in which to overrule legal capacity via substituted decision making.[137] Others however feel this offers insufficient protection for persons with disabilities, and that there exist some situations in which legal capacity ought to be overruled- usually where harm to self or others in concerned.[138]

Comparably there is less discussion on whether overruling legal capacity via self-binding is CRPD compatible. The Committee does not provide an express opinion on this, but based on a strict reading of general comment no.1 it would appear any form of self-binding which had the effect of overruling current will and preference would be prohibited. Support of this interpretation is provided by the Office of the High Commissioner for Human Rights, reporting to the Human Rights Council. They state with regards to advance directives and lasting powers of attorney that "[e]ven when such instruments are in force, persons with psychosocial disabilities must always retain their right to modify their will and service providers should continue to seek their informed consent."[139]

On the other hand however, there remains the question of whether privileging one version of self over another is acceptable so long as the distinction between selves is not being drawn on the basis of a functional approach, as it is currently.

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[137] A. Dhanda, 'Legal Capacity In The Disability Rights Convention: Stranglehold Of The Past Or Lodestar For The Future?' (2007) 34 Syracuse Journal of International Law and Commerce.
Tina Minkowitz, 'CRPD And Transformative Equality' (2017) 13 International Journal of Law in Context.

[138] S. Wessley, 'Modernising The Mental Health Act Increasing Choice, Reducing Compulsion Final Report Of The Independent Review Of The Mental Health Act 1983' (2018) <https://www.gov.uk/government/groups/independent-review-of-the-mental-health-act#governance> accessed 14 January 2021, 12-13.
George Szmukler, 'Submission To Committee On The Rights Of Persons With Disabilities On The Draft General Comment On Article 12' <https://www.ohchr.org/en/hrbodies/crpd/pages/dgcarticles12and9.aspx> accessed 15 January 2021.

[139] UN OHCHR 'Annual Report Of The United Nations High Commissioner For Human Rights And Reports Of The Office Of The High Commissioner And The Secretary-General: Mental Health And Human Rights' (2017) <https://www.un.org/development/desa/disabilities/resources/human-rights-council.html> accessed 4 February 2021, para 28.

There is some consensus in literature on Article 12 that there exists scope for self-binding, provided the grounds for any distinction between versions of self is not based on a mental capacity.

Flynn and Arstein-Kerslake discuss this in reference to an individual refusing support. They state: "[w]e must recognise that in the context of mental health experience and/or dementia, there may need to be a specific clause in a support agreement that provides for exactly the circumstances in which an individual would like support even when she is verbally refusing support in a given moment (sometimes referred to as a Ulysses clause). It must be a carefully crafted and safeguarded clause to avoid any form of forced treatment, or the reverse, a lack of support for a person at a time of crisis when the person actually desired the support."[140]

Bhailis and Flynn interpret the substituted decision making criteria provided by the Committee to mean that "[s]ituations in which someone is appointed a decision-maker as a last resort because an individual's will and preferences are not known or where a person chooses to give a trusted supporter decision-making powers in certain areas of their lives are still permitted under Article 12."[141] In regards to electing a support person to function in a similar way to a lasting power of attorney therefore, there seems to be some support. This is also echoed by Arstein-Kerslake and Flynn who discuss the ability of a support person to apply their knowledge on an individual's 'true' will and preference, to justify removing them against their will from a 'gravely dangerous situation.'

> "[W]e can acknowledge that in emergency situations, where an individual is engaging in self-harm or is non-responsive, those around the individual have to make quick decisions. In making these decisions, support persons have an obligation to utilise any knowledge they have of the individual's true will and preferences. However, we must also allow and even expect that support people will also use the baseline assumption that any individual would not choose to be in a situation in which they were being harmed. Therefore, a support person is complying with the support model when she removes an individual from a gravely dangerous situation in an effort to assist the individual in getting to a place where the individual can better communicate her will and preferences. This type of

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[140] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 96.

[141] C. de Bhailis and E. Flynn, 'Recognising Legal Capacity: Commentary And Analysis Of Article 12 CRPD' (2017) 13 International Journal of Law in Context, 13.

> intervention, however, should never rise to the level of forced medical or psychiatric treatment."[142]

Overruling will and preference via self-binding and electing a support person to overrule some will and preference has therefore been interpreted as within the remits of CRPD compatibility.

Likewise Minkowitz acknowledges that self-binding may be valued by some and is interested in how it can be utilised in a support context as opposed to one reliant on mental capacity.[143] "We know that legal mechanisms can and will be used to take control of a person's destiny contrary to his/her own will and desires. At the same time, some of us have been grateful that someone else took over at certain times, even when it was against the person's own will – although we might not have been pleased with the totality of consequences and outcomes. The mechanism of crisis planning and advance refusals/powers of attorney allows some of us to feel more secure about proactively facing a challenging situation before it comes."[144]

Overall, whether an individual can use an advance plan to self-bind and whether this retains CRPD compatibility is unclear. Mixed signals seem to be offered by the CRPD Committee and Human Rights Council versus academic literature, including from academics heavily involved in the drafting of the general comment. For those who feel there exists some situations in which legal capacity ought to be restricted, and for those who feel there exists some scope for self-binding under the CRPD; questions then arise as to whether a disability neutral trigger to restrict legal capacity- not reliant on an assessment of mental capacity, is possible. This includes questions around what this trigger might look like and whether this alternative is in fact an improvement upon the current system for persons with disabilities.

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[142] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 93.

[143] T. Minkowitz, 'The United Nations Convention On The Rights Of Persons With Disabilities And The Right To Be Free From Nonconsensual Psychiatric Interventions' (2007) 34 Syracuse Journal of International Law and Commerce, 409.
T. Minkowitz, 'CRPD Article 12 And The Alternative To Functional Capacity: Preliminary Thoughts Towards Transformation' [2013] SSRN Electronic Journal <https://www.researchgate.net/publication/272241633_CRPD_Article_12_and_the_Alternative_to_Functional_Capacity_Preliminary_Thoughts_Towards_Transformation> accessed 18 January 2021, 9.

[144] T. Minkowitz, 'Legal Capacity From A Psychosocial Disability Perspective: A Discussion Paper' <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2374733> accessed 14 January 2021, para 9.

Unfortunately the CRPD provides little guidance on what an alternative to mental capacity assessments might look like. As stated by Minkowitz, "[t]he classification of incapacity as a legal construct (sometimes "referred to as "functional capacity," "mental capacity" or "competence to consent") has to be let go, and there is actually nothing to replace it with."[145]

Some guidance on how to trigger a self-binding statement is provided by the Committee in reference to Advance Directives:[146]

> "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…"[147]

This alludes to a user-led and user-controlled written trigger, which is very distinct from the current objective assessments of mental capacity. This also alludes to the possibility of advance directives being triggered before an individual reaches the stage of being unable to communicate will and preference.

This raises questions about what an alternate to mental capacity assessments looks like and what indicators an individual could be expected to draw on. It may be the case that advance directives have been isolated to address situations where an individual experiences a mental health episode and is able to communicate but does so incoherently creating a 'hard case' for supporters and professionals.[148] Another possible explanation is to address emergencies where there is insufficient time available to support the person in delivering coherent will and preference. Therefore it may be with these scenarios in mind that an individual may be expected to draw upon in deciding

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[145] T. Minkowitz, 'CRPD Article 12 And The Alternative To Functional Capacity: Preliminary Thoughts Towards Transformation' [2013] SSRN Electronic Journal <https://www.researchgate.net/publication/272241633_CRPD_Article_12_and_the_Alternative_to_Functional_Capacity_Preliminary_Thoughts_Towards_Transformation> accessed 18 January 2021, 9-10.

[146] It should be noted that the Committee offers no definition of what they mean by an advance directive, given an advance directive in England and Wales concerns decisions on treatment refusal, whereas psychiatric advance directives contain a wider array of decisions on care and treatment.

[147] United Nations Committee on the Rights of Persons with Disabilities, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 17.

[148] A. Arstein-Kerslake and 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' (2015) 20 The International Journal of Human Rights, 482-485.

when the advance directive enters into force. In this sense there may be room for a limited form of self-binding.

However, whilst this provides some limited assistance to one type of hard case- where the individual is expressing seemingly incoherent will and preference, this does not assist with the other type of hard case- where someone expresses harmful will and preference. One of the draws of self-binding is the ability to prevent self and others from harm. Ulysses being tied to the mast to avoid the call of the sirens is a good example. Another example could be someone with bipolar using a lasting power of attorney concerning financial decisions to prevent them from spending large amounts of money during a manic episode. For this reason, there may be some value in extending the Committee's guidelines on triggering an advance directive to other forms of advance planning and decisions beyond advance refusal. If mental capacity assessments and restrictions to legal capacity are prohibited, there is scope to use advance plans to elect some form of state intervention and/or self-bind to overrule some decisions during a mental health experience. This may prove very useful to some with mental health difference.

Some academics believe one way to safeguard harmful will and preference under the CRPD, is by relying on existing legal principles, including the doctrine of necessity[149] and duty of care. [150] However these existing legal principles- while holding great potential do not cover all scenarios in which a person may wish to restrict legal capacity to prevent harm. Therefore something additional may be required.

Unfortunately the Committee provides no further guidance on what this alternative to a mental capacity assessment is for triggering advance directives. Some academics suggest retaining a decision-making assessment decoupled from a diagnostic criterion,[151] or using assessments of harm[152] or adverse risk to justify restrictions to legal capacity.[153]

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[149] P. Gooding and E. Flynn, 'Querying The Call To Introduce Mental Capacity Testing To Mental Health Law: Does The Doctrine Of Necessity Provide An Alternative?' (2015) 4 Laws.

[150] Centre for Disability Law and Policy NUI Galway, 'Submission To The Australian Law Reform Commission Discussion Paper On Equality, Capacity And Disability In Commonwealth Laws' (2014) <https://www.alrc.gov.au/wp-content/uploads/2019/08/130._org_centre_for_disability_law__policy_nui_galway.pdf> accessed 15 January 2021, 16.

[151] G. Szmukler, R. Dawb and F. Callard, 'Mental Health Law And The UN Convention On The Rights Of Persons With Disabilities' (2014) 37 International Journal of Law and Psychiatry. f

[152] E. Flynn and A. 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.

[153] M. Bach and L. Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' (2010) prepared for the Law Commission of Ontario. Available <https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf> Accessed 26th January 2021.

This could also be applied to triggering advance plans. However all these triggers retain an element of the functional approach (discussed in Chapter 5) and are not user-led. This thesis therefore attempts to create new thinking on a CRPD-compatible alternative to mental capacity assessments, guided by the comments made in general comment no.1, for the purpose of triggering an advance plan (discussed in Chapter 6.)

To summarize, the future of advance planning under the CRPD creates a range of important research questions, which this thesis will address.

The weight of will and preference under the Mental Capacity Act 2005

As already alluded to, one of the key differences between advance plans under the MCA versus the CRPD is the different status or importance awarded to incapacitous will and preference. This poses one immediate barrier to CRPD compatible advance planning. This section outlines the role of will and preference under the MCA, including their role in best interest determinations and under what circumstance will and preference can be overruled. This includes discussion of which will and preference should count as an exercise of legal agency and therefore be protected under Article 12. If only some decisions are included as an exercise of legal capacity under the CRPD, there may remain the possibility to overrule harmful will and preference for some decisions. The scope of decisions which count as an exercise of legal agency also relates to which decisions could be included in an advance plan under the CRPD and be legally binding.

The will and preference of an individual considered to lack mental capacity, is considered when determining what is in that person's best interest according to Section 4 of the Mental Capacity Act.

Will and preference is not therefore adhered to outright, and is instead one of many factors for consideration including:

> "(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
>
> b) the beliefs and values that would be likely to influence his decision if he had capacity, and

> (c) the other factors that he would be likely to consider if he were able to do so."[154]

The decision maker must also consider "whether it is likely that the person will at some time have capacity in relation to the matter in question, and…if it appears likely that he will, when that is likely to be."[155] The decision maker must "so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him."[156]

The House of Lords introduced the provision that where best interests relates to life-sustaining treatment the decision cannot be motivated by a decision to bring about death.[157] This was out of fear that the current provisions would result in euthanasia.[158]

Finally, if it is practicable and appropriate to consult them, the views of anyone named by the individual to be consulted, any donee of a lasting power of attorney, any court appointed deputy and anyone involved in the care of the individual or who has an interest in their welfare.[159]

The purpose of providing a check list of factors was to allow flexibility to account for the individual requirements and considerations of each case.[160] Judges have made it clear that these factors do not have a particularly hierarchy, and that will and preference is one of many factors for consideration.[161] There is no explicit hierarchy or presumption which affords will and preference greater consideration.[162] Will and preference is therefore a distinct concept from what is in an individual's best interest. As stated by Mr Justice Hayden in *Sheffield Teaching Hospitals* '"[w]ishes" and "best interests" should never be conflated, they are entirely separate matters which may ultimately weigh on different sides of the balance sheet.'[163]

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[154] Mental Capacity Act 2005 s 4(6).
[155] Ibid s 4(3)(a)(b).
[156] Ibid s 4(4).
[157] Ibid s 4(5).
[158] First discussed by the House of Lords in House of Lords, 'Mental Capacity Bill Volume 668: Debated On Monday 10 January 2005' (Hansard 2005) available at < https://hansard.parliament.uk/Lords/2005-01-10/debates/48204bca-4b78-4c40-9ab3-cb2b6bc8fbf9/MentalCapacityBill> (accessed 23rd June 2021).
[159] Mental Capacity Act 2005 s 4(7).
[160] Joint Committee on the Draft Mental Incapacity Bill 'Draft Mental Incapacity Bill' HL 189–1; HC 1083–1 (2002-03) para 89.
[161] *Re M (Statutory Will), ITW v Z and Others* [2009] EWHC 2525 (Fam) [35] (Munby J).
[162] L. Series, 'The Place of Wishes and Feelings in Best Interests
Decisions: Wye Valley NHS Trust v Mr B' (2016) 79(6) Modern Law Review, 1113
[163] *Sheffield Teaching Hospitals NHS Foundation Trust v TH and Another* [2014] EWCOP 4 [56].

According to Sir James Munby the level of importance awarded to will and preference as a factor in best interest rulings will always be case and fact specific[164] and depends upon:

> "a) the degree of P's incapacity, for the nearer to the borderline the more weight must in principle be attached to P's wishes and feelings …
>
> b) the strength and consistency of the views being expressed by P;
>
> c) the possible impact on P of knowledge that her wishes and feelings are not being given effect
>
> d) the extent to which P's wishes and feelings are, or are not, rational, sensible, responsible and pragmatically capable of sensible implementation in the particular circumstances; and
>
> e) crucially, the extent to which P's wishes and feelings, if given effect to, can properly be accommodated within the court's overall assessment of what is in her best interests"[165]

There are examples in case law therefore of the Court overruling strongly held will and preference, as they were not considered to be in the best interest of P. Illustrative examples include *Re E*[166] and *PH v A Local Authority.*[167]

Considering the importance awarded to will and preference under the CRPD, as shall be demonstrated in the next section, there has been a renewed call as to whether will and preference should be given more explicit importance in best interest considerations.

The 2015 Law Commission consultation paper on Mental Capacity and Deprivation of Liberty propose amendments to place greater emphasis on will and preference, stating that "decision-makers should begin with the assumption that the person's past and

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[164] *Re M (Statutory Will), ITW v Z and Others* [2009] EWHC 2525 (Fam) [35ii] (Munby J).

[165] Ibid.

[166] *Re E (Medical treatment: Anorexia) [*2012] EWHC 1639 (COP).
A woman, E, with enduring Anorexia Nervosa who had twice attempted to create an Advance Directive 'pleaded' with medical experts in the case to have forced treatment withdrawn. Despite her clear will and preference Mr Justice Jackson ruled that it was in E's best interest to continue forced treatment.

[167] *PH v A Local Authority & Z Limited* [2011] EWHC 1704 (Fam).
PH was a man with Huntington's Disease subject to a standard authorisation allowing his continued residence at Z Limited care home. PH made it clear he wanted to return home and had made numerous calls to the police asking them to 'rescue him' [9]. Despite disagreement between the neuropsychiatrist, PH's partner and the treating medical professionals, Mr Justice Baker held PH lacked the relevant capacity. This resulted in PH's continued residence at the care home.

present wishes and feelings should be determinative of the best interests decision." [168] The Court of Protection has made considerable advances in meaningfully involving the individual and considering their will and preference.

Notable examples of this include *Aintree University Hospitals NHS Trust v James* in 2013.[169] The majority judgment communicated by Baroness Hale made it clear that best interests assessments are to be a consideration of matters 'from the patients point of view' placing emphasis on Ps owns views in decision making.[170] This position was of particular influence given Baroness Hale acted as the responsible Law Commissioner and oversaw a large portion of the development of the 'Mentally Incapacitated Adults and Decision Making' report which was implemented in the MCA 2005. Baroness Hale states:

> "The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament…insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being."[171]

Many cases have followed the precedent set by Aintree and the importance of individual will and preference. A good example of this is Mr Justice Peter Jackson's ruling in *Wye Valley NHS Trust v B* in 2015.[172] This case concerned an application by the NHS Trust to amputate Mr B's leg, surgery which was needed to save Mr B's life. Mr B was an older man with a diagnosis of Schizophrenia who had continuously refused treatment for his leg and was clearly refusing amputation. The question for the court was whether this amputation was in Mr B's best interest given he lacked the capacity to consent to this decision himself. Mr Justice Jackson went to meet Mr B to both involve Mr B in proceedings concerning a significant decision about his own welfare and to understand Mr B as an 'individual human being'.

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[168] Law Commission, *Mental Capacity and Deprivation of Liberty: A Consultation Paper* Consultation Paper 222 (London: HMSO, 2015) para 12.47.

[169] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

[170] *Ibid* [45] (Lady Hale).

[171] Ibid.

[172] *Wye Valley NHS Trust v B* [2015] EWCOP 60.

The importance of individual participation, specifically personal contact by the relevant judge(s) with P has been emphasized in *X and Y* v *Croatia* by the European Court of Human Rights.[173] This led to a new rule (3A)[174] and a corresponding practise direction for the Court of Protection, which requires the court to consider how P should participate in proceedings.[175] Mr Justice Jackson commented on how he felt unable to come to a decision without meeting Mr B and "obtained a deeper understanding of Mr B's personality and view of the world, supplementing and illuminating the earlier reports".[176] Mr Justice Jackson made a number of valuable observations on the nature of will and preference in best interest decisions. These include the importance of not depriving persons with disabilities of the reasonable outcomes open to others in favour of presumption of life[177] the unhelpfulness of separating a person with MHD from their 'illness' and the long-standing beliefs which may be attributed to this illness,[178] and the importance of not dismissing religious beliefs related to MHD.[179] Mr Justice Jackson ruled that the amputation was not in Mr B's best interest.

In the recent case of *Barnsley Hospital NHS and MSP* Mr Justice Hayden decided to withdraw life sustaining treatment from MSP in line with his will and preference.[180] This was communicated by MSP through previous conversations with medical professionals and his family. MSP had also attempted to create an advance directive documenting his will and preference, but which was determined invalid as it was not witnessed as required by s 25 ss(6)(c) and (d) of the Mental Capacity Act. Mr Justice Hayden goes to great lengths in this judgment to ascertain who MSP was as an individual and the factors he would have considered, in line with *Aintree*. This includes factors others may not consider of relevance- including the impact the stoma would have on his physical appearance and confidence. Hayden J goes on to say "[t]here is no doubt, in my mind, that he had come to a clear and entirely settled decision that he was not prepared to contemplate life with a stoma or indeed any significant life changing disability. It is not for me, or indeed anybody else, to critique those views or beliefs, but merely to identify them. They are a facet of MSP's broader personality, the expression of which is integral to his own personal autonomy."[181]

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[173] *X and Y* v *Croatia* App no 5193/09 [2011] ECHR 1835, §84.

[174] The Court of Protection (Amendment) Rules 2015 SI 2015/549 (L6), Rule 5.

[175] Court of Protection, *Practice Direction 2A - Participation of P* (London, 2015).

[176] *Wye Valley NHS Trust v B* [2015] EWCOP 60 [18].

[177] Ibid [12].

[178] Ibid [13].

[179] Ibid [140-150].

[180] *Barnsley Hospital NHS Foundation Trust v MSP* [2020] EWCOP 26.

[181] Ibid [17].

Both *Barnsley Hospital NHS and MSP* and *Wye Valley* are examples in which the individuals will and preference has been given sufficient weight to overcome the previously strong presumption towards preservation of life.[182] Following P's will and preference, even where harmful, was considered to be in the individuals' best interest. Best put by Mr Justice Jackson "[t]here is a difference between fighting on someone's behalf and just fighting them."[183]

While the Court of Protection have made strides in regard to respecting will and preference, there remain many instances in which will and preference are overruled or there is a lack in consideration on Ps will and preference. It is worth noting therefore that consideration from P's point of view does not equate to a particular status being awarded to their views. It remains rare for judges to meet with P and it has been argued that willingness to do so considerably varies between judges.[184] Lucy Series highlights that the likely reasons for this unwillingness to meet with P are judicial culture and resource constraints.[185] In regards to resource constraints it will be interesting to see whether the Court of Protections move to online hearings during COVID-19 will have any lasting impact on the use of online tools to allow P to be present at hearings from their home/hospital bed, as was the case in *Avon and Wiltshire Mental Health Partnership v WA & Anor*.[186] A notable example of there being little inclusion of Ps will and preference was a 2020 hearing before Mrs Justice Lieven (yet to be published). This hearing concerned a young women with brain injury and an application brought by her mother regarding an injunction to prevent a man P regularly saw from having contact with her, what care P should receive and how it would be funded. At no point during the hearing were P's will and preference in regards to either matter discussed.[187]

It has already been outlined that advance directives which communicate will and preference regarding treatment refusal, can be overruled if a medical professional is not satisfied the validity criteria for the directive have been met. Advance directives can also

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[182] For a good discussion of sanctity of life see *Airedale NHS Trust v Bland* [1993] UKHL 17.

[183] *Wye Valley NHS Trust v B* [2015] EWCOP 60 [45].

[184] Evidence of Victoria Butler-Cole and others to the House of Lords Select Committee on the Mental Capacity Act 2005, *Oral and written evidence – Volume 1 (A – K)* (UK Parliament, 2013) 357; House of Lords Select Committee on the Mental Capacity Act 2005, *Evidence Session No 14 Tuesday 26 November 2013. Witnesses: Mr Justice Charles, Senior Judge Denzil Lush, District Judge Margaret Glentworth and District Judge Elizabeth Batten* (UK Parliament, 2013) Q306.

[185] L. Series, 'The Place of Wishes and Feelings in Best Interests Decisions: Wye Valley NHS Trust v Mr B' (2016) 79(6) Modern Law Review, 1110.

[186] [2020] EWCOP 37.

[187] C. Kitzinger and others, 'Seven Perspectives On A Court Of Protection Hearing' <https://openjusticecourtofprotection.org/2020/07/01/seven-perspectives-on-a-court-of-protection-hearing/> accessed 21 June 2021.

be overruled if an individual is admitted under part 4 of the 1983 Mental Health Act to protect that individual from harming self or others.[188]

England and Wales are one of many domestic legislators signatory to the CRPD, which permit detention and compulsory treatment on the basis of protecting the individual and others from harm. The will and preference of those detained under the Mental Health Act can be overruled regardless of whether they retain or lack decision making capacity, with the aim of saving the patient’s life, to prevent serious deterioration of their condition, to alleviate suffering and to prevent the patient from being a danger to themselves or others.[189] People detained under section 63 can also be treated against their will and preference for an initial period of 3 months, where that treatment is believed by the relevant clinician to be required to treat mental disorder and its ancillary with the exception of treatment covered under s 57, 58 and 58A. More on the interrelation of harm and will and preference is discussed in Chapter 5.

In theory, under the Mental Capacity Act valid advance directive could be used to overrule the current will and preference of an individual during a mental health experience, who is deemed to lack the relevant mental capacity. Whilst this can occur in theory, there are no recorded instance of this happening.[190] It is likely that this is partially because advance planning and advance directives in particular are underused. Many decisions are also made informally by families or care teams and therefore do not reach court and the public eye. Advance directives also have administrative issues, meaning it is possible a person could contradict their advance directive without medical professionals being aware. It is also worth noting that, depending on the decision, this may be a value decision on behalf of the care team or treating clinician and family members. If Margo’s care team and her nephew both agreed with Margo’s current will and preference to receive treatment and live, it is unlikely this decision would be challenged and brought to court. As outlined by Emily Jackson, although local NHS bodies should refer cases where it is not clear what is in P’s best interests, if professionals and family members are in agreement and are confident they know what is in Ps best interest, there may be no perceived lack of clarity and therefore no referral.[191]

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[188] Mental Capacity Act 2005 s 28.

[189] Mental Health Act s 62.

[190] Law Commission, *Mental Capacity and Deprivation of Liberty: A Consultation Paper* Consultation Paper 222 (London: HMSO, 2015) para 12.46

[191] E. Jackson, 'From ‘Doctor Knows Best’ To Dignity: Placing Adults Who Lack Capacity At The Centre Of Decisions About Their Medical Treatment' (2018) 81 The Modern Law Review, 258.

There may be some safeguarding against overruling a person’s current will and preference in the form of s 25(2)(c) of the Mental Capacity Act which reads “[a]n advance decision is not valid if P…has done anything else clearly inconsistent with the advance decision remaining his fixed decision.” This provision does not state whether P would need to act inconsistently in full capacity or whether this could include will and preference made when the person lacks capacity. This could provide some protection to prevent self with MHD being overruled by an AP, however the MCA guidelines on this section provide no further guidance and no answer to this question.[192] This could potentially make a big difference in terms of protecting incapacitous contrary will and preference as it stands in the Mental Capacity Act.

Some guidance on the meaning of ‘anything inconsistent with the advance decision remaining their fixed decision’ was offered recently by Justice Poole in *Re PW (Jehovah’s Witness: Validity of Advance Decision).*[193] This case involved a woman with Alzheimer’s dementia who made an advance directive in 2001 refusing blood transfusions including where transfusion was needed to sustain life. Despite being created prior to the Mental Capacity Act, the directive fulfilled the validity requirements outlined in section 25(6) and had not invalidated the directive under s25(1)(a) by withdrawing the directive or (b) by creating a valid lasting power of attorney over the same decision. The decision therefore turned on whether Mrs W had done anything inconsistent to the directive remaining her fixed decision. On this Justice Poole states: “I interpret s.25(2)(c) as allowing for the advance decision to be rendered not valid should the person who made the advance decision do “anything else” (other than withdrawal or granting an LPA which displaces the advance decision) which is “clearly inconsistent” with the advance decision remaining their fixed decision, before or after they have lost capacity to make the relevant treatment in question. The question will only arise after they have lost capacity but the court may consider things done before or after that time.”[194] Despite Mrs W including in her directive that this refusal could only be revoked by her in writing, Justice Poole followed Sir James Munby’s interpretation in *HE v A Hospital NHS Trust* that ‘done anything inconsistent’ included words, written or spoken and actions.[195] This burden of proof rests with the applicant- in this case the Trust- to prove on the balance of

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[192] Department for Constitutional Affairs, 'Mental Capacity Act 2005 Code Of Practice' (TSO 2007) 170.

[193] *Re PW (Jehovah’s Witness: Validity of Advance Decision)* [2021] EWCOP 52.

[194] Ibid [50].

[195] *HE v A Hospital NHS Trust* [2003] EWHC 1017 (Fam)[43].

probabilities that P has done something inconsistent with the advance decision remaining their fixed decision.[196]

Of course for some this interpretation may prove undesirable as the very draw of creating a legally binding advance plan is to overrule will and preference made during a mental health experience. This could include harm to the individual or their family, and for those who experience episodes, protection against the harmful consequences of a decision made during a mental health experience.

To summarise, the current position in England and Wales is that an individuals will and preference may be overruled if they are assessed as lacking capacity to make the decision in question, if the decision is contrary to one contained in a legally binding advance plan, overruling will and preference is considered in that persons best interest or the person is sectioned under the Mental Health Act. While progress has been made by the Court of Protection regarding Justice Poole's interpretation of s25(2)(c) to include incapacitous words or actions, participation of P in hearings and by giving P's will and preference more weight in best interest considerations, this is far from a uniform approach. The participation of P and the importance awarded to P's will and preference is judge and fact specific. Emily Jackson advocates for the introduction of a set of rebuttable presumptions to formalize best practice at the Court of Protection and give more weight to will and preference.[197] Lucy Series argues that it is premature to use case law which demonstrates best practice in the court of protection to justify a lack of formal statutory amendment to place greater emphasis on will and preference.[198] Mary Donnelly also advocates for a legislative endorsement of will and preference.[199] Formalizing best practice holds value not only to guide judicial hearings, but also to guide social workers and medical professionals who also regularly engage in best interest decisions. In practice this is also where the majority of best interest decisions are made.

Currently 'good' outcomes can sometimes justify 'the court stepping in and strictly circumscribing the area of [P's] personal autonomy.'[200] Conceptions of 'good' in this regard are usually determined in reference to protecting the individual from harm.

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[196] *Re PW (Jehovah's Witness: Validity of Advance Decision)* [2021] EWCOP 52 [54].

[197] E. Jackson, 'From 'Doctor Knows Best' To Dignity: Placing Adults Who Lack Capacity At The Centre Of Decisions About Their Medical Treatment' (2018) 81 The Modern Law Review, 257.

[198] L. Series, 'The Place of Wishes and Feelings in Best Interests Decisions: Wye Valley NHS Trust v Mr B' (2016) 79(6) Modern Law Review, 1103.

[199] M. Donnelly, 'Best Interests In The Mental Capacity Act: Time To Say Goodbye?' (2016) 24 Medical Law Review.

[200] *RB v Brighton and Hove City Council* [2014] EWCA Civ 561 [46].

However as we shall see in the next section, achieving a good outcome for people who lack capacity does not always mean a person’s rights are being upheld.

Will and Preference and Article 12

Article 12 ‘Equal Recognition before the Law’ awards legal capacity to all and focuses on providing support in expressing will and preference. As mentioned therefore, incapacitous will and preference is to be adhered to in spite of deficits in mental capacity, according to the CRPD. Mental capacity is a distinct concept from legal capacity and is defined by the Committee as “the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors.” [201] This can include decision making deficits cause by or impacted by mental health. The Committee make it clear that “[u]nder Article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.”[202] Therefore in spite of decision making deficits a person is still to be awarded ‘the ability to exercise their decisions at law,’ which has been interpreted to mean decisions have legal enforceability.[203] This is the case ‘at all times, including in crisis situations,’ which are presumably points in time when a persons’ mental capacity may be impacted significantly.[204]

It is clear that the Convention intended decisions made by persons with disabilities to have legal enforceability and not simply be ‘recognised’ at law. The Committee emphasise the importance of being able to ‘enforce’ rights: “[w]ithout recognition of the person as a person before the law, the ability to assert, exercise and *enforce* those rights, and many other rights provided for in the Convention, is significantly compromised”[emphasis added].[205] Without an ability to act on rights it would be difficult to ‘make rights real’ for disabled people which was one of the goals of the CRPD.

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[201] United Nations Commission, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 13.
[202] Ibid.
[203] Anna Arstein-Kerslake and Eilionóir Flynn, 'The Right To Legal Agency: Domination, Disability And The Protections Of Article 12 Of The Convention On The Rights Of Persons With Disabilities' (2017) 13 International Journal of Law in Context, 23.
[204] United Nations Commission, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 18.
[205] United Nations Commission, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 31.

Unlike the Mental Capacity Act, decisions made by individuals with deficits in mental capacity cannot be overruled via substituted decision making. "Substitute decision-making regimes… must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others."[206] This includes both formal and informal substituted decision making,[207] and support in decision making can never amount to substituted decision making.[208] An individual with disabilities has the right to refuse support and can disagree with the decision of the support person. They cannot have their decision overruled by the support person as this would constitute substituted decision making. In many models of support which focus on non-coercive intervention, including open dialogue, family conferencing and circles of support, the individual is present for the decision-making process and must agree with the decisions being made.[209]

If for whatever reason the individual's will and preference cannot be ascertained, decision makers could rely on any advance plan which documents will and preference for said decision, or rely on a 'best interpretation of will and preference.'[210] Best interpretation of will and preference would therefore replace best interest decisions, and since the CRPD nor CRPD Committee mention any additional factors for consideration, the will and preference of the individual would become - not one of many factors of equal weight to be balanced- but the only factor. There is no definition or expansion of 'best interpretation' by the Committee on who the interpreters would be and what would happen if two or more interpreters disagreed. Given it is to replace best interests it is likely a 'best interpretation' would rely on the same parties currently consulted in a best interests ruling i.e. carers, donees of a lasting powers of attorney, anyone named in a written statement and any court appointed deputy.[211] There is no reason a conflict could not be resolved using wishes contained in an advance plan i.e. to uphold the majority vote or privilege certain people's opinions. Resolving conflict could also be a role for the Court of Protection, who currently handle disputes on what is in a person's best interests.

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[206] Ibid para 9.

[207] Ibid para 52.

[208] Ibid para 17.

[209] E. Flynn and A. 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 52-54.

[210] United Nations Commission, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 21.

[211] Mental Capacity Act (2005) s4(7)

If the will and preference is to be adhered to, even in crisis situations, this appears to challenge the possibility of self-binding using advance plans. However self-binding is not discussed expressly by the CRPD or CRPD Committee and there appears to be scope for self-binding to be permitted under the CRPD. It has already been identified in Chapter 1 that there is some academic support from Flynn and Arstein-Kerslake that a carefully crafted provision akin to a Ulysses agreement may be necessary.[212] Minkowitz also acknowledges there may be situations in which an elected support person may need to take over for certain decisions during a crisis.[213] Moreover the Committee state that the point at which an advance directive enters into force and ceases to have effect should be decided by the individual. If the individual decided to trigger the advance directive at a point when they were requesting said treatment, or- if we could extend beyond advance refusals- making a decision contrary to that in the advance plan, this may be a legitimate use of self-binding. Chapter 7 will outline the benefits of self-binding as a way of opting into state intervention for persons with mental health difference. Therefore while the weight awarded to will and preference seems to rule out self-binding, this is less of a drawn conclusion and more of a debate, one in which self binding may provide a CRPD compatible tool to strike the balance between safeguarding on the one hand and adhering to will and preference on the other.

To summarise therefore, the CRPD places paramount weight on respecting individual will and preference by awarding legal capacity to all in spite of deficits in mental capacity. This includes during crisis situations, by allowing individuals to refuse support, and by replacing best interests with ‘best interpretation of will and preference.’ This is in stark contrast to will and preference under the Mental Capacity Act, which - while gaining more weight in Court of Protection case law- allows will and preference to be overruled when the individual lacks mental capacity.

Under the Mental Capacity Act there are a number of factors to be taken into consideration when considering whether will and preference ought to be adhered to. Some of these include the practicality of implementing will and preference within budgetary constraints and that an individual cannot make demands in regards to positive obligations i.e. requesting specific treatment. Another dominant consideration is the level

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[212] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 96.
[213] T. Minkowitz, 'Legal Capacity From A Psychosocial Disability Perspective: A Discussion Paper' <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2374733> accessed 14 January 2021, para 9.

of harm respecting will and preference will incur. The question for the CRPD therefore is whether *all* will and preference constitutes an 'exercise of rights at law' under Article 12.

Legal capacity includes the right of an individual with disabilities to hold legal rights (legal standing) and exercise those rights at law (legal agency.) Little clarification has been awarded regarding the definition of legal agency and what constitutes an exercise of legal agency.[214] It is described by the Committee as 'the ability to act on rights accrued from legal standing, and to have those actions recognized by the law.'[215] However questions remain over which decisions count as an exercise of legal agency and are therefore protected by Article 12, and to what extent the law has to 'recognise' an individuals will and preference when that will and preference is imminently harmful or opposed to wishes contained in an advance plan.

The scope of decisions which fall within 'legal agency' has ramification for advance plans under the CRPD, as it would determine which will and preference could be included in an advance plan *and* given legal enforceability.

One interpretation is offered by Flynn and Arstein-Kerslake. They define legal agency as "an action or inaction that the individual intended, and which has legal consequences."[216] This interpretation therefore relies on 'intention' and legal consequence. Flynn and Arstein-Kerslake define intention as '[a]ny indication that there was purpose and deliberation behind a particular action, decision or omission.'[217] Regarding which decisions accrue legal agency- Flynn and Arstein-Kerslake make it clear that not all decisions made by an individual are an exercise in legal capacity. Decisions which constitute an exercise of legal agency are those with legal consequence.[218] This seems in line with the Committee's general comment which states that "[l]egal capacity to act under the law recognizes that person as an agent with the power to engage in transactions and create, modify or end legal relationships."[219] This is also in line with the

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[214] Office of the High Commissioner of Human Rights, 'Background Conference Document on Legal Capacity (Prepared as Part of the Ad Hoc Committee Deliberations Following the Fifth Session) COM (2005) A/AC.265/2005/2

[215] United Nations Commission, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 14.

[216] A. Arstein-Kerslake and E. Flynn, 'The Right To Legal Agency: Domination, Disability And The Protections Of Article 12 Of The Convention On The Rights Of Persons With Disabilities' (2017) 13 International Journal of Law in Context, 25.

[217] Ibid 26.

[218] C. Bhailís and E. Flynn, 'Recognising Legal Capacity: Commentary And Analysis Of Article 12 CRPD' (2017) 13 International Journal of Law in Context, 13.

[219] United Nations Commission, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 12.

examples provided by the committee on how states should facilitate the recognition of persons with disabilities as legal agents, including owning or inheriting property, controlling their own financial affairs, having equal access to bank loans, mortgages and other forms of financial credit, and property rights.[220] Flynn and Kerslake also leave legal consequence deliberately broad to encompass informal spheres such as group or family homes, where Article 12 does not immediately seem to apply, but in which 'some of the most damaging decision-making denials occur.'[221] They provide the example of a man in a group home who is denied daily decisions including when to watch TV, whether to attend church and what time to go to bed. This denial of daily decisions becomes an exercise of legal agency when the man refuses food in protest, which risks violating his contractual agreement with the group home to provide him with food and nourishment.[222] This thereby creates the legal consequence and intent required for Flynn and Arstein-Kerslake's definition.

If we accept their definition, this has an impact on how advance plans will look under the CRPD. The first requirement for intent will be fulfilled because the individual has created an advance plan. However if legal consequence is required for a decision to be protected under Article 12, this narrows the scope of legally enforceable decisions in advance plans. This would likely result in a version of advance planning very similar to what we currently have under the Mental Capacity Act, namely – refusal of treatment and financial and welfare decisions (which involve obvious legal consequence.) More subjective wishes however could not be included in the advance plan and be protected under article 12, unless the individual could create legal consequence.

A wider scope of legal agency is drawn by Tina Minkowitz who criticises Flynn and Arstein-Kerslake's definition on the grounds that it adds an 'extra step' to legal agency and fails to recognise legal capacity as a substantive right- not just a trigger for challenging discrimination.[223] Minkowitz believes that all expressions of will and preference are an exercise of legal capacity, and therefore support and systematic re-structuring is needed to adhere to these wishes. Unlike Flynn and Arstein-Kerslake therefore, Minkowitz does not believe an exercise in legal agency requires legal consequence and instead is an innate right to have decision making respected. Applied to

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[220] Ibid.

[221] A. Arstein-Kerslake and E. Flynn, 'The Right To Legal Agency: Domination, Disability And The Protections Of Article 12 Of The Convention On The Rights Of Persons With Disabilities' (2017) 13 International Journal of Law in Context, 24.

[222] Ibid 29.

[223] T. Minkowitz, 'CRPD And Transformative Equality' (2017) 13 International Journal of Law in Context, 79.

advance planning, this would result in a much more expansive form of advance planning which could afford more subjective will and preference legal enforceability despite their lack of legal consequence.

Both definitions have their own merit and challenges. Flynn and Arstein-Kerslake's definition would presumably mean that will and preference which falls outside of their definition would be advisory as opposed to absolute as it lacks the legal enforceability which accompanies legal agency. This would allow for will and preferences contained in an advance plan to be subject to change as self changes with mental health; or would allow a decision which creates an unreasonable or onerous positive duty on another or which cannot be met because of resource constraints, to be overruled. However this definition seems flawed when considering decisions which carry great personal importance to an individual but which lack legal consequence in and of themselves, and when that individual lacks the capacity to generate that legal consequence themselves i.e. through hunger strike. This seems out of step with principles established by *Cheshire West* – that a person's complacency or seeming cooperation does not mean they are not being deprived of their liberty.[224] It seems odd this principle would apply for deprivation of liberty but would not apply for exercising legal capacity.

The wider definition presented by Minkowitz would resolve this issue by not requiring the 'extra step' of creating legal consequence. It also appeals given the weight awarded to will and preference by the Committee in general comment no.1. It also makes sense for the scope of decisions contained in an advance plan to be wide, given best interpretation of will and preference replaces best interest decisions and given the prominence – seemingly to the exclusion of all other factors – the CRPD awards to will and preference under an absolutist interpretation. If legal capacity is indeed a substantive right it makes sense for will and preference regardless of legal consequence to be awarded legal enforceability. Participant responses presented in the next Chapter also supports a desire to self-bind decisions which lack legal consequence. The problem then becomes how to give effect to a wide scope of will and preference in practice where they contain positive obligations in light of resource constraint. A reasonability requirement may therefore be required.

Ultimately the scope of will and preference which constitute an exercise of legal agency is unclear and has practical implications for the future of advance plans.

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[224] *Cheshire West and Chester Council v P Surrey CC v P* [2014] UKSC 19.

If legal capacity is to be awarded to all, despite deficits in mental capacity, concepts of self which have been used to separate version of self on the basis of mental health, decision making deficits and mental incapacity, to restrict rights accordingly, needs to be considered. The next Chapter identifies a fundamental and conceptual barrier to CRPD compatibility for advance plans by examining theories on self with mental health according to dominant social and legal theories.

Chapter 2

Why thinking about 'self' is important: The dividing line in social and legal theory that is mental health difference and its incompatibility with the CRPD

Introduction

Referring to Ulysses contracts as a form of 'self-binding' is very telling, both generally and with regards to this research. This thesis makes the point that the first and potentially most lucrative point for consideration in addressing CRPD compatibility for advance plans, is to explore the concept of 'self.'

There exists a commonality in elements of self which run throughout many dominant social theories. These include a rational, self-directing, wholly autonomous moral agent, with their own conceptions of the good, operating on the basis of mutual benefit. There exists in these social theories a conceptual divide between a 'healthy' self who possesses these traits and an 'ill' self who does not. Frequently this 'ill' self includes persons with disabilities, who are either left out of social theory considerations or are directly juxtaposed with the 'healthy' self. As stated by Nussbaum "[i]t is clear…that such theories must handle severe mental impairments and related disabilities as an afterthought, after the basic institutions of society are already designed."[225]

One of the main purposes of the Mental Capacity Act is to safeguard the will and preference of the autonomous self. Therefore it is argued that the purpose of mental capacity assessments is to isolate the autonomous self capable of cognitive and rational decision making, from the non-autonomous self. Decision making standards within mental capacity assessments are therefore set to reflect what the autonomous self ought to be capable of. While it is true that mental capacity is not the same as moral and political philosophies of autonomy, their legal functions are closely analogous.[226] In the same way autonomy means that "freedom and responsibility flow from a person satisfying competence and authenticity requirements…[m]ental capacity law is structured similarly: a person is accorded legal rights and responsibilities only insofar as they are found to be competent and their decisions are authentically theirs."[227] Anyone who fails to meet the criteria of mental capacity assessments therefore has their legal capacity restricted in regards to certain decisions.

Since mental capacity assessments divide selves on the basis of a 'disturbance in the function of the mind or brain,' they manifest a divide line in selves between the autonomous and non-autonomous self on the grounds of mental health difference.[228] While prima facia, capacity assessments do not discriminate against persons with mental health difference, in practise a mental health diagnosis is used as a threshold indicator to disprove a person's ability to understand and nature the consequences of their actions.[229] In the same way that social theories create a conceptual divide between a 'healthy' and 'ill' self therefore on the basis of disability, so to do mental capacity assessments divide the autonomous from non-autonomous self on the basis of a mental health diagnosis.

Law has manifest these dominant commonalities in self for a number of reasons. These include concepts around free will, protectionism, decision making and property

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[225] M. Nussbaum, *Frontiers Of Justice: Disability, Nationality, Species Membership* (1st edn, Harvard University Press 2006) 98.

[226] L. Series, 'Relationships, Autonomy And Legal Capacity: Mental Capacity And Support Paradigms' (2015) 40 International Journal of Law and Psychiatry, 81.

[227] Ibid.

[228] s2(1) Mental Capacity Act (2005).

[229] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 87.

possession. As already discussed in Chapter 1, law seeks to uphold and protect the critical interests of the 'true' self from any disingenuous and harmful will and preference expressed by self with mental health difference. This provides the theoretical justification on which advance plans are currently based and is not CRPD compatible.

The 'self' reflected in historical and political rights discourse, also termed the 'myth system' by Quinn and Arstein-Kerslake is not an accurate reflection of everyday human experience.[230] This conception is particularly challenged by the CRPD, particularly Article 12 which "confronts the question of personhood and shifts from a rationality-based idea of the person to a more holistic one that more accurately reflects human reality."[231]

Because the CRPD prohibits mental capacity assessments (the legal tool used to divide the autonomous from non-autonomous self) and promotes universal legal capacity, the CRPD would not uphold a division in selves on the basis of disability and mental health difference.

Instead the CRPD challenges the divide between an autonomous and non-autonomous self, a 'healthy' versus 'ill' self, and moves away from a 'true self' conception and its ties with cognition, by promoting the idea of a universal self.

If self is no longer to be understood by reference to such a divide it calls into question how self should now be understood, and how we can begin to rethink elements of self to bridge the conceptual gap between people with and without mental health difference. This justifies a move away from the traditional autonomy theory, which is deeply entrenched with dominant conceptions of self which are not CRPD compatible. The purpose of this is to re-imagine a self worthy of full legal capacity, in spite of mental health difference and decision-making deficit.

If there is to be some role for self-binding in the CRPD therefore, the distinction made between the two selves cannot be based on mental health difference or a finding of mental incapacity. Instead the trigger must be disability neutral. Chapter 4 further explores how self changes with mental health difference according to participants with experience of varying types of mental health difference. Chapter 6 builds on this to

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[230] G. Quinn and A. Arstein-Kerslake, 'Restoring The 'Human' In Human Rights – Personhood And Doctrinal Innovation In The UN Disability Convention', *The Cambridge Companion to Human Rights Law* (1st edn, The Cambridge University Press 2013) 37.

[231] T. Minkowitz, 'CRPD Article 12 And The Alternative To Functional Capacity: Preliminary Thoughts Towards Transformation' [2013] SSRN <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2371939> accessed 16 February 2021, section 2.

explore how ‘self’ may provide new thinking on a possible alternative to mental capacity assessments, for the purposes of triggering self-binding advance plans.

Concepts of self underpin the law

‘Self’[232] needs to be understood on a very fundamental and basic level to be able to form legislative rules. The way we tend to behave and the elements which go into forming who we are need to be generalised across society to enable common rules by which to govern us. This argument therefore proceeds on the assumption that there is ‘self,’ however loosely defined and socially formed that self may be.

There is much social and philosophical discussion around what forms ‘self.’ Generally this is a combination of cognitive abilities and a learning of how to be. Cognitive capabilities such as memory, recollection and recognition provide us with the foundation on which to perform social learning and connectedness. For example, internalising social norms and using the ‘othering’ of those around us helps us know what we are by what we are not, and form beliefs, values and identity.

Elements or characteristics of self needed to accrue full rights and legal personhood can be identified in law. For example, the perceived absence of some characteristics has led to groups historically being denied full legal personhood. This includes women, whose personhood was historically fused with that of her husbands or fathers and rationalised, to an extent, by misplaced paternalism on the basis that women were somehow lacking or lesser than men.[233] The same can also be said for slavery, which justified the restriction of legal capacity on similar grounds, whereby slaves were only considered three-fifths of a person under the law of American colonies.[234] This has led to discrimination and viewing of these groups as sub-human, becoming subjects of charity and sympathy as opposed to subjects at law.[235] As society progresses and perceives

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[232] I have deliberately chosen to use the singular word ‘self’ because it is my belief that self is individual. I am also not proposing a new theory of self applicable to all. Therefore ‘the self’ which pertains to an overarching model is not accurate for use in this research.

[233] G. Quinn and A. Arstein-Kerslake, 'Restoring The ‘Human’ In Human Rights – Personhood And Doctrinal Innovation In The UN Disability Convention', *The Cambridge Companion to Human Rights Law* (1st edn, The Cambridge University Press 2013) 43.

[234] Article I, Section 2, U.S Constitution (1787).

[235] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 85.

elements of self differently, moral injustices within law are exposed and legal rules become no longer fit for the times. It is now recognised that gender, ethnicity and race are not legitimate reasons for restricting legal capacity.

In the same way that social changes on topics like women's rights and slavery have exposed outdated and even immoral traits of legal personhood, the same process has been and continues to happen in the context of disability rights. Societal and rights-based progressions have challenged the way we think about mental health difference. This is optimised by the CRPD, which re-imagines the legal self as one deserving of equal legal recognition regardless of perceived mental incapacity. Its prohibition of mental capacity assessments forces us to see disability differently and leaves us to question the nature of the moral judgments left in its wake. This specifically relates to the elements of self drawn from mental capacity assessments and the autonomous legal self, and how these can be challenged in light of Article 12.

It is important to first consider where these elements of self have come from in order to re-imagine them from the ground up to be more inclusive of self with mental health difference.

Social and philosophical theories on self: the division between 'healthy' and 'ill' self

There exist generalisations in dominant theories on self about what self should be and be capable of. These are formed from common threads within social and philosophical theories on self, personhood and the like.

These commonalities include viewing self as rational, independent, fully autonomous, moral agents, acting on self interest and mutual benefit and choosing freely to engage in political power. Many theories talk about self having the ability to attain a higher state of being or as achieving self-actualisation through some higher purpose.[236] These general elements of self are purported as being the pillar stones by which to achieve this self actualisation, self-liberty, to accrue rights and make decisions.

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[236] Gadamer's conception of soul gained through constant deliberation and recollection, in *The Enigma Of Health* (1st edn, Polity Press 1996) 147; political power and possession of property according to Hobbes *Leviathan* (1st edn, 1961) and Locke's *Second Treatise Of Government* (1st edn, Awnsham Churchill 1689); primary goods according to Rawl's *A Theory Of Justice* (Harvard University Press 1971) and Kant's 'Enlightenment' and 'highest good.'

It has been argued that this portrayal of self is not an accurate representation. This critique is especially exacerbated when considering disabled persons in the context of these theories.

Martha Nussbaum successfully critiques social contract theories from a disability perspective in her book 'Frontiers of Justice.'[237] She explains how social contract theories (specifically Rawls 'A Theory of Justice') imagine everyone as "free, equal and independent" beings who are "fully co-operating members of society over a complete life," with an innate rationale.[238] These characteristics however are not typical for all disabled people who Nussbaum describes as an afterthought to these theories.[239] The so-called commonalties portrayed by social theories on self, create at best- a conception of self where mental health was an obvious afterthought or is not discussed, and at worst- an anti-disability conception of self. One way in which this is demonstrated and which presents another commonality amongst dominant social theories, is to create a divide line between a 'healthy' and 'ill' self.

A 'healthy' self is a term being used here to describe a self who possesses the qualities accredited by the dominant social theories summarised above. An 'ill' self is one who does not. This often includes people with disabilities and mental health difference. When an individual does not possess the attributes of self necessary for the social theory- and are therefore excluded from the 'healthy' self conception- they are forced to align with the alternate or 'ill' self, framed in negative terms and in reference to what they lack. [240] This creates a conceptual divide between selves. This can be done by failing to discuss or include persons with disabilities in conceptions of self, or by discussing them in direct juxtaposition to the healthy self.

This distinction means people with mental health difference largely cannot identify with 'healthy' self conceptions, cannot conceive of these characteristics within themselves, nor feel they can achieve self-actualisation in the ways prescribed. This division re-enforces essentialist criteria of personhood, in this case cognition and the characteristics of the healthy self, and whose absence denotes a loss of reduction in personhood. Therefore

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[237] M. Nussbaum, *Frontiers Of Justice: Disability, Nationality, Species Membership* (1st edn, Harvard University Press 2006)

[238] Ibid 98.

[239] Ibid.

[240] 'Lack' being a term used by Gadamer to describe imbalances in the internal equilibrium. H. G. Gadamer*, The Enigma Of Health* (1st edn, Polity Press 1996) 42, 55.

*It is worth mentioning that some social theories provide much more scope for the meaningful inclusion of persons with disabilities- particularly Axel Honneth's recognition theory- particularly the potential of his concepts 'disrespect' and the potential to change the pre-requisites of 'rational will formation' under the CRPD.

this conception of self in dominant social theory creates a discriminatory exclusion against people with mental health difference.

While the overview of social theories presented here is in no way exhaustive, it is possible to review some dominant and more modern social and philosophical theories on self to demonstrate this conceptual divide. It is not within the scope of this thesis to conduct an in-depth portrayal of disability (or its lack thereof) according to these theories. However, for the purposes of demonstrating the presence of this conceptual divide in selves, this section includes a brief discussion of social contract theories including Hobbes 'Leviathan'[241] 'Elements,'[242] Locke's 'Second Treatise'[243] and Rawls' 'A Theory of Justice'[244]; as well as more modern theories including Gadamer's 'The Enigma of Health,'[245] and Parson's sick role in 'The Social System.'[246]

First let us examine self with mental health as portrayed in the social contract theories of Hobbes, Locke and Rawls.

Hobbes' social contract theory in 'Leviathan' begins by outlining the features of 'natural man' in the first five Chapters. The features of this natural man include the senses, reason, language, imagination or memory and the mechanism of 'trayne of thoughts' or 'trayne of imaginations' (latterly referred to as train of thought)[247] which 'hunt the causes, of some effects, present or past' and enable us to forecast the probable result of various courses of action.[248] Reason also plays a dominant role in determining which course of action an individual should take to satisfy their will. This is called deliberation and from this comes the will to act and voluntary action.[249] In terms of decision making therefore, Hobbes' natural man are perceived as machines which seeks action conducive to continuous motion based on experience of which actions will aid and halt this motion.[250] This rationale of humans as self-moving and self-directing machines is necessary to explain the struggle Hobbes presents of every man against every man in the state of nature.[251] Reason, memory, self-direction and trayne of thoughts therefore

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[241] T. Hobbes, *Leviathan* (1st edn, 1961).
[242] T. Hobbes, *The Elements Of Law, Natural And Politic* (1640).
[243] J. Locke, *Second Treatise Of Government* (1st edn, Awnsham Churchill 1689).
[244] J. Rawls*, A Theory Of Justice* (Harvard University Press 1971).
[245] H.G. Gadamer, *The Enigma Of Health* (1st edn, Polity Press 1996).
[246] T. Parsons, *The Social System* (2nd edn, Routledge).
[247] C. B Macpherson, *The Political Theory Of Possessive Individualism* (Oxford University Press 2011) 30-32.
[248] T. Hobbes, *Leviathan* (1st edn, 1961) Chapter 3, 20.
[249] Ibid) Chapter 6, 47.
[250] Ibid Chapter 6.
[251] C. B Macpherson, *The Political Theory Of Possessive Individualism* (Oxford University Press 2011) 33.

play a dominant role on Hobbes theory and his conception of the natural man, many attributes of which persons with mental health difference in particular may not always possess.

Locke in his 'Second Treatise of Government' assumes all men are born free and rational, capable of looking after themselves and protecting their property- that is their life, liberty and estate.[252] Locke's state of perfect freedom also involves a lack of dependence on others, which includes any relationships which are not mutually beneficial and likely excludes care for disabled persons.[253] Locke only briefly mentions persons with disabilities in 'Second Treatise of Government' stating "… if, through defects that may happen out of the ordinary course of nature, any one comes not to such a degree of reason, wherein he might be supposed capable of knowing the law, and so living within the rules of it, he is never capable of being a free man, he is never let loose to the disposure of his own will (because he knows no bounds to it, has not understanding, its proper guide) but is continued under the tuition and government of others, all the time his own understanding is uncapable of that charge. And so lunatics and idiots are never set free from the government of their parents."[254] Locke goes on to quote Hooker, that "[C]hildren, who are not as yet come unto those years whereat they may have; and innocents which are excluded by a natural defect from ever having; thirdly, madmen, which for the present cannot possibly have the use of right reason to guide themselves, have for their guide, the reason that guideth other men which are tutors over them, to seek and procure their good for them."[255]

People with mental health difference are therefore referred to by Locke as 'lunatics' and 'idiots' and are described as possessing defects outside the ordinary course of nature. They are described by Locke as lacking the developmental capacities of children, which he uses to justify restricting them from political membership.[256] Elsewhere Locke uses discussion of persons with disabilities to "disprove the maxim of innate ideas and test the limits of species membership."[257] Persons with disabilities are therefore firmly situated as 'other' or 'ill' in Locke's theory.

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[252] J. Locke, *Second Treatise Of Government* (1st edn, Awnsham Churchill 1689) s.87.

[253] Ibid s.4.

[254] Ibid s 60.

[255] Ibid s60.

[256] G. Quinn and A. Arstein-Kerslake, 'Restoring The 'Human' In Human Rights – Personhood And Doctrinal Innovation In The UN Disability Convention', *The Cambridge Companion to Human Rights Law* (1st edn, The Cambridge University Press 2013) 43.

[257] S. Clifford, 'The Capacity Contract: Locke, Disability, And The Political Exclusion Of "Idiots"' (2014) 2 Politics, Groups, and Identities, 91.

Rawls also shares in the assumption that parties to the contract are free, equal and independent,[258] that mutual benefit provides the drive for social cooperation as opposed to any innate benevolence; and that individuals are driven by self motivation or self interest.[259] Rawl's Original Position includes persons whose physical and mental abilities lie within the 'normal' range. Likewise citizens of his Well-Ordered Society who act as Trustees for those in the Original Position are "fully cooperating members of society over a complete life."[260] Rawls himself acknowledges that his theory of justice is lacking when considering what is owed to persons with disabilities.[261]

More recent social and philosophical theories which include a portrayal of self with mental health difference include Parsons 'Social System' and Gadamer's 'Enigma of Health'. Parsons conceptualises disability within the 'sick role'- as a deviation from norms and involving the passive avoidance of obligation (i.e. production of labour) and overt dependency on others.[262] "Illness, in our society, is undoubtedly motivated to a high degree and therefore may legitimately be regarded as a type of deviant behaviour. There is little doubt that illness belongs predominantly in the passive alienative category…[i]llness is predominantly a withdrawal into a dependent relation, it is asking to be "taken care of." It uses disability as the basis of legitimation of this claim."[263]

Gadamer discusses how mental health difference is an illness which creates an imbalance in a person's internal equilibrium- in other words, their internal health.[264]* He believes a feeling of 'lack' is what alerts an individual to this imbalance, meaning illness is framed in reference to 'lack.'[265] "The sick person is no longer simply identical with the person he or she was before. For the sick individual 'falls out' of things, has already fallen out of their normal place in life. But the individual who now lacks and misses something previously enjoyed still remains oriented towards returning to that former life."[266] The 'ill' self

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[258] J. Rawls*, A Theory Of Justice* (Harvard University Press 1971) 126-130.
[259] M. Nussbaum, *Frontiers Of Justice: Disability, Nationality, Species Membership* (1st edn, Harvard University Press 2006) 26-35.
[260] Ibid 104.
[261] J. Rawls, *Political Liberalism* (1st edn, Columbia University Press 1996) 21.
[262] T. Parsons, *The Social System* (2nd edn, Routledge) 285.
[263] Ibid.
[264] H. G. Gadamer*, The Enigma Of Health* (1st edn, Polity Press 1996) 35-38.
*It is worth noting that Gadamer later goes on to question what constitutes illness using the conception of 'lack,' so it is not clear whether he expressly regards mental health difference as illness or a category in and of its own.
[265] Ibid 42, 54.
[266] Ibid 42.

therefore is posited as a disconnected new self who has departed from the norm and seeks to return to their 'former life.'

One of the aspects of his work particularly relevant for persons with disabilities is his discussion around losing self and the soul. Gadamer believes we use recollection (memory with specific purpose i.e. to perform tasks,) to self-reflect.[267] It can be seen how this idea resonates with Hobbes' 'trayne of thoughts.' Only in consumption of thought about others, our ideas and with an understanding of our surroundings, history and so on, do we become aware of our 'self.' The analogy he provides is that of light and how it only comes into existence by illuminating its surroundings.[268] He believes this to be a symbiotic relationship by which we need the darkness in order to see the light and vice versa. Only by illuminating our surroundings i.e. by self-reflecting, do we become aware of our own self. This constant self-reflection and recollection of a multitude of possibilities is the soul according to Gadamer.[269]

This would imply that those without the ability to recollect and self-reflect lack soul, which from a mental health and disability standpoint is problematic. This is in regard to persons with progressive types of mental health difference including dementia and Alzheimer's who commonly experience memory loss and lose the ability to self-reflect based on their current surroundings- for example by reverting back to an earlier version of self during childhood. This could equally apply to those who experience episodes, during which the individual is unaware of, or cannot accurately reflect upon, current surroundings or events i.e. because of delusion or paranoia. If these individuals are unable to self-reflect or recollect- have they lost self and soul according to Gadamer?

In summary therefore, many dominant social and philosophical theories on self often contain either inadequate consideration or an outright exclusion of persons with disabilities in models of self and society. This can be seen to create a divide between the 'healthy' and 'ill' self, this divide being based on a lack of 'healthy' self characteristics and the presence of disability.

This divide in selves is highly problematic in light of the CRPD, particularly in how they have influenced legal personhood.

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[267] Ibid 144-147.
[268] Ibid 144-148.
[269] Ibid 147.

The autonomous self as a legal theory manifestation of the ‘healthy’ self and mental capacity assessments as the dividing line

The legal autonomous self bears striking resemblance in many of its characteristics to the social theory ‘healthy’ self.

The autonomous self is a self with free will and self-direction, able to make rational decisions independently from others. Autonomy is defined as ‘self governance,’ and includes the power to be morally and politically self-directing, free from dependence and in possession of one’s own faculties.[270] The autonomous self is a cognitive one. It possesses the capacity to predict and influence outcomes for desired results, and to some extent the self-consciousness to realise both the internal and external limitations placed on choices and behaviours.[271] According to Flynn and Arstein-Kerslake “[t]he dominant discourse on legal personhood has prized cognition and rationality as indicators of autonomy, and distinguishing features between human persons and others not deserving of legal personhood.”[272] It is strongly linked with concepts of liberalism and individualism.[273]

The autonomous self is the model on which legal personhood is based.

It is present in many areas of law in the form of the reasonable person (formally man.)[274] The reasonable person is postulated as being the average person, therefore containing objective attributes of self which accord to the average person. Thereby it sets a standard of self and is described as a one-size-fits-all concept.[275] It is used most notably to establish negligence in criminal law and tort law (although with different thresholds) and in contract law to establish a breach in duty in care.

It is particularly present in capacity law, which is intimately linked to the philosophical concept of autonomy.[276] One of the purposes of the Mental Capacity Act is to safeguard

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[270] *Collins English Dictionary* (1st edn, HarperCollins Publishers 2006) 35.
[271] J. Nedelsky, *Law's Relations: A Relational Theory Of Self, Autonomy And Law* (Oxford University Press 2012) 135-136.
[272] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 81.
[273] J. Nedelsky, *Law's Relations: A Relational Theory Of Self, Autonomy And Law* (Oxford University Press 2012) 118.
[274] G. Quinn and A. Arstein-Kerslake, 'Restoring The ‘Human’ In Human Rights – Personhood And Doctrinal Innovation In The UN Disability Convention', *The Cambridge Companion to Human Rights Law* (1st edn, The Cambridge University Press 2013) 41, footnote 11.
[275] M. Baron, *The Standard Of The Reasonable Person In The Criminal Law* (Oxford University Press 2011) 12.
[276] G. S. Owen and others, 'Mental Capacity And Decisional Autonomy: An Interdisciplinary

individual autonomy. One of the ways it does this is by restricting legal capacity to those who do not meet certain decision-making criteria and are therefore viewed as not being fully autonomous. These decision-making criteria could not be reached without possessing the qualities of a 'healthy' self.

As stated by Series "[a]lthough 'mental capacity' is not synonymous with moral and political philosophies of autonomy…in many respects its legal functions are closely analogous…autonomy [means] that freedom and responsibility flow from a person satisfying competence and authenticity requirements. Mental capacity law is structured similarly: a person is accorded legal rights and responsibilities only insofar as they are found to be competent and their decisions are authentically theirs."[277]

These decision-making standards include the ability to understand, weigh and retain relevant information to a decision and then communicate that decision to others free from undue influence, independently.[278] There are certain elements of self which are required to make such decision making possible. To understand, weigh and retain information there is a presumption of certain cognitive capabilities. These include memory and self-reflection- to understand the decision, why it matters, who they are and so on; recollection- to be able to recall memory with purpose- to draw predictions about what the likely outcomes of a decision will be based on past experience; the ability to deliberate- which necessarily infers the ability to reason, and an understanding of what is in self-interest. To communicate a decision free from undue influence an individual must also possess self-governance and independence. These are all elements of self present in the 'healthy' self.

The purpose of mental capacity assessments therefore, becomes to determine when the 'healthy' autonomous self is present, versus the non-autonomous 'ill' self- who does not always possess the capabilities of the 'healthy' self, and may therefore not be able to meet these decision making standards. This divide is made on the grounds of a 'disturbance in the function of the mind or brain' which will disproportionately effect those with mental health difference. As outlined by Minkowitz "'[f]unctional capacity' as a way to retain the binary system of legal capacity/incapacity has a definite adverse impact on people with psychosocial disabilities…"[279] According to Flynn and Arstien-Kerslake,

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Challenge' (2009) 52 Inquiry, 80.

[277] L. Series, 'Relationships, Autonomy And Legal Capacity: Mental Capacity And Support Paradigms' (2015) 40 International Journal of Law and Psychiatry, 81.

[278] For legal authority for undue influence see *A Local Authority v A* [2010] 1549 (Fam). *Re T* [1992] 4 All ER 645 (CA). and UNCRPD Article 12 (4).

[279] T. Minkowitz, 'CRPD Article 12 And The Alternative To Functional Capacity: Preliminary Thoughts Towards Transformation' [2013] SSRN, section 1.

disability is nearly always a threshold factor used to disprove that an individual understands the nature and consequences of their actions.[280] Therefore this divide in selves in mental capacity assessments has the effect of excluding the 'ill' self, which disproportionately includes persons with disabilities.

In essence, mental capacity assessments therefore become a manifestation of the divide line present in dominant social theory, between different versions of self.

Reasons why law has manifested a divide line between different selves

There are many reasons why law has manifested a standard of self, specifically one sharing many of the common characteristics of the healthy social theory self.

As we have already established, in order for law to provide common rules for society, a certain generalisation of its subjects is needed. Likewise in theories on the formation of society, certain standards of self need to be present to justify forming a collective. For Hobbes' Leviathan this means people must be able to sacrifice their rights to a sovereign for collective governance.[281] In order to sacrifice these rights, people must be capable of holding them in the first place and have the individual liberty and rationale to understand why they should sacrifice those rights. For Locke, law and governance is about protecting property rights, meaning people must be capable of property ownership and the rationale to protect their property rights by entering under collective governance.[282] Without a standard of self, collective society according to many dominant theories would not exist. The autonomous self and reasonable person embodies this standard of self for the collective governance that is law.

Another conceptual justification for this divide rests on the association of the autonomous 'healthy' self with the 'true' self.' This was discussed in relation to the conceptual justification for advance planning in Chapter 1- in that they safeguard the wishes of the 'true' unimpaired self. This true self is formulated as being the authentic self who represents the genuine wishes of a person, and who has the most longevity in character,

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[280] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 87.
[281] T. Hobbes, *Leviathan* (1st edn, 1961).
[282] J. Locke, *Second Treatise Of Government* (1st edn, Awnsham Churchill 1689).

capabilities, beliefs, values and decisions.[283] It is the self free from any mask or masquerade and free from performance to meet expectations; and 'true' in the sense that it is unimpaired by mental illness.[284] In western culture especially, being authentic and 'true to who you are' is a very popular concept on which many entertainment shows and media conceptions of self are based.[285] When the true self changes with mental health difference, there is a tendency to view this self as an imposter. Nancy initially describes his sick self as 'le intruder,' the trespasser on ones normal, healthy self.[286] "The Intruder [L'Intrus] enters by force, through surprise or ruse, in any case without the right and without having first been admitted."[287] This concept of the true self being held hostage or under duress by an intruder 'ill' self, is used to rule any decisions made by the imposter self and which are contrary to the wishes of the 'true' self, as disingenuous. This is especially the case when those wishes are harmful. At the least, it provides justification to subject their decision making to higher scrutiny. In this regard the law is therefore motivated by protectionism to safeguard the 'true' autonomous self. There exists in many legal systems a shared sentiment that there exist some situations in which a person is unable to make legally enforceable decisions for themselves. Therefore this divide in selves is made to protect the integrity of individual decision making and uphold the principle of informed consent.

Property rights also likely play a role in why law has manifest characteristics of a healthy self. The social theory healthy self very much depends on a capability to own and possess property. Social contract theories including Hobbes' and Locke's place great weight on property in the creation of a collective society, and view law as central in enforcing and maintaining property rights.

Macpherson in his book '*The Political Theory Of Possessive Individualism*' argues that writers including Locke and Hobbes were very much influenced by the social, economic and political time in which they were writing- this being a possessive individualist society. [288] MacPherson argues therefore that these social theorists essentially 'read-in' elements

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[283] For authority of 'longetivy' of wishes being considered in theory and by court judgements see J. Savulescu and D. Dickenson, 'The Time Frame Of Preferences, Dispositions, And The Validity Of Advance Directives For The Mentally Ill' (1998) 5 Medicine and Health 229.
Newcastle upon Tyne Hospitals Foundation Trust v LM [2014] EWHC 454 (COP).
Re MB (Adult, medical treatment) [1997] 38 BMLR 175 (CA).
J. Herring, Medical Law and Ethics (3rd edn, Oxford University Press 2016) 222. (In his discussion of Dworkin's experimental versus critical interests.)

[284] E. R. Saks, *Refusing Care* (1st edn, University of Chicago Press 2002) 204.

[285] S. Lawler, *Identity : Sociological Perspectives* (2nd edn, Polity Press 2015) 116-118.

[286] J. Nancy, 'L'intrus' (2019) 2 The New Centennial Review, 1-14.

[287] Ibid.

[288] C. B Macpherson, *The Political Theory Of Possessive Individualism* (Oxford University Press 2011).

a modern man needs to fully participate in a possessive individualist society, into the condition of natural man. This includes the propensity for unlimited accumulation of property. Since property and possession are king in a possessive individualist society therefore, it makes sense for the characteristics of man akin to property ownership to be privileged in these social theories.

Law within these social theories has a special role in upholding and protecting property rights for the healthy self.

According to MacPherson "[t]he possessive market model [which has parallels with our competitive market society] requires a compulsive framework of law. At the very least, life and property must be secured, contracts must be defined and enforced."[289] Hobbes' man without law lacks the goods of civilised society- namely property- and being without these goods is contrary to the desire of man's nature. It is these desires which drive men out from the state of nature.[290] According to the Levellers, the primary function of government is to secure property and enforce rules which allow men to make the most of their own capacities.[291] Harrington links property with the political power of the state and explains how property ownership must firmly be in the hands of the few to retain a balance of power and avoid war- very reminiscent of Locke's beliefs around full members of society being property owners.[292] This links law makers and governments with the protection and sustainment of property. And finally the most famous advocate of property and law- Locke, states "[t]he great and chief end…of men's uniting into commonwealths, and putting themselves under government, is the preservation of their property."[293] Law is about protecting 'lives, liberties and estates.'[294]

Historically property has played a significant role in law and has restricted property rights to the 'ill' self, including persons with disabilities.

Prior to 1959, the principle of 'parens patriae' saw a lot of legal applications being made in pursuit of control over property rights.[295] 'Parens patriae' refers to the crown's "responsibility for those without the capacity to look after themselves." [296] It initially

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[289] Ibid 57-58.

[290] T. Hobbes, *Leviathan* (1st edn, 1961) 98.

[291] C. B Macpherson, *The Political Theory Of Possessive Individualism* (Oxford University Press 2011) 144.

[292] J. Harrington, *The Art Of Law-Giving* (JC 1659).

[293] J. Locke, *Second Treatise Of Government* (1st edn, Awnsham Churchill 1689) section 124.

[294] Ibid s123.

[295] P. Bartlett, 'Law And Nonsense: Delusion As The Limitation Of Sanity In Nineteenth-Century Law', *Law and the Senses: Sensational Jurisprudence* (Pluto Press 1996) 21-26.

[296] J. Munby, 'Protecting The Rights Of Vulnerable And Incapacitous Adults – The Role Of The Courts: An Example Of Judicial Law-Making' (2014) 26 Child & Family Law Quarterly, 66.

included the wardship of children but later subsumed people with mental health difference.[297] Although the origins of such a principle are said to be "lost in the mists of antiquity," the most probable theory is that Edward I had assumed the authority from the feudal lords "who would naturally take possession of the land of a tenant unable to perform his feudal duties."[298] Therefore it was most likely founded in concerns around property. Also prior to the Mental Capacity Act of 2005, the main piece on mental capacity legislation for England and Wales was Part VII of the Mental Health Act 1983 which concerned 'management of property and affairs.' Indeed one of the purposes of the Mental Capacity Act 2005 was to shift focus away from property rights and towards more personal and welfare decisions.

It is possible therefore that these elements of self have been enshrined because of the similar privilege both law and social theory place on property, and because these elements are the ones perceived as being needed for property ownership. Indeed property rights still hold a special place of privilege in law in the form of financial lasting powers of attorney and last will and testiments.

Times they are a' changing: Conceptions of Self in the CRPD and their Incompatibility with the Divide Line

The divide between 'healthy' autonomous self and 'ill' non-autonomous self, manifest by mental capacity assessments and the functional approach are problematic with regards to Article 12 of the CRPD. So too is the association of the 'healthy' or 'autonomous' self with being a 'true' self. This divide and these conceptions around self and mental health difference need to be dispelled or reconsidered in order to achieve CRPD compatibility for advance plans.

There are many critiques of the autonomous self, which mental capacity assessments- and by extension advance plans- seek to protect. First, it is acknowledged that the elements of self attributed to the autonomous self are not an accurate portrayal of who we are and how we make decisions. The political and historic concept of personhood in rights discourse is described by Quinn and Arstein-Kerslake as a 'myth system'- a rational, self-directing, wholly autonomous moral agent freely choosing their own conceptions of the good, wandering freely and purposely, interacting with others and

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[297] *Re Eve* [1986] 2 SCR 308 [74-75].
[298] Ibid [32].

opting to engage in and influence political power.[299] This ‘myth system’ however is strikingly at odds with peoples everyday experiences and “[r]ights-talk itself is impoverished by this disconnect.”[300] Those who lack these features of legal personhood are placed in a position of disadvantage in relation to equal legal recognition, including persons with disabilities (specifically those with cognitive and psychosocial disability.)[301]

First, people are not always rational. It has been shown through decision making literature that pursuing rationality is not an accurate reflection of the way we make decisions.[302] People can be impulsive, irrational and make ‘unwise decisions.’ This is recognised in the Mental Capacity Act and is not to be taken as grounds on which to justify a finding of incapacity.[303] People also often make knowingly harmful decisions. These can include smoking, drinking excessively, eating unhealthily, making bad investments or relationship choices and refusing life-saving blood transfusions on religious grounds.[304] This includes harmful decisions made with capacity and full informed consent.

Second, people are not wholly independent.[305] Instead individuals are highly relational beings and dependency is an integral part of what it means to be human.[306] One aspect of this is via caring relationships- both the provision and receipt of care, something which garners little attention in the dominant social contract tradition. We depend on others for care- during infancy, old age, because of long term impairment or in the short-term following injury or illness. The provision of care and the presence of impairment is something which affects virtually all families in every society.[307] Eva Kittay in her book ‘Love’s Labour’ discusses dependency from a feminist perspective in relation to both receiving and providing care.[308] She emphasises that disability and dependence pose major challenges for theories of justice, including the dominant social contract tradition.

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[299] G. Quinn and A. Arstein-Kerslake, 'Restoring The ‘Human’ In Human Rights – Personhood And Doctrinal Innovation In The UN Disability Convention', *The Cambridge Companion to Human Rights Law* (1st edn, The Cambridge University Press 2013) 37.

[300] Ibid.

[301] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 82.

[302] S. Conley, *Against autonomy: Justifying coercive paternalism (*Cambridge University Press 2013).

[303] Mental Capacity Act (2005) s1(4).

[304] *Newcastle upon Tyne Hospitals Foundation Trust v LM* [2014] EWHC 454 (COP).

[305] M. Fineman, 'The Vulnerable Subject: Anchoring Equality In The Human Condition' (2008) 20 Yale Journal of Law & Feminism.

[306] E. Kittay, 'Love's Labor Revisited' (2002) 17(3) Indiana University Press Hypatia, 237.

[307] M. Nussbaum, *Frontiers Of Justice: Disability, Nationality, Species Membership* (1st edn, Harvard University Press 2006) 101.

[308] E. Kittay, *Love's Labor* (1st edn, Routledge 1999).

Kittay urges us to move beyond this conception of personhood in order to provide justice to, and recognise the citizenship of persons with disabilities, to provide adequate care and support for them and their carers.

Another aspect of dependency is in relation to decision making. In relational autonomy "individuals are considered to be relational beings, rather than isolated units who make choices and decisions separated from the considerations of others."[309] Relational autonomy literature therefore critiques the concept of 'agency'- of the individual at the heart of decision making as a 'lone rights bearer.'[310] This has generated criticism from Communitarians and Feminists, who argue that such a formulation ignores the impact and consequence of 'social embeddedness.'[311] This is the idea that free choice is 'socially constructed and situated' by or within a person's background- including their culture, family relations, social status and power relations.[312] This socialisation affects our decision making, meaning we do not make decisions in isolation from others. For example, Gilbar et al's study on medical decision-making involving women with breast cancer, demonstrated that all women involved in the study consulted their partners before making treatment decisions.[313]

Relational autonomy literature also highlights how the right kind of support relationships can help foster greater individual autonomy.[314] Nedelsky critiques the link between autonomy and independence, emphasising that no matter how powerful or self-sufficient we believe ourselves to be, we are not independent. We are situated in a network of interdependent relations, meaning "[p]eople who falsely believe they are independent, and falsely believe that their independence means that they are autonomous, are likely to feel autonomous without being so."[315] This is supported by contemporary neuroscience which demonstrates how the conception of the mind is relational and develops through relationships with others.[316]

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[309] I. Gremmen, G. Widdershoven, A. Beekman, R. Zuijderhoudt and S. Sevenhuijsen, 'Ulysses Arrangements In Psychiatry: A Matter Of Good Care?' (2008) 34 Journal of Medical Ethics 78.

[310] M. Donnelly, *Healthcare Decision-Making and the Law* (1st edn, Cambridge University Press 2010) 34.

[311] Ibid.

[312] P. Wolpe, 'The Triumph of Autonomy' in R. G DeVries and J. Subedi, *Bioethics and Society* (1st edn, Prentice Hall 1998) 54.

[313] R. Gilbar and O. Gilbar, 'The Medical Decision-Making Process And The Family: The Case Of Breast Cancer Patients And Their Husbands' (2009) 23 Bioethics.

[314] J Nedelsky, 'Reconceiving Autonomy: Sources, Thoughts And Possibilities' (1989) 1 Yale Journal of Law & Feminism.

[315] J. Nedelsky, *Law's Relations: A Relational Theory Of Self, Autonomy And Law* (Oxford University Press 2012) 138.

[316] A. R. Damasio, *Self Comes To Mind* (Knopf Doubleday 2010).

An alternative to the autonomous independent self is advocated for by Martha Fineman in the form of the 'vulnerable subject.'[317] Fineman argues that vulnerability forms an innate part of the human condition and believes it to be more representative of lived experience and human dependency. Fineman believes state support would be much more responsive were personhood re-framed in such a way and believes reimagining self in this way to be essential in achieving a more equal society.[318]

Dispelling unrepresentative and unhelpful elements of self, associated with the healthy autonomous self, helps actualise a more equal concept of personhood - one which does not divide between versions of self on the basis of mental health difference. This is key given the concept of universal legal capacity in Article 12 and the model of personhood it promotes.

In the past sixty years there has been growing acknowledgement within the international human rights community, that a more expansive notion of personhood is required and that all should be recognised as persons before the law.[319] This is epitomized by the CRPD and Article 12: 'Equal recognition before the law.'

As discussed in Chapter 1, the CRPD believes everyone is capable of exercising their legal capacity by expressing will and preference with appropriate support. This is despite deficits in mental capacity and remains the case even in emergency situations, when it can be presumed an individual's mental capacity is diminished. The CRPD's model of legal personhood therefore separates itself from cognition and rationality, to create a universal self which enjoys legal capacity on an equal basis with others. Legal capacity therefore forms a basic right all ought to be accorded under the CRPD.

The right to equal legal capacity challenges us to re-conceive the concepts of personhood which form the basis for the 'healthy' autonomous self we are supposedly protecting by restricting legal capacity. It also makes us reconsider the 'human' of human rights- the

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[317] M. Fineman, 'The Vulnerable Subject: Anchoring Equality In The Human Condition' (2008) 20 Yale Journal of Law and Feminism.

[318] Ibid 2.

[319] Amita Dhanda, 'Legal Capacity In The Disability Rights Convention: Stranglehold Of The Past Or Lodestar For The Future?' (2007) 34 Syracuse Journal of International Law and Commerce.
Tina Minkowitz, 'The United Nations Convention On The Rights Of Persons With Disabilities And The Right To Be Free From Nonconsensual Psychiatric Interventions' (2007) 34 Syracuse Journal of International Law and Commerce.

basis on which rights are granted. As stated by Quinn and Arstein-Kerslake "[t]he interesting thing about the [CRPD]…is that it forces to the surface many of these suppressed suspicions about the disconnect between 'rights' and the human condition…[i]n effect, it is built on a much more three-dimensional view of the human condition and of human flourishing than would have been possible by simply working backwards from the logic of rights."[320]

The CRPD therefore challenges conceptions of legal personhood via legal capacity and has the potential to enrich 'self' in rights discourse.[321]

The CRPD self is a more relational and holistic conception of the human condition. It is one premised on will and preference as opposed to cognition. As observed by Quinn and Arstein-Kerslake "[n]othing in the convention pivots on the 'myth system' of the rational and masterless man."[322] The CRPD self is also one able to take more individual risk and privileges free will over paternalism.[323] This is a result of replacing best interest decision making with will and preference and universal legal capacity. The CRPD self is also one capable of owning property and partaking in all aspects of economic, private, social and political life.[324] It acknowledges that persons with disabilities have developing capabilities and that a state's role is to aid citizens in this development. This echoes capability theories like those of Nussbaum and Sens.[325] This opposes past paternalistic disability philosophy, which assumed that unlike children, persons with disabilities lacked this capacity for development and improvement over time.[326]

The CRPD self is one which recognises intersectionality to an extent.[327] Disability itself is an evolving concept according to preamble paragraph e, which develops as people interact with environmental and attitudinal barriers. Multiple discrimination is also acknowledged in preamble paragraph q, Article 6 and 7- concerning women and children

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[320] G. Quinn and A. Arstein-Kerslake, 'Restoring The 'Human' In Human Rights – Personhood And Doctrinal Innovation In The UN Disability Convention', *The Cambridge Companion to Human Rights Law* (1st edn, The Cambridge University Press 2013) 38.

[321] Ibid.

[322] Ibid 49.

[323] Ibid 41.

[324] Article 29 'Living independently and being included in the community'; Article 23 'Respect for home and the family'; Article 12(5) UNCRPD.

[325] M. Nussbaum, *Frontiers Of Justice: Disability, Nationality, Species Membership* (1st edn, Harvard University Press 2006)
A. Sen, *Development As Freedom* (Oxford UP 1999).

[326] G. Quinn and A. Arstein-Kerslake, 'Restoring The 'Human' In Human Rights – Personhood And Doctrinal Innovation In The UN Disability Convention', *The Cambridge Companion to Human Rights Law* (1st edn, The Cambridge University Press 2013) 42.

[327] Ibid 50-51.

with disabilities respectively. The CRPD self is one dependent on human flourishing within community as a way to achieve self-realisation, by creating opportunities to participate in public and political life.[328] Above all the CRPD self is universal. It recognises the shared fragility of the human condition which needs support.[329] It recognises the role of interdependence as well as independence. In summary then, "[w]hat [the CRPD] brought to the surface was an insistence on the capacity of all persons with disabilities to forge their own destinies, a frank acknowledgement of shared personhood and of the myriad of supports formal and informal that we all rely on to help us forge our own pathways– and the critical importance of participation and the ethic of belonging that it instils."[330]

In light of this therefore, it is clear that the CRPD would not uphold a conceptual divide in selves on the basis on mental health difference and cognition. As outlined in Chapter 1, the CRPD prohibits mental capacity assessments and the functional approach. Given it is argued that mental capacity assessments enforce a divide between the autonomous healthy self and non-autonomous ill self, by prohibiting mental capacity assessments the CRPD is in effect removing this divide line. By awarding equal legal recognition to all regardless of perceived mental incapacity, a division in selves could not be maintained conceptually under the CRPD.

Concepts of self therefore needs to be reconsidered in light of mental health and the CRPD.

Although the CRPD uses the word 'autonomy' therefore, it is unlikely this is proof that the Committee advocates for an autonomy model approach nor an autonomous self. In order to improve compatibility with the CRPD, advance plans must therefore move away from the autonomous self and its entrenched manifestation of the healthy social theory self. The autonomous self has been so influential to mental capacity assessments, that moving away from such assessments whilst retaining a theory based in autonomy would be theoretically difficult. What is required is to go beyond autonomy theory to reconsider the self on which autonomy theory was formed from a mental health perspective. This includes moving away from relational autonomy, which- while meaningfully updating the autonomous self- is never-the-less grounded in its conceptions.

Self-binding need not necessarily be precluded by this universal CRPD self. Any division in selves would presumably be opted into as opposed to enforced and would be based on

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[328] Ibid 39.
[329] Ibid 40.
[330] Ibid 38.

triggers decided by the individual as opposed to a mental capacity assessment. One such alternative is presented in Chapter 6.

The next Chapter outlines the methodology for the empirical research of this thesis. This includes individual interviews and focus groups involving a total of 25 participants with both first and second-hand experience of various types of mental health difference. The following Chapter on 'Understanding Self with Mental Health Difference' draws upon findings from this empirical research to explore further whether some remaining conceptions around self with mental health which remain and justify restrictions to legal capacity in mental capacity law; are accurate according to how participants believe self changes with mental health. These include whether there is an ill self 'othered' from the healthy self; whether there is such a thing as a 'true' self; and whether individuals equate mental health experience with a loss of the qualities of a 'healthy' autonomous self- including a loss of cognition and rationality. This is with the aim of seeing whether such a divide in selves is actually representative of participant experiences. If it is, there may remain some conceptual grounds to justify limits to legal capacity. If it is not, this aligns closer with a CRPD conception of self.

These findings are also used for the purposes of Chapter 6 to explore whether a user-led statement on change in self could form new thinking on an alternative to mental capacity assessments.

Chapter 3: Methodology

Research Questions

A number of barriers to CRPD compatibility for advance plans have been identified thus far. These include the difference in weight given to incapacitous will and preference under the Mental Capacity Act versus the CRPD; the use of mental capacity assessments to trigger advance plans, which are clearly prohibited by the CRPD Committee; and the role harm plays in justifying restrictions to legal capacity under the Mental Capacity Act, which is clearly not mirrored by the Committee. [331] Chapter 2 also outlined another

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[331] United Nations Committee on the Rights of Persons with Disabilities, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 22.

barrier to CRPD compatibility regarding how advance plans uphold a problematic conception of self with mental health in dominant social and legal theory.

It is unclear whether self-binding is permitted under the CRPD and in what capacity, for example, to opt-into support or intervention to prevent harm. If desired, self-binding would need to be triggered without reference to a mental capacity assessment and would instead need to rely on a disability neutral trigger according to the Committee. This calls for non-arbitrary grounds on which to justify privileging one version of self over another.[332] New thinking on a CRPD compatible alternative to mental capacity assessments is therefore needed.

The research questions of this thesis are therefore as follows:

- Do the barriers to CRPD compatibility for advance plans identified, resonate with persons with mental difference who would be using advance plans as a method of support? And
- If they do, how can advance planning provisions be made more compatible with the CRPD?

More specifically this thesis asks:

- How do participants view self with mental health? How does self change with mental health? Do participants conceptions support traditional social/legal concepts of an ‘ill’ non-autonomous self and uphold a divide line?
- Would persons with mental health difference want the option to self-bind some decisions, thereby restricting their own legal capacity?
- How do participants factor harm into decisions on whether to adhere to will and preference during a mental health experience? Is there a justified limit to will and preference adherence in relation to harm?
- What is a possible alternative to mental capacity assessments in triggering an advance plan? Can an advance plan be utilized as an alternative to mental capacity assessments to opt-into intervention and support?

These questions will be answered using empirical research involving persons with varying mental health experiences. This is because this group are the ones most likely to engage in advance planning provisions, meaning how they wish to use advance plans as a method of support is of key importance. They also have direct experience of decision

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[332] M. Scholten et al, 'Psychiatric Advance Directives Under The Convention On The Rights Of Persons With Disabilities: Why Advance Instructions Should Be Able To Override Current Preferences' (2019) 10 Psychiatry, 11.

making during a mental health experience which gives them a unique insight into the barriers outlined. A dominant concern voiced by the Independent Review of the Mental Health Act is that attempting CRPD compatible reform would leave people who lack capacity with insufficient protection.[333] This has been used as justification not to pursue clear blue thinking on CRPD compatible reform. This research aims to explore this concern by asking people with mental health difference for their opinion on whether CRPD-compatible reform would indeed leave them with insufficient protection. It is hoped participants with first-hand experience will be able to create vital new thinking on the research questions of this thesis.

Overview

This research is approached with an understanding grounded in the pragmatist tradition, specifically one that opposes a 'foundational' conception of the self and which understands self to be socially situated and subject to reconstruction (disintegration and re-integration, as Mead put it.)[334]

Specifically, what has come to be known as an 'old' as opposed to a 'new' pragmatist approach is adopted, [335] which allows the nature of the self as it is utilized by individuals to be open to investigation, rather than representing it as a presupposition of investigation.[336] Given part of this research asks participants to reflect on concepts of self to challenge pre-existing conceptions, this was a pragmatic as well as a theoretical decision.

6 focus groups and 6 individual interviews were conducted, involving a total of 25 participants. All participants had first and/or second-hand experience of mental health difference. This included people whose mental health was characterized by episodes

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[333] S. Wessley, 'Modernising The Mental Health Act Increasing Choice, Reducing Compulsion Final Report Of The Independent Review Of The Mental Health Act 1983' (2018) <https://www.gov.uk/government/groups/independent-review-of-the-mental-health-act#governance> accessed 14 January 2021, 12-13.

[334] G. H. Mead and C. W Morris, *The Philosophy Of The Act* (University of Chicago Press 1938).

[335] J. C. Isaac, 'Is The Revival Of Pragmatism Practical, Or What Are The Consequences Of Pragmatism?' (1999) 6 Constellations 561-587.

[336] J. Holmwood, 'Reflexivity As Situated Problem-Solving A Pragmatist Alternative To General Theory' (2014) 1 Sociologica.

*Regained in as much as it is possible to regain a past version of self after a mental health experience and over time.

including psychosis and bipolar, and those whose mental health could be characterized as progressive, meaning self is changed more so over time, including Alzheimer's, dementia and memory loss. This diverse range of mental health experience was deliberate, to see how participants experiences influenced their responses to the research questions and activities, and whether there existed any key differences in approach.

Of the 25 participants involved, 4 had experiences of depression, 3 bipolar, 2 schizophrenia, 2 psychosis, 1 post-traumatic stress disorder, 1 obsessive compulsive disorder, 1 personality disorder, 1 borderline personality disorder, 2 undisclosed mental health differences characterized by episodes, 2 early stage dementia, 1 memory loss caused by stroke, 1 undiagnosed memory loss, 2 carers for spouses with late-stage progressive mental health, and 1 father with secondary experience of manic bipolar via his daughter who was also a participant.

To direct discussion and pick out particular themes, research included three main data gathering activities. First, to challenge the dominant conceptions of self with mental health difference in social and legal theory, participants were asked to engage in an interactive activity where they were asked to communicate self. Each participant was given a pack of cards with elements of self commonly articulated in social and legal theory and were asked to use them in whatever way they wished to communicate self. Participants were then asked how they felt self changed with mental health difference, to see whether a different self emerged and whether these changes aligned with dominant conceptions.

The second activity involved case study vignettes involving fictional scenarios of people with varying mental health difference, making situational decisions. These vignettes focused on situations where a person makes a decision during a mental health experience which is contrary to one recorded in an advance plan, and where different types and severities of harm could be caused depending on whether the persons contrary wish is upheld or overruled. This sought to address Dworkin's question concerning 'Margo' in Chapter 1, on which self we listen to and when. The vignettes involve different types of mental health difference (including progressive mental health and mental health characterized by episodes,) different kinds of planning in advance, contrary wishes, different types of decisions, different types/levels of harm and different levels of family/carer/professional interest. The inclusion of these factors was to see whether, how and to what extent these factors influence participant decisions and the process of their decision making, on whether will and preference during mental health experience should be upheld or overruled. Participants were therefore asked to 'think out loud.'

Finally, semi-structured questions were asked to prompt participants to consider further or more explicitly some of the topics/questions which had been addressed.

Analysis in later Chapters draws on the responses from these three main data sets. Chapter 4 is built on findings from the interactive activity on self, Chapter 5 utilizes participant responses to case studies, and Chapters 4 and 6 are informed by responses to semi-structured questions.

Choosing Focus Groups and the Process of Ongoing Reflexivity

Focus groups were the chosen research methodology of this thesis. This was because of the insight they offer into participants internal conversations, because of the plurality of voices focus groups offer, their relationship with power dissemination, and to distance this research from individual medical assessments or therapy.

Focus groups as a methodology, reflect the belief that self and the process of decision making is socially constructed and situated. The process of decision making and the creation of an advance statement is highly reflexive and informed by others. It is therefore a dialogic process and involves the 'rehearsal' of 'stances' others may take in the mind of the individual as part of coming to know their 'own mind'. People's decisions and their account of their internal conversation is impacted and negotiated by the experiences and opinions of those around them. This ongoing formalizing and strategizing of a position is something focus groups allow us to observe. Focus groups are therefore a "formal instance of many of the kinds of everyday speech acts part and parcel of everyday life- conversations, group discussions, negotiations and the like."[337] They provide a forum to witness individual reflexivity and how that dialogue is impacted by others as thought processes are 'externalised' and made available to others for reflection. They allow something analogous to an internal conversation- something which would normally be unavailable, to be witnessed externally. The individual therefore undergoes continuous self-reflection in the social setting of the group, meaning the process of ongoing negotiation between the internal and external, is observable. It is this ongoing process of dialogue and reflexivity that is of most interest for the purposes of this research. This will inform understanding of how participants think about and weigh relevant factors and decisions, which will create some practical guidance on where

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[337] G. Kamberelis and G. Dimitriadis, 'Focus Groups: Strategic Articulations Of Pedagogy, Politics And Inquiry', *The SAGE Handbook of Qualitative Research* (3rd edn, 2005) 887.

additional considerations need to be directed in achieving greater CRPD compatibility for advance planning.

This research is not concerned directly with the generalisability or replication of results- an often cited flaw of focus group methodology.[338] Interest instead lies in the *process* of decision-making and whether this will be similar amongst participants even where situational factors are different and may lead to different outcomes. It is the process of decision making and the relevant factors for consideration therefore that are of interest, as opposed to specific outcomes in terms of responses.

Another dominant reason for choosing focus groups was because of their benefits specifically in the context of mental health research.

First, the group format helps distinguish this research from individual medical assessments and therapy. [339] This is important given many participants had experience of these types of one-to-one sessions and some described them as being negative or coercive, resulting in a wider skepticism of mental health services. This skepticism can make for reluctant research participants.[340] Therefore differentiation of methodology from what they might have experienced through the operation of the 'medical model' was key for initial recruitment.

Also by placing participants with experience of mental health difference in a group and as part of the majority, they will hopefully feel less inclined to agree with the researcher in pursuit of providing the 'right' answer, because of their position as 'researcher'.[341] This is related to considerations of power within research. Power is a dominant concern in research methodology, in that power can be seen to reside with the researcher or 'expert' and is exerted directly or indirectly on participants to generate inaccurate results. This is particularly relevant in the context of this research given some participants shared past experiences of being coerced into agreeing with a respective professional. This perceived coercion is rooted in the medical model and traditional conceptions of self as rational- allowing the rational self- the professional, to overrule the irrational self. This was not a desirable phenomenon to recreate as participant bias could impact the validity

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[338] L. Vicsek, 'Issues In The Analysis Of Focus Groups: Generalisability, Quantifiability, Treatment Of Context And Quotations' (2014) 15 The Qualitative Report, 123-124.

[339] B. Schulze and M. C. Angermeyer, 'Subjective Experiences Of Stigma. A Focus Group Study Of Schizophrenic Patients, Their Relatives And Mental Health Professionals' (2003) 56 Social Science & Medicine.

[340] S. Peters, 'Qualitative Research Methods In Mental Health' (2010) 13 Evidence-Based Mental Health, 35.

[341] M. M. Hennink, *International Focus Group Research: A Handbook For The Health And Social Sciences* (Cambridge University Press 2007).

and reliability of data collection, and more importantly, would be an unpleasant and distressing experience for participants.

Focus groups have previously gained acclaim in feminist research methodologies as they are believed to be an effective method of redistributing power away from the researcher and towards participants.[342] The format of focus groups was therefore chosen in the hopes of distribute power more equally between all members of the group, as opposed to power residing solely or in the majority with the researcher. It is also important to note that the language throughout was very conscious to reaffirm this power relation, for example by stressing that there was no wrong answer and that research was participant led.

Focus groups reveal the nature of a conversation and the differing 'weight' given social roles within it. Those roles are situationally specific and may vary in the weight associated with ostensibly similar roles across settings. By being present in the group and occupying a role as 'expert' (researcher), it is acknowledged that I am part of the process. I therefore do not practice self-effacement as my interactions with and presence within the group will inevitably shape responses.

Because of my awareness of playing an active role in the group, a 'reflective log' was kept for each session. This log included pictures from the interactive activity and key details about participants including their names and any mental health disclosures. It also included field notes on the thoughts and feelings of the researcher as well as anything considered note worthy. The purpose of keeping this record was to allow for later scrutiny during analysis, to aid transparency and better understand the rigor and validity of findings by reflecting on the role I played as moderator and how this impacted findings.[343] As part of this reflection it is worth noting that at the time the research was conducted, I was a twenty-three year old, white, sis-gender female, PhD student, with a working-class background, from Salford and with secondary experience of psychical disability and mental health difference.

Because of the nature of the focus group and the ongoing reflexivity they entail, there was, I believe, an interchange and shifting of power throughout the dialogue between researcher and participants. Power was therefore fluid, rather than static, and did not

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[342] See for example Barbara Pini, 'Focus Groups, Feminist Research And Farm Women: Opportunities For Empowerment In Rural Social Research' (2002) 18 Journal of Rural Studies, 341. Sue Wilkinson, 'Focus Groups In Feminist Research: Power, Interaction And The Co-Construction Of Meaning' (1998) 21 Women's Studies International Forum, 144.

[343] S. Peters, 'Qualitative Research Methods In Mental Health' (2010) 13 Evidence-Based Mental Health, 39.

reside solely with one person. This can be evidenced through interactions with participants. One such instance involved a participant turning the question on the researcher and asking how I would respond to the case study vignette. Another involved a participant using my ‘power’ as an external researcher to obtain additional support.

Finally, the kind of plurality of voices involving different experience of mental health difference was something of particular interest. Any differences and similarities of opinion were of interest amongst groups involving both first and second hand experience and groups where people had different types of mental health difference. A hypothesis I was interested in testing, was whether the characterization of mental health (whether episodic or progressive) was a consistent factor which impacted participants responses. Given advance planning currently works the same way for all regardless of the type of mental health difference, it would be interesting to see whether this is an area in need of reconsideration going forward, in order to deliver the best support to what can be very different characterisations of mental health difference.

In terms of communicating how self changes with mental health difference, it would also be interesting in seeing how first and second hand accounts of these changes were discussed and described. I was fortunate enough in one case to have both Michelle- a participant with manic bipolar- and her father Joseph in the same group, to allow reflection on these perceived changes in Michelle from two different perspectives. Focus groups therefore allow me to capitalize on the richness and complexity of group dynamics and afford access to the “kinds of social interactional dynamics that produce particular…positions, ideologies [and] practices…among specific groups of people.”[344]

While focus groups were the preferred research method, individual interviews were also conducted. This was for two main reasons. The first was practicality, as it was difficult to host a focus group all interested participants could attend, and as a result prospective participants risked being lost. Second, one participant, Anthony, advised that some prospective participants may prefer a one-to-one individual interview because of the privacy it offered and because some may be too quiet to participate meaningfully in a group environment.

Taking these considerations on board, and in hopes of broadening participation, an application was made and granted approval by the Research Ethics Committee, to conduct mixed methods research.

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[344] G. Kamberelis and G. Dimitriadis, 'Focus Groups: Strategic Articulations Of Pedagogy, Politics And Inquiry', *The SAGE Handbook of Qualitative Research* (3rd edn, 2005) 904.

Individual interviews did indeed provide the flexibility and responsiveness needed to both aid recruitment and tailor approaches to address individual needs and particular situations.[345]

Participant Selection

Participants with first-hand experience of mental health difference- including medical diagnosis and self reported mental health difference- were the target of recruitment. It was decided not to make formal diagnosis a requirement of participation as this would be practically difficult for the individual to prove and to validate; and would be problematic given formal diagnosis can sometimes be incorrect. Therefore the individuals' self-identification of mental health difference was privileged over formal diagnosis. It likely would have also felt jarring to ask people for their diagnosis at the start of research and would have felt like a labeling exercise. In most scenarios participants disclosed their mental health diagnosis or experience during discussion, which felt more organic and put the person ahead of the diagnosis.

Initially recruitment was limited to people who experience mental health episodes but was soon expanded to those with early stage progressive mental health difference and those with secondary experience. The scope of participant selection was widened to compare the experiences and responses of individuals with different types of mental health difference to explore any similarities/ differences in change in self and opinions around the barriers to CRPD compatibility for advance plans- particularly self-binding. The aim of recruitment therefore was to gather a wide range of diverse views to examine how and whether thought process and reflexivity differed, as opposed to a representative sample of one group.[346] Because of ethics requirements for informed consent, recruitment was limited to those with early-stage progressive mental health difference. Second-hand accounts have therefore had to be relied on from spousal carers and family members concerning persons with late-stage progressive mental health difference for the purposes of this research.

Recruitment

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[345] L Cohen and L Manion, *Research Methods In Education* (Routledge 1989) 273.

[346] S. Peters, 'Qualitative Research Methods In Mental Health' (2010) 13 Evidence-Based Mental Health, 38.

Leaflets advertising the research and explaining how to become involved were distributed via twitter, at the University of Nottingham Law School, the members lounge at START Inspiring Minds in Salford, the Institute of Mental Health and at a number of its events.I also attended a monthly dementia patient and public involvement group hosted by the Institute of Mental Health to meet people in the early stages of progressive mental health difference and their carers. The leaflets distributed encouraged people to get in touch by emailing a dedicated email address created solely for the purposes of this research.

Drop-in sessions were hosted at START and the Institute of Mental Health to meet potential participants and provide a forum whereby anyone interested in being involved could meet me and ask questions. These events were important to help participants feel more comfortable about participating and to help foster trust, an important exercise given engagement with mental health related research can be low given the often sensitive and private nature of the topic.[347] These drop-in sessions also meant those unable to use email or who lacked access to a computer could express their interest.

I am very grateful to have been given an additional bursary to conduct research by my funder the Institute of Mental Health. This allowed me to provide refreshments and offer participants a nominal £10 to assist in covering travel costs.

An attempt was made to recruit more participants after my first round of focus groups/interviews. This included reaching out to the Radford Care Group to recruit more participants with early-stage progressive mental health difference, and those with close secondary experience. However, just as recruitment efforts were rebooted, COVID-19 meant it was no longer safe to conduct research. It was jointly decided by me and my supervisors to discontinue recruitment and therefore avoid having to re-apply for research ethics to conduct research online- which would, in any case, have been very difficult given the chosen methodology and use of an interactive activity. The current level of involvement - 25 participants – was therefore deemed sufficient, given my interest in the *process* of reflection, rather than the responses as replicable results.

Participant Involvement

In total 25 participants were involved in the research, with a wide variety of first and second-hand experiences of mental health difference. In summary, the majority of participants had mental health experiences which could be characterized as occurring in

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[347] Ibid 35.

episodes. 4 participants experienced depression, 3 bipolar, 2 schizophrenia, 2 psychosis, 1 post traumatic stress disorder, 1 obsessive compulsive disorder, 1 personality disorder and 1 borderline personality disorder. Therefore of 25 participants, 15 had first-hand experience of more episodic typologies of mental health.

2 participants had first-hand experience of early-stage dementia, 2 had experience of other progressive mental health difference, and 2 had secondary experience of late-stage progressive mental health. Therefore 6 of the 25 participants had experience of progressive mental health difference.

2 individuals had undisclosed mental health difference or difference they did not relate to a diagnosis, and 1 had secondary experience of episodic mental health experience. 5 participants also had experience working in a professional capacity with persons with mental health difference, 4 had first-hand experience of mental health difference and secondary experience of progressive mental health i.e. a parent or in-law, which arose during discussion, and 1 had experience of both first and second hand experience of different types of episodic mental health.

24 of my 25 participants were Caucasian (white British,) and one participant was black (Kenyan.) This is reflective of other research on mental health, where people of other cultures and ethnicities are underrepresented because of low participation rates. This is likely due to cultural and religious differences in beliefs around mental health. Ages ranged from approximately 25- 85, with the average age of participants being approximately 50 years old. Only 8 of my 25 participants identified as male, and 17 identified as female. This is likely due to social norms around masculinity which means men are less likely to be involved in mental health research. Indeed this point was raised by Peter in focus group 3, in which he was the only male participant.

The majority of participants had not heard of advance planning prior to being involved in this research. 2 participants had financial lasting powers of attorney, 2 were the donees of financial powers of attorney for their spouses with late-stage progressive mental health difference, and 3 talked about making recovery plans which are not legally binding. None disclosed having a lasting power of attorney over welfare decisions or an advance directive - despite at least one participant likely having benefited from one.

Many authors believe it is valuable to consider the group phenomena, provided that different group compositions can lead to different responses.[348] A brief summary of focus group/individual interview composition has therefore been provided in the appendix.

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[348] See for example J. Sim, 'Collecting And Analysing Qualitative Data: Issues Raised By The Focus

Research Setting

Research was hosted at two locations - the Institute of Mental Health at the University of Nottingham, and START Inspiring Minds which is a mental health and suicide prevention charity in Salford.

Both venues were secure, had staffed front desks for check-in and check-out, and had private rooms which were fully accessible for persons with disabilities and could be booked privately. They both provided utilities for refreshments and offered established support systems for both researcher and participants, which could be relied on during research.

START Inspiring Minds offers courses of six weeks in duration, with the possibility for extension, in a number of creative groups including woodworking, textiles, photography, music, art, crafts, gardening and pottery. They have a dedicated Centre which members attend twice a week. Individuals are referred to START for a number of mental health related reasons by their general practitioner, therefore the majority of members have some form of mental health diagnosis. Both my grandparents volunteer at START and I met with the service delivery manager, who- after a formal visit- allowed me to host research on the premises. I was resident at START from Thursday 14th November-Friday 15th 2019, and the following week, Thursday 21st-Friday 22nd.

The Institute of Mental Health is a research institute based on Jubilee Campus at the University of Nottingham. They fund this research. The Institute focuses on research in all areas of mental health and employs researchers, hosts events and public patient involvement groups for those with mental health difference and their support persons/carers. The ground floor offers rooms for private hire which I was granted access to from September- November 2019 to host research.

Research Design

Group' (1998) 28 Journal of Advanced Nursing.
L. Vicsek, 'Issues In The Analysis Of Focus Groups: Generalisability, Quantifiability, Treatment Of Context And Quotations' (2014) 15 The Qualitative Report, 123-124.
J. Kitzinger, 'The Methodology Of Focus Groups: The Importance Of Interaction Between Research Participants.' (1994) 16 Sociology of Health and Illness.

During focus groups/ individual interviews, participants were asked to engage in two activities and were asked semi-structured follow-up questions. These activities included an interactive activity on how participants communicated self and how self changed with mental health difference. This was proceeded by several follow up questions. Participants were then given a copy of three case study vignettes which presented decision specific, fictional scenarios involving advance plans and decisions made during mental health difference. Again this was followed with another set of follow-up questions.

First, the interactive activity on self formed a kind of ice-breaker at the start of research, whereby individuals were given a pack of cards with 'elements' or characteristics of self written on them. Participants were asked, in their own time, to use these cards as they saw fit to communicate self. Participants could use the cards in any way they wanted, including not using the cards at all, only using some and discounting others and adding new ones. This was facilitated by blank cards in the centre of the table which participants could write on, to add any elements they felt were missing. Participants were also told that they could organise them in whatever way, shape or pattern they saw fit. They were assured that there was no right or wrong way of doing this activity and it was expressly stated that this activity was led by them. The cards were simply aids.

The purpose of this activity was to better understand everyday conceptions of self according to participants who have first-hand experience of mental health difference, and how they perceive self to change during a mental health experience. This was to explore whether some remaining conceptions around self with mental health which remain and justify restrictions to legal capacity in mental capacity law; are reflected in participant responses on self and how self changes with mental health. These include whether there is an ill self 'othered' from the healthy self; whether there is such a thing as a 'true' self; and whether individuals equate mental health experience with a loss of the qualities of a 'healthy' autonomous self in dominant social and legal theory. This is with the aim of seeing whether a divide in selves is conceptually accurate according to participant's everyday conceptions of self. How participants communicate self and the role mental health plays in their concept of self will likely provide suggestions of how conceptions of self can start to be reconsidered to be more inclusive of self with mental health difference. Those with secondary experiences were asked to either reflect on their own self or their loved ones self.

The purpose of this activity was to better understand self with mental health from the ground up, according to participants. Therefore it would have been undesirable to limit the elements/characteristics of self to one social or philosophical theory. To avoid shoe-horning 'self' into a dominant conception or a pre-made model, as many of the elements included in the theories discussed in Chapter 2 were included. The 'elements' of self chosen for participants to interact with are therefore an amalgamation from different social theories.

A summary of the elements of self included on the cards given to participants therefore is as follows. A simple accompanying definition was provided for some elements to aid in participant understanding:

- Reason
- Rationality
- Beliefs
- Value
- Ability to produce labor
- Independence

These elements were included because of their prominence in social contract theories including Hobbes, Locke and Rawls, which optimize a 'healthy self' and are reflected in the autonomous self, discussed in Chapter 2.

- Memory (capacity for memory and retention of memory)
- Reflection (to be able to use surroundings to assess where/who you are, what you are doing, when etc.)
- Recollection (being able to recall experiences and facts relevant to a purpose to decide what to do/complete a task)

'Recollection,' 'reflection' and 'memory' were included because of the role they play in both Derek Parfit's 'Reasons and Persons[349] and Hans George Gadamar's 'Enigma of Health.'[350] Memory plays a role in Parfit's continuity of self, in that direct memory connectedness is one of the things that creates continuity between different versions of self;[351] and the concept of self-reflection and recollection is believed by Gadamer to be necessary for thought and soul.[352] These elements were also included because of progressive mental health difference and its association with memory loss, to examine how this impacted concepts of self.

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[349] D. Parfit, *Reasons And Persons* (Clarendon Press 1984)

[350] H G. Gadamer, *The Enigma Of Health* (Polity Press 1996)

[351] D. Parfit, 'Later Selves And Moral Principles', *Philosophy and Personal Relations* (1st edn, Routledge and Kegan Paul 1973) 140-141.

[352] H G. Gadamer, *The Enigma Of Health* (Polity Press 1996) 141-152.

- Self-recognition (knowing who you are)
- Mutual recognition (recognising loved ones and recognition from others including loved ones)
- Identity

'Self recognition' and 'mutual recognition' were included because of the central role recognition plays in Axel Honneth's 'Recognition Theory.'[353] These characteristics allude to a more social concept of self (and therefore a more CRPD aligned concept of self,) in contrast to a self focused on reason. Identity was included as it is both a general term used in everyday portrayals of self in popular western media and is a contested concept in Butler[354] and Goffman's[355] work around self, discussed in more detail in Chapter 4.

- Experience

'Experience' was included as it is important for any theory which relies on learned behaviour shaping a person's self in some way. It was also hypothesized that this element would be of great importance given part of this activity asks how self has change following the experience of mental health.

- Dependence

'Dependence' was included because of the role it plays in theories such as Relational Autonomy, Nussbaum's Capabilities Approach[356] Kittay's 'Love's Labour'[357] and Fineman's Vulnerability Theory as an instrumental part of the human condition.[358]

- Behaviour

'Behaviour' was an element of self added into the later focus groups and interviews because of how often it was added by participants when reflecting on how self changed with mental health. Since participants consistently viewed this as an important element

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[353] A. Honneth, *The Struggle For Recognition* (1st edn, Polity Press 1995).

[354] J. Butler, 'Gender as Performance' in Peter Osbournes, *A Critical Sense: Interviews with Intellectuals* (London: Routledge, 1996). And J. Butler, *Undoing Gender* (New York; London: Routledge, 2004).

[355] E. Goffman, *The Presentation of Self in Everyday Life* (Penguin Books 1959).

[356] M. Nussbaum, *Creating Capabilities: The Human Development Approach* (Harvard UP 2011).

[357] E. Kittay, 'Love's Labor Revisited' (2002) 17(3) Indiana University Press Hypatia.

[358] M. Fineman, 'The Vulnerable Subject: Anchoring Equality In The Human Condition,' (2008) 20 Yale J.L. & Feminism.

of what makes a person who they are, ’behaviour’ was added as a new card in the activity.

The way in which participant’s organised elements of self was photographed and documented in the reflective log for analysis. This was accompanied by any explanation they gave for why they organised the cards in this way, which was also audio recorded. This information appears in the appendix and is analysed in the next chapter.

After individuals completed this activity, they were asked semi-structured questions which are as follows:

Follow up:

- Has anyone ever thought about self like this? If I would have asked you to describe yourself without these prompts what kinds of things would you have said?
- Can you talk me through why you have arranged them this way? Are there any which do not apply? Are there any elements missing?
- Have you ever made a decision which goes against (or is incompatible with) your model of self?

Questions (first set)

1. Do you notice a change in these elements of self or your loved ones self during mental health difference? Which elements? How do they change?
2. Do you feel you or your loved ones could communicate this change to others? If not, why not? If yes, how could you/they do this?
3. Do you think self can ever completely change or do you think self changes over time and with experience but largely remains the same? If so, which elements do not change? Have you or your loved ones ever experiences a complete change in self because of mental health difference?
4. Do you/does your loved one have an advance plan? If not, could you tell me a bit more about that? Have you ever thought about getting one? Would you get one? If you do, what drew you to create one?
5. Has anyone ever experienced a mental capacity based assessment? If so, what did you think of it? Do you think they could be improved upon? Do you think they are in need of replacing?
6. Do you think a statement about a change of self by that individual- maybe something similar to what you have in front of you, could be a good alternative? Is there anything not here you would like the statement to say?

7. (Raised by participants) Who would be the one to trigger this statement and interpret changes in self?

These questions were therefore not only to reflect on the activity and how self changed, but also to build on this to explore other research questions. This includes participant experiences of advance planning and mental capacity assessments while conversations of self are still fresh in their minds, to encourage them to draw on self as a lens of analysis for this reflection. Participants were asked whether a written statement on change in self could provide a possible alternative to mental capacity assessments, in hope of providing new thinking for the final research question of the thesis- how might self-binding statements be triggered if not in reference to mental capacity assessments.

Case study vignettes were then distributed, which contained decision specific scenarios to try and draw out specific factors in participant decision making. These vignettes contain fictional scenarios involving persons with different types of mental health difference, they involve different decisions, different levels of potential harm and different types of harm, a variety of advance planning formats, with different levels of family/carer involvement.

These case studies were read aloud to participants who were then asked to essentially 'think out loud' about whether they think the individuals will and preference should be adhered to over the advance plan, or whether the advance plan should be upheld. It was made clear that participants did not have to provide a definitive answer and that it was their thought process that was of interest. It is hoped that in providing a case study which both encourages participants to deal with specific issues and to which they have something to actively apply their thinking, this will increase the quality and consideration of participant responses. There were also some topics I knew I wanted participants to explore, hence why they were expressly included.

The case studies and their respective follow-up questions read as follows:

John

John has been a devout follower of the Jewish faith for the past 50 years. He is in the later stages of dementia and is living at a residential care home. One morning a care staff member asks him what he wants for breakfast and he asks for a bacon sandwich. The carer knows that the consumption of pork is strictly prohibited in the Jewish faith and asks if John is sure. He says that he's sure- he's never eaten bacon and wants to know how it tastes. To make it more complicated, John has an advance plan which states that he wishes, to the best of the care home's ability, to uphold his religious beliefs- including not consuming pork products. The carer asks him about the advance plan and he says he remembers it.

1. Should the carer serve him the bacon sandwich? Can you tell me more about your reasoning?

Mary

Mary is an older woman who also lives full time in a residential care home. She has troubles with her memory and often seems to be living as her much younger self-believing she lives at home still with her mum and dad. Mary is capable of making everyday decision for herself, despite these frequent lapses in memory. One day Mary approaches one of the caring staff with a request. She wishes to change her will as there are some names in there she does not recognise. These are the names of her two grandchildren. The carer informs Mary that they are her grandchildren, but she insists she does not know them, wants them removed, and instead wants to spend the money on buying more figurines. Mary has begun collecting ornate figurines, which are a few hundred pounds per figure. Her family are concerned that her many purchases are consuming her savings which are being used to pay for her current standard of care. If she continues to spend in this way, she would have to move from her current care home where she has lived for the past 7 years or so, to a less expensive care home, considered not as nice. This has been explained to Mary, who understands, but says she wishes to buy the whole collection because of the happiness they bring her.

1. Should Mary’s will be changed per her request?
2. Should Mary be allowed to continue buying figurines?

Ken

Ken is a man in his forties with psychosis. He lives in a secure mental health facility and believes himself to be a messenger of God. He has given himself a new symbolic name to reflect his new status, has changed his behaviours, and undergoes periods of fasting. He has an advance plan which refuses treatment Y on the grounds that it makes him paranoid and causes hallucinations. It also stipulates that he wishes to be given any treatment for his mental health difference at home with his wife, where he feels most secure. Kens beliefs are criticised by another member of the mental health facility, which prompts a particularly bad episode. During these episodes he has a tendency to self harm. Treatment for his psychosis to prevent this self harm involves treatment Y. His wife reminds doctors about his wish to receive any treatment at home, but they are concerned that he would suffer more self harm if allowed to leave the facility because she can’t provide the same level of monitoring the facility can and because he has more access to materials for self harm.

1. Should Ken be given treatment Y?
2. Should Ken be allowed to go home to receive treatment?

There are a number of factors deliberately included in these case studies.

These were added to see whether, how and to what extent these factors influence participant opinions on whether a decision made during mental health experiences- more specifically decisions which contradict those previously stated in an advance plan, should be adhered to. This was essentially to get participants thinking about self-binding statements.

These include subjects with different typologies of mental health difference to see whether and how the perceived change and then regaining of self informed their decision. Ken therefore has psychosis, a mental health experience which could be described as occurring in episodes, whereas Mary and John have dementia- a more progressive mental health difference.

Different types of decisions were included, which carry varying levels of subjective/ objective importance to the case study subject and society as a whole. The objectively important decisions include those involving Mary’s finances and Ken’s decision to refuse treatment. The more subjective wishes include John’s wish to eat bacon and Ken’s wish to be treated at home.

Different forms of harm were also included, namely the risk of potential direct, physical harm to Ken at one end of the scale and subjective moral harm to John at the other. There is disagreement among academics and UN Treaty bodies about whether harmful will and preference can be legitimately overridden under the CRPD, and where that cut-off point lies. [359] This is discussed in more detail in Chapter 5. There seems to be a consensus among those who believe some decisions can be legitimately restricted, that

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[359] See for example E. Flynn and A. 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.
M. Bach and L. Kerzner, 'A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY' (Law Commission of Ontario 2010)
T. Minkowitz, 'CRPD And Transformative Equality' (2017) 13 International Journal of Law in Context.

serious, direct, physical harm is sufficient to constitute a restriction to legal capacity against an individual's current will and preference. Therefore, the inclusion of different types and levels of harm may shed light on whether participants agree that there exists a cut-off point based on harm and whether in their experience- some will and preference during mental health difference ought to be overruled.

Including decisions beyond financial, welfare and advance refusals also allows us to question whether participants believe the scope of legally binding advance plans should be widened. This is based on the premise that other decisions outside this scope can be just as important if not more so to the individual, and that individuals should have the option to have these decisions protected using advance planning provisions. This also pushes the limits of which decisions a person should be able to self-bind.

Finally, these vignettes contain different levels of family, carer and/or spousal involvement. This is because family currently plays a large role in influencing best interest decisions and in validating advance plans in the Court of Protection.[360] Family involvement can also raise concerns of undue influence where the individuals will and preference is not believed to be their own but a product of the influence generated by their family.[361] Family/carer involvement was therefore included to see how and to what extent harm to others and the will and preference of family members ought to influence whether an individual's contrary wish is upheld or overruled.

Some participants found these vignettes easier to address than others, some were creative in the way they approached their answers, for example by trying to make all parties happy, and others found this very challenging and could not decide. Reflecting on these case studies also led to participants relaying their own experiences of decision making during mental health difference and whether they themselves would want their wishes to be overruled. This provided a useful way of allowing participants to divulge their experiences as and when they chose to, as opposed to being directly asked, which could have been abrasive and caused discomfort.

Participants were then asked a final set of semi-structured follow up questions, which are some of the central questions of this thesis which earlier activities/questions had been building to:

Questions (second set)

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[360] See for example *Barnsley Hospital NHS and MSP* [2020] EWCOP 26.

[361] See for example *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649 (CA).

1. Do you think people’s decision making should be restricted because of or during mental health difference? If so, which types of decisions should be restricted?
2. Should contrary wishes be adhered to? What factors go into your consideration?

Data analysis

Data from focus groups and individual interviews was analysed using thematic analysis. This is a method for analyzing data which consists of identifying themes in data. Thematic analysis has the benefit of being flexible as it is not tied to a methodological epistemology in the same way grounded theory and Interpretive Phenomenological Analysis are.[362] This flexibility therefore allowed research to be free from problematic conceptions of self as may arise in methodological theory.

The data corpus consisted of three data gathering activities including responses to semi-structured questions, the elements of self interactive activity and responses to case study vignettes. Thematic analysis was therefore used to examine all three data sets.

Analysis was inductive- from the bottom up- whereby themes were sourced from participant responses. The questions asked and the topics brought up in case study vignettes were formed from knowledge of pertinent questions in this research area. This is because “data [is] not coded in an epistemological vacuum."[363]

Data analysis has semantic components and in many cases uses what participants said expressly. Occasionally analysis strays into latent level analysis to explore the reasons why some participants may have answered the way they did. This is because, according to Clarke and Braun “your analytic claims need to be grounded in, but go beyond, the ‘surface’ of the data…[t]he sort of questions you need to be asking, towards the end phases of your analysis, include: ‘[w]hat does this theme mean?’…”[364]

Epistemologically I believe the motivations of participants, their responses and the meaning they assign to certain questions/topics, to be socially constructed and largely

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[362] V. Braun and V. Clarke, 'Using Thematic Analysis In Psychology' (2006) 3 Qualitative Research in Psychology, 80.
[363] Ibid 84.
[364] Ibid 94.

dependent on their experiences of mental health. I am also assuming that they are going to be able to draw on those experiences to provide a relatively accurate account of their own concept of self, how self changes with mental health, and their experiences of decision making during mental health experiences. I am also assuming they can apply this knowledge to other questions/scenarios.

Analysis began as a reflective process during data collection and using the reflective log. After all data was collected, the data was transcribed verbatim and read and re-read to identify themes across the whole data corpus for the relevant data set, for example what all individual interviews and focus groups had said in response to the elements of self activity. This was done using mind maps and by colour coding any common themes. 'Key' themes were driven by the research questions, and the prevalence of certain themes was determined by looking at the number of times a theme was discussed by participants- either expressly or implicitly. For example conversations about feeling coerced by medical professionals were discussed by some, though not in direct reference to conversations of power. This was despite power clearly being a latent theme of their discussion.

Once key themes were identified, responses from two of the data sets - responses to case study vignettes, and the semi-structured questions, were entered into NVIVO 12. NVIVO was used as a secondary analytic tool to check no obvious themes had been missed. I did this by querying each document and conducting a word frequency search. This was to draw attention to any recurring words/themes not yet considered. NVIVO 12 was also used for these data sets to code and store the data, which made organisation and access much easier considering the amount of data collected.

Responses to the element of self activity were not input into NVIVO because of how highly individualistic the data was. Therefore there was little benefit by way of word frequency of data item comparison for this data set.
Once content with the key themes the process of writing up the themes for each data set began. Clear definitions to represent the content of each theme were formulated, and multiple themes were grouped under one subheading where they contained strong relation with one another and would benefit from being discussed together.
There was an ongoing process of review once write up began, to see whether any more latent themes were emerging which would benefit from inclusion. Analysis was therefore an ongoing process, whereby later chapters prompted reflection on themes represented earlier.

The responses of those with first-hand experience of mental health difference were privileged in analysis, as these participants have the insight into mental health difference required to answer the research questions of this thesis. Those with secondary experience allowed comparison between the two groups and provided insight into research questions involving support persons.

The elements of self interactive activity, its follow up questions and the semi-structured questions on how self changes with mental health, inform Chapter 4 'Understanding Self with Mental Health Difference' and Chapter 6 'Generating New Thinking: A User-led Written Statement on Change in Self because of Mental Health Difference as a Potential Alternative to Mental Capacity Assessments.'

Responses to case study vignettes and the second set of questions, inform Chapter 5 'Awarding Self with Mental Health Difference Full Legal Capacity and the Impact of Harmful Decision Making According to Participant Experience.'

Research Ethics

This research was granted research ethics approval by the Research Ethics Committee at the University of Nottingham Law School on 28/06/2019 and was followed by a series of amendments which were all approved. An ethics-as-process approach is adopted for this research and allows for additional awareness and responsiveness to ethical concerns as they arise, which therefore extends far beyond the granting of formal approval.[365] This is particularly relevant here given mental health research can involve disclosure of intent to suicide or self-harm.[366]

At the end of each interview/focus group I took the time to go round to each participant, thank them for their involvement and make a positive comment about their contribution.

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[365] J. R. Cutcliffe and P. Ramcharan, 'Leveling The Playing Field? Exploring The Merits Of The Ethics-As-Process Approach For Judging Qualitative Research Proposals' (2002) 12 Qualitative Health Research, 1007.

[366] S. Peters, 'Qualitative Research Methods In Mental Health' (2010) 13 Evidence-Based Mental Health, 35.

This helped end the research on a positive note, helped participants feel appreciated, and provided time to allow any emotions to be felt and to settle.

I also distributed additional support information at the end of research in leaflet form, including details on local support groups/events relevant to participant experience. This was in case participants felt in need of more ongoing support, which I alone could not provide.

I contacted the committee again on 25/11/20, to inform them of a sensitive situation which had arisen during research and the steps I had taken to manage it. During research a participant informed me of their plans to commit suicide on New Year’s Day 2020. When they disclosed this during the interview, I feel I remained professional yet sensitive and decided to continue with the interview so as not to make this disclosure taboo or to give the impression that the participant had done something wrong by shutting down the interview. This entire interaction was captured on audio recording which I have copies of as per my data management policy. Once the interview was concluded and the audio recorder was turned off, I explained that the consent form they had signed stated that if I became aware of any serious harm to themselves or others I had a duty to disclose this to the relevant authorities. They understood and wanted me to pass on what they had told me, so there was no conflict there. I ended the interaction by checking how they would get home and thanking them for their involvement. Their plan to end their life was in no way a result of or linked with my research. The interview concluded after the relevant members of staff had left the premises. Therefore, I emailed both my two supervisors and my point of contact- the service delivery manager the next day (23/11/20) informing them of this information. The service delivery manager passed this onto the participant’s key worker in the mental health team, and I was told that I did not need to take any further action, other than by keeping this disclosure confidential from other members of the charity. I emailed again on 27/12/20 to ensure that this disclosure had been followed up on by the participant’s mental health team. I was assured it had been and the participant was in regular contact with them. I was not required to take any further steps by the research ethics committee.

Consent and Withdrawal

Information sheets were distributed at the start of research to all participants and had to be read in full before signing the consent form. They included information about the researcher, the research, benefits and risks, data collection and storage, withdrawal, anonymity, contact details and the university’s complaints procedure.

Participants could withdraw from taking part in any further research at any time during a focus groups or individual interview, and for up to three weeks (21 days) from the date of any individual interview, with no explanation required. The reason for not allowing the same retrospective withdrawal for focus groups was because of the nature of this method. As focus groups are intended to be group discussion, it would have been extremely difficult if not impossible in some scenarios to retract the voice of one participant from group discussion and still have that discussion make sense. My supervisors and I were concerned that the withdrawal of one participant could jeopardize the data of the group, and therefore decided against letting participants withdraw after the focus group had been conducted. This was agreed by the Research Ethics Committee.

Data Collection and Storage

Data was collected using an audio-recording device and a reflexive log- which, as already discussed, included field notes and photographs of the elements of self activity.

The photographs contained no sensitive data and were transferred from the camera to reflective log as soon as was reasonably possible and deleted from the camera. Audio recordings were deleted from the recorder as soon as was reasonably possible and transferred to the University of Nottingham's Onedrive. A copy of the recordings was also saved to an external hard drive which is kept in a secure location along with the physical copies of consent forms filled out by participants. Focus group discussions/ individual interviews were then transcribed and anonymised by substituting participants' names for others using a key. Any personal sensitive data which was not anonymised- including the reflective logs and the key of anonymised participant's names, were saved onto a password protected external device. No third parties are allowed to access any of this data.

Anonymised transcripts will be made accessible to the university for the purpose of assessment of the PhD if necessary and to deal with any complaints. My supervisors and PhD examiners will have access as required for the administration and examination of the PhD.

Data was stored in accordance with the 2018 General Data Protection Regulations, the University's Handling Restricted Data Policy, Data Security Breach Incident Management Policy, The Data Protection Act 1998, The School of Law's Data Management Policy and the Code of Research Conduct and Research Ethics.

Follow up

I followed up with participants at the start of data analysis, to prevent 'hit and run' research. This essentially involves researchers taking what they want from the relationship established between themselves and participants and promptly moving on, meaning participants cannot gradually withdraw and are not kept informed regarding research progress.[367]

This kind of research promotes bad relations with participants where the research takes and gives little back. [368] To avoid this and promote good research governance, emails were sent out a few days after research had concluded, thanking people for their participation. After data had been collected and initial analysis had been conducted, an accessible easy-read leaflet was created outlining main findings thus far. This was to provide insight for participants on how their data was being used and what the results of that data were. This was distributed by email where possible, and copies of the leaflet were displayed in STARTs member's lounge. Participants also retained my email address- made specifically for this research- which they could use to raise any further inquiries.

The following chapter titled 'Understanding self with Mental Health' is the first substantive chapter to review findings in relation to the elements of self interactive activity and follow-up questions.

Chapter 4: Understanding Self and Mental Health: Room for Improvement in Law and Social Theory

Introduction

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[367] J. R. Cutcliffe and P. Ramcharan, 'Leveling The Playing Field? Exploring The Merits Of The Ethics-As-Process Approach For Judging Qualitative Research Proposals' (2002) 12 Qualitative Health Research, 1005.

[368] Ibid 1006.

This chapter is the first substantive chapter analyzing data from participant responses. It challenges one of the barriers to CRPD compatibility identified in Chapter 2 on concepts of self with mental health. Specifically participant responses inform questions on how self is perceived by participants with mental health difference and how self is perceived to change with mental health. This is to see whether findings validate or challenge the dominant social and legal theory conception of self and the 'true' self conception used to justify self-binding.

Findings allow us to reflect on whether some remaining conceptions around self with mental health remain and justify restrictions to legal capacity in mental capacity law. These include whether there is an ill self 'othered' from the healthy self; whether there is such a thing as 'true' self; and whether individuals equate mental health experience with a loss of the qualities of a 'healthy' autonomous self in dominant social and legal theory. This is with the aim of seeing whether a divide in selves is conceptually accurate according to participant's everyday conceptions of self.

This chapter outlines findings from the interactive elements of self activity. As detailed in Chapter 3, cards containing elements of self from a range of social theories were given to participants to arrange howsoever they chose, to communicate self. This is in the hope of illuminating how participants perceive self with mental health - a concept not yet the focus of any social/philosophical theory. Communicating self was also important to form a baseline participants could use to judge how self changed with mental health. This chapter is accompanied by Appendix 1 which contains pictures of how cards were organised.

In order to answer the second question of how self changes with mental health, thematic analysis was conducted on participant responses to the question and which elements they indicated as changing. Some participants also re-arranged the elements of self cards to communicate this- which are included in pictorial form in Appendix 1.

The main themes or codes under which responses are discussed are as follows: the magnification versus shrinking of self; dissociation and compartmentalisation of selves; ability to work and a change in social role; isolation fear and loneliness; change in cycles; the impact of medication; awareness; and change as positive- mental health as a process for self understanding, reconstruction and recovery. Findings are then discussed in relation to whether a true self conception is reflected in participant responses, and therefore whether a divide in selves is warranted to some extent. This is to see whether allowing one version of self to be privileged over another using advance planning is conceptually justified in line with participant conceptions of self. Chapter 6 moves onto discuss how any conceptual justification for self-binding could be brought in line with the CRPD.

This chapter concludes by relating these findings back to advance planning, CRPD compatibility and the new questions/possibilities these findings pose. If participants support a 'true' self conception and believe there is a new 'ill' self created during a mental health experience, then self-binding this new self may be justified. Alternatively it may seem unfair to hold this new self to the will and preference of the old.[369]
If a true self conception is not reflected in participant responses, and this divide in selves is not present, then this affirms the need to reconceptualise understandings of self with mental health difference. If we move away from a true self conception and move towards seeing self as a more holistic and individual entity- not easily capable of being categorised using a divide line- this may help us better understand how the CRPDs call for expanding legal capacity to all, including those in crisis situations and those with actual deficits in mental capacity, can be achieved.
These findings also provide new thinking on how social and philosophical theories on self could be more inclusive of persons with mental health difference going forward.

Participant perceptions of 'Self': How elements were organised and the prevalence of mental health

Compiling this data was challenging. It was immediately evident that this activity had produced highly individual results which would be difficult to collate. This is hopefully reflected when looking at the photographic elements of self for each participant in Appendix 1. This activity was in no way meant to shoehorn participants into a model(s) of self, and largely this is reflected in the results. Different elements held different levels of importance depending on the individual. How self was communicated was also highly individual.
Elements of self cards were most commonly organized hierarchically or in categories. Some participants felt elements 'went together' and grouped cards accordingly. One participant- Jessie- organized them into a shape which she felt was indicative of how she saw self. Two participants talked about wanting to scrunch all the elements up together into a ball, and one thought they would be best laid out in a circle. Three participants felt all elements

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[369] R. Dresser, 'Life, Death, And Incompetent Patients: Conceptual Infirmities And Hidden Values In The Law' (2021) 28 28 Ariz L Rev.

were important and so chose to go through them one by one and describe how they relate to them.

Elements added by participants to communicate self included ‘love and pain,’ ‘knowledge,’ ‘group belonging,’ ‘behaviour,’ ‘personality,’ ‘empowerment,’ ‘agency,’ ‘self acceptance,’ ‘respect’ and ‘spirituality.’

Some participant’s excluded elements they felt hostile towards, including ‘dependence,’ ‘power’ and ‘ability to work.’ Despite the progress which has been made to place dependence at the heart of the human condition, the majority of participants viewed dependence negatively.[370] Jessie for example turned ‘dependence’ blank side up and put it off the table saying “…I never want to get there! I *hate* [emphasis] the thought of being dependent, I hate the thought of ending up in a dementia warehouse, I hate the thought of someone making decisions for me… I think I’d like it off the table all together!”

Participants ability to communicate self also varied greatly. Many participants, particularly those who experience mental health in episodes, expressed difficulty in communicating self for this activity. Often this was explained by them as being unsure of who they were following a mental health experience. As put by Rebecca “…with mental illness…you kind of forget who you are a bit, or struggle to find who you really are.” This could be interpreted as mental health being a period of self-deconstruction. Both self-deconstruction and reconstruction were dominant themes in participant responses. Self-reconstruction was present in the sense that people either wanted to re-build their self or had already undergone a self-making process post mental health.

The participants who expressed difficulty in communicating self often changed their elements of self as others in the group spoke, struggling to decide on their elements/ordering and being easily influenced by others comments.

For example Layla, who has borderline personality disorder, said: “I don’t really know what [self] means… people have definitely said they don’t think I have [a sense of self].” Layla talks about being told by others that she does not have a sense of self, that she thinks of it as a passing notion, and that she disagree with medical professionals’ views on her self. Peter also found the exercise very difficult and became emotional at one point saying,

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[370] M. Fineman, 'The Vulnerable Subject: Anchoring Equality In The Human Condition' (2008) 20 Yale Journal of Law & Feminism.

"there's a lot of stuff about myself I don't like…I could be a better person…I tend to be very self critical." The self-reflective aspect of this activity was something the majority of participants found difficult. As put by Humphrey: "…it's…about you…it's never easy when it's about you is it."

It also became evident in analysing this data that it is difficult to separate perceptions of self from how self has changed with mental health. Many frame them as one and the same. All participants organized the elements of self with mental health in mind. This included grouping categories according to mental health in some way or laying out two different selves using the same elements. The overall impact of mental health difference was that it appeared to make some elements more important, cause others to be lost, others to be greatly changed in some way, or made them more precious for fear of them changing or being lost in the future.

To summarize then, participant communications of self with mental health were highly individual in many ways, and all elements used in the activity played an important role at some point, to some individuals. To have a more holistic understanding of how self was portrayed by participants please see the Appendix in combination with the group composition information.

In spite of this individuality, it has been possible to summarize themes on how self was communicated, which elements were of recurring importance to participants, and which were frequently left out because participants felt did not they applied to nor represent their self. This discussion is grouped loosely according to the different characterisations of mental health difference - being mental health characterized by episodes and progressive mental health. This should make any commonalities in how self was communicated within certain groups more comparable. This need for comparison is based on the presumption that the type of mental health difference and its permanency is different among these two groups and may impact their perceptions of self and how self changes.

If we begin by looking at responses from those with experience of progressive mental health difference - Olive, Sandra, Betty and Robert- placed 'independence,' 'memory,' 'experience' and 'identity' consistently high in their hierarchy. 'Power' and their perceived lack of power, 'dependence' and 'ability to work' were shunned by the majority. This may reflect elements participants are afraid to lose or are scared of being considered to have lost- the ability to work, their lack of power or their inability to live independently.

As predicted, memory also played a crucial role within this group in relation to identity and participant fears over losing memory.

Samantha and Molly who care for spouses with late-stage frontotemporal dementia and dementia respectively, gave a second-hand perspective on self with mental health difference. These accounts may be different from how the individual themselves would perceive or communicate self. Whilst this does add another layer of insight- how the self is perceived by others, it is debatable as to whether this gives us a more accurate portrayal of self. It is interesting however for the purposes of later conversations on the role of elected support persons in triggering advance plans. This will be discussed more so in Chapter 6.

Samantha used quite divisionary language during discussion, including phrases like "my old husband," "their old self" and used past tense often by way of comparison.

Samantha felt the elements which were most changed were most indicative of her husband's self. Self and change in self were therefore intertwined. The main elements of self highlighted were 'behaviour,' 'empathy' (which played a large role but did not end up becoming an element in its own right,) 'dependence' and 'independence.' Empathy was particularly emphasized by Samantha as she felt that because of the type of dementia her husband had, his empathy for others and his understanding of others had been impacted. She found this one of the more challenging aspects of his self. 'Behaviour' was also one of the highest placed elements for Molly, alongside 'experience' and 'memory.'

The sample size for participants whose mental health could be loosely characterized as manifesting in episodes was much larger. This is because of the requirement for informed consent which greatly reduced the involvement of individuals with dementia and Alzheimer's.

Mental health was actively considered more so amongst this group than amongst those with progressive mental health. For example, at the start of the activity in focus group 2 Anthony asked "[t]his is our well self? Or our whole self?" and Nicole communicated self in three categories, including "the best things that have come out of [mental health difference]," elements they have had to deal with post mental health difference, and elements they view as more their day-to-day self. Elements also rose up the hierarchy and became more important because of mental health experience. When asked whether their mental health had influenced elements of self, Layla who has borderline personality disorder commented: "…yeh some of these I think…are…definitely more important because you lose them…when you're unwell."

For Nicole, who grew up in Kenya, her psychosis caused her to challenge her conceptions of self. "I grew up in a society where mental health wasn't spoken about, because they say you're demon possessed and you have to go through all th[ese] spiritual things…I have questioned almost every belief I have…because all that happened I realised my beliefs were not empowering, they were disempowering…" This explains why one of Nicole's categories was 'the best things to come out of mental health.'

Daria, who has manic bipolar and autism, also framed self in reference to mental health and viewed self reconstruction as being a process of self acceptance and self-understanding. She also spoke about the difficulties in gaining acceptance from others- specifically she wanted her family to acknowledge that she does not need fixing or treating, and that mental health is part of who she is: "…understanding…that, a lot of me issues…it's just how I'm wired, and learning myself that that's just, me- behaviours…are just how I am, and it's not necessarily that I need to be fixing something, like I've been spending most of my life trying to fix all these problems and all these mental health issues and it's just how I am… trying to get people to understand…"

Power is worth flagging here as it was often discussed in one of two ways- either in the negative- as someone having power over someone else, or in the positive- as self-empowerment. This contrasts with those with progressive mental health who viewed 'power' as loss of power. Some participants expressed a feeling of powerlessness during a mental health experience, or linked it to disempowering relationships. Others felt empowerment -having control over oneself, was key to self-reconstruction and acceptance.

It was difficult to surmise which elements were thematically of most importance given not all elements were organized uniformly or in priority order. That being said, 'identity' and/or 'self-recognition,' (which seemed to be used interchangeably amongst participants) 'behaviour,' 'beliefs' and 'values' placed consistently high. Likewise 'dependence,' 'ability to work' and 'power' (not empowerment) seemed to place consistently low or be excluded. There was more focus within this group on self-reconstruction compared with those with progressive mental health where the focus was more so on deconstruction. Reconstruction of self post mental health or mental health as a process for self-understanding was therefore more prevalent in the way discussion was framed. More on reconstruction is discussed in the section 'Change as Positive.'

When participants from both groups were asked if they would have communicated self in this way, most said they would have but not using the same exact words included on the cards. Some said they would have told a story to describe self in context, and some said they would have included their hobbies, likes and dislikes. One participant Michelle, said she would have set up a list of contingencies needed to achieve her 'well self' and described self perceived personality traits/characteristics she believes she has when these contingencies are met.

How self changes with mental health difference

After communicating 'self' using the elements of self cards, participants where then asked whether they noticed a change in self because of mental health and whether/how that change impacted any of the elements. Of the 25 participants involved, all but two acknowledged a change in self because of mental health difference. As already outlined, many communicated this change immediately when asked to communicate self, making perceptions of self and changes in self caused by mental health, one and the same.
The two outliers were Olive who is in the early stages of dementia: "I don't think I've had any changes- still the same!" and Simon who has active long-term psychosis. There may be many reasons why Olive may not have registered change. These include that she is in the early stages of dementia and therefore a change has not yet occurred. Olive may also not want to acknowledge a change. Simon on the other hand, likely does not perceive a change as he described having long-term, ongoing/untreated psychosis. Therefore he likely does not perceive change because mental health is his norm and his experiences do not therefore come in episodes. Although Simon did not acknowledge a change, he did feel his 'memory,' 'experiences' and 'beliefs' had been affected by mental health and vice versa.

As was the case with communication of self, change in self because of mental health was also individual. Almost all the elements were identified by participants as changing because of mental health difference, although this varied from individual to individual:

> "…independence, power, ability to work, my identity, and my reasoning and rationality, I think have gone completely out the window since I've been, the way I've been…" [Jill, undisclosed mental health difference]

> "…things I used to be able to have like beliefs, identity, self recognition, like knowing who you are cause I don't anymore, and these ones I definitely don't have- ability to work and independence…" [Michelle, bipolar with psychotic episodes]

> "…these are the sort of things I lose… when I'm in a phase of mental difference, so reason rationality, issues of memory, recognition and self recognition and they, really did impact upon who I feel I am and what I feel my values are, things like that…" [Jessie, "living with the impact of deep traumatic, mental and moral life wounds, broken and reborn, mad and not requiring to be fixed"]

> "…his characters changed so much, and his rational thinking has completely changed, his behaviour has changed, if I'm honest I'm looking after a toddler in a way, well maybe not a toddler, but a child…he's changed beyond all recognition…" [Samantha, carer of spouse with late-stage frontotemporal dementia]

There were however enough similarities in how change was communicated to conduct thematic analysis of participant responses. These themes will not be separated according to the typology of mental health- instead the impact of these different typologies will be discussed within the themes, the first of which was magnification versus shrinking of self.

Magnification versus Shrinking of self

A common theme in how change in self was communicated by participants included either a magnification or shrinking of self. First magnification of self will be evidenced and discussed before moving onto shrinking.

Magnification is a term used here to describe the feeling that all elements which make up self, or more specifically, the more undesirable elements of self are being magnified to the extreme during a mental health experience. This change in self was often expressed by participants with experiences of mania including type 1 bipolar and psychosis, and by participants with second-hand experience of these diagnosis.

This magnification was described by participants as an 'amplification,' 'like putting someone under a microscope and receiving mega mega doses' of that person's self. Elements which feel lost or weak when well were described as regained and amplified to the point where these elements undergo drastic change. For example, Michelle begins to rearrange the element of self cards so that the cards previously in the 'things which I've lost or things which don't pertain to me' pile, become very strong during mania:

> "…when I'm poorly…[moves cards into 'things which pertain to me' pile] I've got a very strong sense of self, a very strong sense of beliefs, values , self recognition, I feel very powerful when…I'm manic… and I'm having a great experience like I'm having a great time, I feel, super independent, I feel a great ability to work…"

Michelle's father Joseph, who therefore has secondary experience of witnessing this happen, adds:

> "…what happens when you're poorly, especially when you're manic poorly, is that…they [elements] get, amplified, to, mega and mega doses of Michelle…and that's everything, it isn't selective it doesn't amplify the…bad bits it amplified everything, the bad bits the good bits the whole thing…"

Jessie describes witnessing her colleague with bipolar undergo a manic episode, in which she describes their personality and behaviours being amplified:

> "…she's completely the opposite- she becomes, such a party animal…when she is in another state, and normally she's quite an introspective but…she is what is described as being on a high, all the world is her friend and she has connections with people…and she can feel them…I've spent time with her when she's been in…that state…and I really do believe that she feels…sees these connections! I don't understand it, but she is very changed at that time…"

This phenomenon was also described by Molly who has secondary experience of watching their spouse, both parents-in- law and their mother go through the later stages of dementia. They describe magnification of a persons' 'essence'- a core behaviour shaped from social background and experiences- which they feel becomes stronger in the later stages:

> "….my feelings are that often, the real essence of the person somehow becomes much more, prominent, and usually, it's…part of themselves that they've probably

> moderated through life to cope with life…to get on with life, but, often…that, becomes a stronger…. part of who they become I think…
> I: So you think some elements of self have a magnifying glass on them?
> Molly: I do I do!”

Shrinking on the other hand, is a term used here to describe feeling as though the elements of self which are strong when well subside and become ‘quiet’ during a mental health experience, meaning the person does not feel fully themselves. This was expressed as a common change by participants with experience of clinical depression, anxiety, PTSD, bipolar, OCD, schizophrenia and personality disorder. Shrinking of self was discussed in reference to feelings of isolation, fear and dependence- which either trigger or contribute towards this shrinking sensation of self. The more isolated, fearful and dependent a person becomes the more likely it is their self will continue to shrink. Hopefully this sense of shrinking will become clearer as the theme ‘isolation, fear and loneliness’ is discussed.

> “…I know I’m feeling unwell, when my sense of self becomes very small, and I always sort of see my, existence, as, a…shape… and depending how much of that I’m inhabiting is how well I’m feeling, so when I’m inhabiting every bit of it, then I’m totally myself and I’m telling myself- life is great and I’m feeling very…positive…as I feel less and less well I shrink to occupy a very, very, very tiny, still there, the self is still there but its surrounded by nothingness” [Jessie]

<u>Dissociation and Compartmentalization</u>

Another common trend amongst participants was to dissociate or wish to compartmentalize their ‘well’ self from their ‘ill’ self during mental health. This was most common in participants with negative behavioural changes and by carers with secondary experience of progressive mental health. This is likely because they have witnessed the change in self which occurs from pre-diagnosis into the later stages, when the person is very different from the person they once were. A large amount of past tense was used when discussing their loved one. For example, Samantha corrects herself here before saying ‘my old husband’:

> “[H]e’s obsessed with dancing, which my old...he would be mortified!”
> [Samantha, carer of spouse with late-stage frontotemporal dementia]

Most of the participants who wished to dissociate self experienced negative behavioural changes, with the most drastic changes seeming to be amongst those with experiences of mania:

> "…when you're so manic and you're so psychotic, and you don't know what's going on and you're violent, and when I was ill last time...I was drawing all over the walls with my feces and just, peeing in the corner, I didn't think they were letting me go to the toilet, and I was crying and begging them to let me out, and they had me in the isolation booth for about 2 weeks…" [Michelle, bipolar with psychotic episodes]
>
> **"**I lost my job as a result of my behaviour- my behaviour was not very good..." [Diego, clinical depression and anxiety]
>
> "…if you're on a psychotic state… all your prohibitions disappear and you just like feel you're free to do anything…" [Nicole, psychosis]
>
> "I have a personality disorder, a sever one, so, that can affect my behaviour..I can be fine and feel okay and confident one minute, then the next minute, that person doesn't like me they hate me, why do they hate me [nagging noises] it goes on, me husbands probably gunna leave me, I've put loads of weight on and I've got no job and what must he think, and so it goes on my mind…" [Debbie, personality disorder]
>
> "…my father in law, hallucinated, and there was violence- there was a change in behaviour to the extreme, and very sadly, my mother in law could see people you know, and her sexuality was quite, it was very upsetting to see what happened to the behaviour…then you have the, sort of the opposite where like my mother's behaviour became very very dependent, very pathetic…" [Molly, spousal carer with various second-hand accounts of late-stage dementia]
>
> "…mainly behaviour changes…you get rattie, you do get unreasonable…" [Steph PTSD]

Ultimately most participants acknowledged this changed self was fundamentally a part of them and still therefore a part of their 'self'. However that did not stop them from wanting to compartmentalize their 'well' self from their 'ill' self- and with them the negative thoughts and behaviours which come with mental health:

> "I look back with a sense of shame as to like how on earth could I have believed that, or looked at it in that way…and there's this sense I almost want to disown… that facet of the experience and kind of say, that's not who I am…" [Anthony, Schizophrenia]
>
> "During this break Peter says he feels like he wants to dissociate from his ill self, he's ashamed of some of the things he thinks when unwell. This feeling was shared by Rebecca who said she feels the same, and they found I think some comfort in their shared experience of that" (anecdote from focus group 4 taken from my reflective log, recorded with both participants express permission.)
>
> "I've got [Ella] and [Elle]…[Elle] is me, the bouncy happy getting on with it, [Ella] is the mental health, the crying the drinking the screaming and shouting, that's [Ella] and [Elle] is the happy fun me, so there's two parts of me…" [Ella, bipolar]

There is a definite sense of separation and dislike for self during mental health, with participants using separatist language like 'him' and 'that person':

> "…Yeh I think especially with me when I go manic…you look back like…like…well that person I really don't like…" [Daria, bipolar]
>
> [Ella in reference to her partner Humphrey] "you have had, in the past…that element of you you didn't like and – 'I don't want to be him,' 'I don't want to go back to being him, I want to be me'" [Humphrey- mild cognitive disability, seizures and depression; Ella- bipolar]

For some this division was fueled by how opposing self during a mental health experience was to self 'normally':

> "…my mental health does show itself as a completely different version of who I am…" [Peter, schizophrenia]

Common sub-themes within this wish to dissociate include feelings of guilt and shame over some of the thoughts, behaviours and decisions made during a mental health experience, accompanied by a wish to avoid discussing or revisiting them:

> "Some things I've done I wouldn't even [laugh] necessarily like to bring up, you know…like in terms of sexual partners and things, and like, actually cheating on people…things I'd never dream of doing normally, and, me not really at times understanding…afterwards, why I brought myself to do it…" [Daria, bipolar]

> "I don't like to, think about, when I was ill…" [Jill, undisclosed mental health difference]

This was accompanied by strong self-criticism from most episodic participants:

> "…I feel really rubbish about myself in many ways…" [Debbie, personality disorder]

> "…there's a lot of stuff about myself I don't like to tell you the truth…I tend to be, you know very self critical…you judge yourself more, I think you know…if you're not well you start judging yourself" [Peter, schizophrenia]

> "…don't get me wrong I think I'm a pretty…terrible person…I feel like a pretty terrible person most the time and like I do everything wrong," [Rebecca, OCD]

> "…you just give yourself a hard [emphasis] time…a much much much harder time, than normal why did I do that, why did I say that or just feel really, really, really angry…" [Layla, borderline personality disorder]

This self-criticism, guilt, shame and dislike of self during a mental health experience can result in self harm and self-neglect in the form of direct harm and indirect harm i.e. addictive behaviours and self medication. This harm of course can arise as an impact of the mental health itself, however it is also probable that dissociation could create a desire to punish self:

> "Diego: …mentally you can't cope without being able to punish…I think depression is self-punishment, it's internalized anger, to a certain extent…
> Jessie: I think my falls- I've had 15 falls this year, in 12 months- and I think that is a very subtle form of self harm…it's self punishment, isn't it?
> Lulu: Yeh…we may not physically put ourselves in harm but mentally you know [we will]
> Jessie: Yeh, or forgetting to take my tablets, I'm talking about heart tablets…when I look at them you know I think 'this is a form of, self neglect, self harm, self hatred, self punishment' and again as you say, turning it in on yourself" (Focus Group 2)

> "…in the real throws of a depressive episode, I mean it is neglect, when I will not… have a shower…" [Lulu, Borderline Personality Disorder]

> "…self harm- self-medication, and I think that's something I do, addictive behaviours, inappropriate relationships…you name it I've done it…" [Jessie]

Stigma was also a motive to dissociate from self with mental health- to avoid the negative associations and labels mental health can still attract:

> "…when they say in the media you know, schizophrenia- we're all violent …and because at times I have been judged as being a risk to others, that adds to the sense of stigma and shame…" [Anthony, schizophrenia]

Daria worries people will judge her for her actions during a manic episode without understanding that they are behaving this way because of bipolar. In this sense Daria desires compartmentalization so that she can 'blame'- for want of a better word- her actions on the bipolar:

> "…afterwards you realize what you've done and, guilt sets in and then you tend to find you go into a depressive episode cause you feel so bad about the actions you might of took, but…back then people weren't aware it were bipolar, so there's no, like people just thinking I'm just, you know, being a bit, wild and reckless kind of thing…" [Daria, bipolar and autism]

Gergel and Das et al also note dissociation as one way in which participants in their study involving 932 people with bipolar, discuss distorted thinking during a mental health experience. "Such responses might represent a deliberate hyperbolic attempt to distance themselves from their so-called ill self—a distancing also expressed by presenting distortion as a fundamental change of identity."[371]

Ability to work and a change in social role

A change in self via an inability to work was another dominant change brought about by mental health and related physical ailments. This was expressed by a majority of participants, with the exception of a couple who felt they were still able to work in a limited capacity, i.e. volunteering. It was also clear that for some ability to work was an aspiration they were working toward:

> "…ability to work is a big one, I wanna be working… but at the moment, with the way my body is and my, everything else, [I can't]….I [was] a support worker… and I really enjoyed it, until my health, made me, basically not be able to do it anymore," [Humphrey, mild cognitive impairment, seizures and depression]
>
> "…I think it should be more an inability to work rather than ability to work…I'd love to be able to get back into work and other stuff…it just doesn't feel like anything that's going to be possible anytime in the future…" [Daria, bipolar and autism]

This change was less so the case for people with first and secondary accounts of progressive mental health, many of whom were retired. Therefore ability to work was not dominant in discussions of change.

Connections were made by participants between an inability to work and a loss of social recognition, connectedness and a feeling of being wanted. Some participants felt their work gave them social connections with colleagues, respect and a sense of recognition and power, and they derived part of their identity from their work:

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[371] T. Gergel and others, 'Reasons For Endorsing Or Rejecting Self-Binding Directives In Bipolar Disorder: A Qualitative Study Of Survey Responses From UK Service Users' (2021) 8 The Lancet Psychiatry, 604.

> "…I used to do inspections for the [NUA], they don't want me now, I've never met this new chief exec, or his assistant [laughs] we used to have chats, the others…when we were there, they've all gone, [talking about work colleagues] they've all gone, I've got no connections, it just leaves you in a void." [Robert, undiagnosed memory loss]

> "I felt like they took away in a way who I was…you're no good to us, and that made me feel useless, I've lost my identity I've lost who I was…" [Jane, clinical depression]

There was also an expression of feeling 'useless' and being self-critical because of an inability to work. Participants also talked about considerable social pressure from family and concern about how society will view them, adding to the sense of stigma discussed in the previous section:

> "…I don't work anymore, I feel terrible pressure, from family and constantly asking 'are you not working yet,' my husband will come home and say there's a job going… I feel completely, utterly useless, especially, the girl next door she's a nurse [Debbie used to be a nurse] you see her coming off shifts and you know, some days I can't do anything…" [Debbie, personality disorder]

> "…I'm a very harsh self-critic…and I worry about what others will think about me not working, and, like, being on benefits and stuff, because, I've grown up with the stereotype of people on benefits, and when you hear about like benefit frauds and stuff, I know that like, there's plenty of people who aren't like that, but I worry what they'll think of me," [Rebecca, OCD]

The stigma caused by a change in social role, emphasizes the permeation of the healthy social theory self in modern day society and shows how value and success is inextricably bound in our individualist market society with employment.[372] Those without employment are dependent on the state, and this dependence is politically demonized and policies enacted by the welfare state to reduce a 'culture of dependence.'[373]

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[372] C. B Macpherson, *The Political Theory Of Possessive Individualism* (Oxford University Press 2011).

[373] M. Oliver, *The Politics Of Disablement* (1st edn, Macmillan 1990) 25-42, 78-94.

Jane expressed anger and felt betrayed by the system because of how quickly she felt perceptions of her changed once she was unable to work:

"…the benefits agency then decide to take me to court…I thought I've worked all my life, the only time I've had off was a year for each child, I've come out of work, never been out of work before, and you're telling me I'm fraudulent!...how could these people do this to me?!" [Jane, clinical depression]

Isolation, Fear and Loneliness

Post mental health experience participants believe self became more isolated, fearful and lonely. This was expressed by a large majority of participants but manifests in different ways depending on the individual and the type of mental health difference. These themes have been grouped because they were often discussed together or interrelate with one another.

First, isolation was reported by many participants with both episodic and progressive mental health. People with progressive mental health described isolation in the sense of forced isolation leading to loneliness. This was largely caused by a lack of social connection and an inability to get out and about easily- because of both physical and mental health mainly in the form of memory i.e. forgetting locations and street names:

> "…I can't remember street names or how to get there- I mean I used to go to Derby quite often- driving…[inaudible] I couldn't get a Sat Nav going [laughs] …these are all the little things which make a difference." [Robert, undiagnosed memory loss]

Indeed loneliness caused by isolation was a dominant theme in my focus group with participants in the early stages of progressive mental health:

> "…I don't like being on my own, I said to someone this morning- oh please come round and just have a cup of tea, but no one comes round you see…well I'm on my own 24/7 really, unless someone comes over or I really go out, you know… I look at the phone sometimes and think- I wish someone would just phone me up…" [Betty, early-stage dementia]

A loss of ‘mutual recognition’ was expressed by participants who felt they have lost social connection because of isolation. For this participant this realization came after a physical ailment:

> “Sandra:...I thought I’d got a lot of friends and people who cared, and I found I didn’t have anybody at all…. and I’m lonely just desperately, desperately lonely, because I don’t have anyone else…that’s why I go to all these groups and things
> Robert: Well I’m with you on that, yeh I come here to speak to people…” (Focus Group 1)

Participants also outlined ways physical disability can interact with and aggravate mental health to cause isolation:

> “…I’m very clingy now and very apprehensive, because you get that frightened of falling- having fell… I get on the bus…but [I get] agoraphobia and panic attack...from walking down the road…” [Sandra, early-stage memory loss]

This non-voluntary isolation also applies to those with episodes.
Some participants expressed feeling socially isolated because they feel alienated and constantly preoccupied by mental health, meaning they cannot participate in ‘normal life:’

> “…I don’t have a middle ground…I’m either depressed or I’m manic…I want to be able to do what other people do…I just feel so isolated and I’m just like…what do normal people do with themselves?” [Michelle, bipolar and psychotic episodes]

Some also expressed being isolated from family members because of a lack of understanding about their mental health:

> “…everything I do is so slow, which is a source of huge frustration, I mean really slow, people get really, annoyed with me sometimes, family, particularly my husband…” [Dawn, personality disorder]

Two sub-themes which came from isolation include ‘self-preservation’ and ‘fear’- choosing to isolate to protect self from stigma, protect self and others from negative thoughts and behaviours, and to avoid being hurt emotionally and physically. This isolation is connected to a desire to be independent from others, and this independence impacts participant relationships and mutual recognition:

> "…I don't want to feel dependent on anybody because I don't trust a lot of people, because of things that have happened…feeling that your being attacked, and, not necessarily attacking back but closing off, from people…so you don't, get, hurt, but then, that comes out as, an abruptness, so it's not the closeness" [Steph, PTSD]

> "I'd just rather lock myself away and just be in my own little bubble, it's like, no, I don't need you, go away…I didn't even want people to call, I didn't want people to speak to…it was my own fault, I pushed them all away…" [Jane, depression]

> "I move from dependence to just complete isolation- so I've added group belonging…in an episode I feel I retreat…" [Anthony, schizophrenia]

> "I think just most people just feel safe in their own, space…" [Layla, BPD]

Participants also discuss feeling paranoid and wanting to stay isolated because of a lack of trust in others:

> "…I just kind of, cut myself off… I just thought everyone's against me… someone's got it in for me, I actually believed I was being targeted…" [Jane, depression]

> "…I just become very fearful so, yeh [sighs]…so very paranoid, and because I'm having experiences where I'm sort of seeing and hearing these three, evil presences, I assume that everyone is, working with them against me" [Anthony, schizophrenia]

Fear and how it works to reduce independence and social activity was clear in participant responses.

> "… I can be mostly independent, but there are some things that, I'm scared of, doing, which would make me more independent so then, I guess it's fair…" [Rebecca, OCD]

> “…I don’t feel confident anymore, I feel scared in a way…” [Jane, depression]

Humphrey, who has depression and cognitive impairment caused by seizures, discusses how being unsure about what triggers his seizures has made him fearful and less social:

> “…I used to quite enjoy going out and sort of, meeting people…socializing and all that and I’m quite happy if I don’t do it now…that’s upset me, and it goes back to that whole thing of being scared … unfortunately I’m living that…it has, impacted me and, it…scares me, that’s the honest truth it scares me, and you know I wake up…every day and I’m basically scared...”

Change in cycles

Change in self was described as occurring in cycles. Talk of ‘building self back up’ and being ‘knocked down’ by mental health, physical pain or people/events beyond individual control was frequent. Many participants felt their mental health was triggered by events in their life which begin this cycle.

For one participant this included a house fire at their family home, their spouse who was an alcoholic returning to drink after a failed rehabilitation, and a divide in the family caused by child custody arrangements. This was worsened by being in a job for 40 years they disliked:

> “…it is a pattern, I can see that now having been so low, it might be something will happen…[house fire, family being divided]… so it’s like a circle and I think that’s where my depression started kicking in again… and I thought this time I need to break it…” [Klein, depression]

Jane describes how her change in self was triggered by a string of events within a two-year period, which they had no control over and felt helpless to prevent. Loss and grief was a clear theme in Jane’s response:

> “…[I had] an accident in work… I came out with a condition called fibromyalgia, which affected all my joints all my body parts, so I’m in pain constantly…I’d lost my job, my son left home…my partner died, I’m like, this can’t be happening… the

> benefits agency then decide to take me to court because they said…I was fraudulently claiming…my ex-husband who I'm still close with cause he's the father of my kids, turns out he's got cancer, he's only got 45 months to live, so to take the strain off my kids, I agree to be there for him and take him to his appointments this that and the other, while doing that my dad died, just like, a phone call out the blue…although I'd done everything I could, (my ex-husband) died in the May, so I lost my dad in the March lost (my ex-husband) in the May, I'd lost (my partner) the previous July, everything was going wrong with my life…" [Jane ,depression]

A sense of helplessness and a lack of control over one's life seems to be connected to change in self and therefore may cause a loss of control over one's self. More on the importance of individual control is discussed in Chapter 6 on the importance of negotiation when dealing with harmful will and reference to prevent further harm.

The role of others, particularly family members, also played a role in 'knocking people down':

> "…but there will be days…you've had problems with family or whatever, and you nosedive, and you struggle to get back up…" [Ella ,bipolar]

Participants also discussed how it was much easier and faster to be knocked down, than it was to pick themselves back up and reconstruct self:

> "…I'd hit this, floor, and I suppose the only way eventually is up, but it takes you a long time to get yourself off that, I mean it took me…nearly eighteen months to actually get myself off the floor…it took a lot longer to get off it than it did to go down…" [Jane, clinical depression]

For many this cyclical change in self is caused by mental health difference and is a continuous repeating cycle with little respite, described as being relentless and exhausting. Michelle links these cycles with changes in social circles and as a cause of isolation:

> "…I don't have a middle ground…excuse my French but it's fucking relentless, I'm either depressed or I'm manic, and it's exhausting, I want to be able to do what other people do… I go through cycles of stuff…my personality changes, like one

> day…I'm working…and I've got…a boyfriend and I've got his friends and my friends and then I get poorly I break up with him, I lose my job, I end up taking an overdose, I'm in hospital, I lose everything to do with that life, so I start again, I'm working at a tattoo place, I've got new friends a different boyfriend, and then I become poorly and I lose my job, or I quit my job because I'm not well, and then I start again…being how I am it's difficult to maintain relationships, jobs, who I am, I go in cycles so it's just [exhale] you know, quite a lot of these people who are in hospital… I was thinking well why isn't anyone visiting them, but I can understand, because people, they can't keep going through, what you're putting them through, and they just leave you…" [Michelle, bipolar and psychotic episodes]

More on how people build themselves back up in this cycle of change is discussed under the theme 'Change as Positive- Mental Health as a process for self-understanding, recovery and reconstruction.'

The Impact of Medication

Medication was discussed often in response to my question on how self changes with mental health. It seems medication can also cause changes or losses in elements of self. Many participants describe medication in reference to memory loss, a change in behaviour, creating a lack of empathy, and causing a loss of identity and self-recognition- leading them to feel 'zombified' and not like themselves:

> "I don't know if it's…the illness or a side effect of the medication, but I find my memory is not as good as it was…" [Nicole, psychosis]

> "…all that got thrown at me was more and more different medications…that just made me feel confused…[i]t took more of me away, my identity became nothing, I was just like a zombie! I was just like, my memory had gone, my recollections had gone," [Jill, depression]

> "Daria: That were definitely me with diazepam, because I definitely didn't feel like me on that- it did make me feel like a different person,
> Ella: Like a zombie,
> Daria: I think it can make you into something that you're not if you know what I mean…diazepam did level me off, like no emotion, like flat…" (Focus Group 3)

There was also doubt over whether medication worked and was being administered to best retain the persons self. Michelle describes being treated with anti-psychotics which she feels were making her more unwell and therefore caused more of her self to be lost:

> "…they just kept increasing, increasing, increasing it when they saw I wasn't getting any better, and obviously it just made me worse and worse and worse and my parents pulled me out of hospital and took me off it…I think a lot of people in hospital are experiencing that, because I've got my mum and dad, but they haven't got anyone to come visit them…" [bipolar and episodes of psychosis]

Michelle also talked about the more degrading aspects of medication for mental health, which no doubt have a negative impact on sense of self:

> "…they medicate to bring you down, and when you're at a level they can tolerate, which is normally you're weeing yourself, you're doing other toilet to yourself, you're dribbling everywhere, you know your whole body's just completely done…"

The drastic impact both mental health and medication had on Michelle's self was a source of serious concern for her dad Joseph, who was concerned her self would be permanently lost:

> "…I thought, will we ever get [our daughter] back, cause you were so heavily medicated and so, poorly…"

Awareness

Awareness of a change in self was also something widely reported by participants with both early-stage progressive and episodic. It is linked with the concept of self-understanding and knowing one's own mental health:

> "…I think I've got the ability to recognize what's going on with me, you know if I'm not feeling good or you know, the swings and roundabout of, anxiety and depression…" [Peter, schizophrenia]

This was with the exception of one episodic participant Steph, who described behavioural change caused by mental health as snowballing- building up over time so change was less noticeable. Retrospectively Steph knows she changes but is not aware of this change during an episode:

> "You don't notice it, when, you're doing it…when you're experiencing it, or in it, it doesn't really seem, different…you don't wake up and think, I'm a different person today…you just don't" [Steph, PTSD]

It is also possible that people in the later stages of progressive mental health are also unaware they have changed. This can only be accounted for secondarily in this research and overall carers seemed unsure:

> "…he doesn't know there's anything wrong with him, which makes it quite frustrating…you know I'm second guessing cause I don't know, that maybe he does know deep down that this is a different him…" [Samantha, carer for husband with fronto-temporal dementia]

Awareness was linked with the idea of self-control, meaning individual insight could allow participants to control changes in self and potentially limit harm to themselves and others by taking precautionary steps:

> "Diego:…oops I'm going down that path, I wanna control that, it's not the right thing to do… it depends on the level of illness but it's understanding the self, understanding yourself is very very important…if I'm talking too much, go off track, my behaviour becomes…I do strange things and I think, hang on! What's happening, you know certain things in certain areas will flag up…
> I: So you actually feel a change of behaviour coming on then?
> Diego: with myself, yes…" [clinical depression and anxiety]

Nicole also explained how she could tell her self had changed because of the way people were reacting to her:

> "I: So you've got kind of an awareness?
> Nicole: Cause of how other people react to me, so…I can tell something's wrong …"[psychosis]

However, even though participants notice this change in self that does not always translate into seeking support:

> "…[E]ven though I know that [I'm not thinking rationally] I, still won't listen to people sometimes… so when people say you should go to A&E or something and you're like no I'll be fine… someone actually, rang the police once and they sent them round to my house, I had to promise the police that I'm going to the hospital…" [Rebecca, OCD]

Some do not reach out for help despite noticing changes because they wish to avoid being sectioned under the mental health, being made to take certain medication, and avoid having their decisions limited. This can lead to a simultaneous desire to get help, while avoiding help because of the consequences.
Michelle described how she would not often reach out for help because she 'enjoys' the episodes of mania. This is because she regains elements of self previously lost and feel on a 'high.' This is preferable to her comparable state of depression:

> "Michelle: ….I was trying to get help but I wasn't, I mean, when I'm poorly no offence dad, but he just takes me to A&E and I get sectioned and obviously I don't like being sectioned…all my friends have my dad's number, and I say 'when I'm poorly, when I'm manic and psychotic, you've got to all ring my dad,' cause he's the only one I'm safe with really…but obviously when I'm poorly I'm like- 'don't call my dad, I'm fine, let's all go out for drinks!'
> I: Why do you ask your friends not to call your dad when you're unwell?
> Michelle: I think it's because I know that he's going to section me, and I don't want to be sectioned,
> Joseph:…I think there's a part of you that wants help, and there's another part of you that thinks way hey this is great!
> Michelle: Yeh I'm having a great time! [laughs]
> Joseph: And I can see, now that I've sort of taken a step back, I can see why, [Michelle] would- because it always filled me with fear when [Michelle] said- 'oh I really enjoy my manic episodes'… [but] I can see why because, you'd prefer to be really happy and flying high rather than being in the depths of low depression"
> (first and secondary accounts of bipolar and episodes of psychosis)

Nicole talked about how- despite having awareness of changes in self- her psychosis would actively prevent her from reaching out for help. Instead she would try to manipulate those trying to help her to avoid the consequences of treatment:

> "…I felt the voices… didn't want me to talk about them, it was meant to be a secret…I remember how we used to, as a patient…try and work out how we can get away as soon as possible, and…once you come out of the very distressing stage, you kinda play mind games with the doctors and nurses because you're like- oh they ask me that- more medication, if I say no- less medication…" [Nicole, psychosis]

This awareness coupled with a simultaneous desire to obtain and avoid help, could justify self-binding to opt into state intervention during an episode, despite contrary will and preference. It also emphasizes the importance of quality support so patients are not afraid of seeking help during an episode. This feedback also makes a case for reducing or irradicating forced treatment and detention in line with a strict interpretation of the CRPD, as fear of coercion may be preventing/discouraging people from seeking help during a mental health episode. Earlier intervention may therefore be achieved with self-binding provisions and an eradication/reduction in coercive treatment.

Change as Positive- Mental Health as a Process for Self-understanding, Recovery and Reconstruction

Change in self caused by mental health difference was not always framed as negative. Some participants discussed it positively as a logical process for dealing with trauma, moving towards a 'healed self,' and as a process of reconstruction, self-understanding and self-improvement, which has generated positive change in their lives.

First, some participants felt mental health experiences were a natural and logical way of coping with trauma and are therefore part of the process of moving towards a more healed self. This resonates with literature which favors a trauma centered approach to treatment "based on the recognition that many behaviours and responses (often seen as symptoms) expressed by [people with psychosocial disabilities] are directly related to traumatic experiences that often cause mental health, substance abuse, and physical concerns."[374]

> "I think for me and for some people I know…we go to what I call the theatre of madness, in order to hear the un-hearable, to tell ourselves the untellable…. some

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[374] T. Minkowitz, 'Norms And Implementation Of CRPD Article 12' [2010] SSRN Electronic Journal, para 5.

> of the discussions I've had with other survivor's- we can see the madness is the place where we hear these stories, cause we can't bear to hear them anywhere else…we can't bear the pain of what's happened, so you know it's gone down and it can [resurface] in these very, very, very different ways, and you know- you say you look back and feel ashamed, I can still…see the logic...'well of course this is what we're saying!'...I think its discovery… I think it is a form of sense making, and can be a form of moving towards a healed self" [Jessie, "living with the impact of deep traumatic, mental and moral life wounds, broken and reborn, mad and not requiring to be fixed"]

Jessie also shared two anecdotes about how mental health relates to trauma. First, Jessie's adopted daughter had a birth mother who used to burn her feet as a child, so now during a mental health experience her daughter burns her feet. Jessie believes this is not 'adverse behaviour' but a logical, learned reaction to negative feelings, rooted in childhood trauma. The second example involves an acquaintance of Jessie's who would clear out a space in the kitchen cabinet of the mental health facility, fill it with sanitary products and label it with a sign that said 'do not enter my sacred space.'

> "…there was all sorts of things logged about her you know- challenging behaviours…to me quite clearly she was talking about the invasion of her childish body, during father rape, you know it was so obvious what she was doing…"

These anecdotes show how trauma manifests in the way mental health is enacted. Mental health as it relates to trauma certainly creates the impression of mental health as logical and human. It may therefore be positive in the sense that for some it serves a purpose as part of a logical process of dealing with trauma.

In terms of mental health being a process for self-reconstruction, it has already been discussed how mental health can deconstruct self and cause participants to lose a sense of identity. However mental health also provides for self-reconstruction, whereby people have to put themselves back together following a mental health experience. This process can force individuals to confront elements of self they do not like and prompt them to deal with traumatic events, in order to work towards a more healed, reconstructed self.

> **"...**I feel like I am pulling myself out of the swamp, I've reconnected with some, friends, and I'm actually, trying to find me again, and I'm trying to get interested in things again… actually getting me out and meeting people," [Jill, depression]

> "I'm trying to undo twenty odd years of a bad marriage, bullying at school, so, again it goes back to your recollection and reflection of things, I've got to start reflecting on me again because I've lost me, and I'm trying to find me again and I'm really, really struggling with it…" [Ella, bipolar]

Participant discussions of self-reconstruction focused on building relationships, finding purpose through work, research, volunteering or by helping others.

Reconstruction and confronting the triggers which begin the cycle of mental health, can also generate positive changes in peoples' lives and their self. Klein talks about how the desire to break the cycle of his mental health gave him the drive and passion to pursue a different career and retrain, in the hopes of doing something he enjoys and giving back to others in need of support. Therefore this desire for positive change in one's own life, can translate into positive change for others:

> "… I thought this time I need to break [the cycle,] I've had some weird ideas- I fancy going to university [scoffs] you know I'm sixty years old! So, you know, I said this to the doctor at the time, I just want to make a change in myself…coming here has opened my eyes a little bit about others things, not just about myself, but about other people…what I've gained from coming here I want to give back, and if I can pass a little bit of what I've got, I'd like to…" [Klein, depression]

Another positive impact mental health can generate is a positive change in some elements of self. Rebecca talks about how they feel they have gained better understanding and more empathy for others:

> "Rebecca: I think mental health experience maybe changes your values, maybe in a good way,
> I: Could you elaborate a bit on that?
> Rebecca: Like, I think it makes you think more about, how, to treat other people, or, you, learn to, listen, to each other more,
> Peter: Yeh (in agreement)
> Jill: I think you've got more sympathy…
> Rebecca: Yeh, so…before you might have been 'oh you'll be alright,' now you have more of an idea what others are dealing with"

Samantha also highlights that not all changes in her husband's self are negative:

> "…he's happier now- it sounds ridiculous! [laughs] he used to get upset about very minor things- if you broke something…it was the end of the world! He's…got very passive…" [Samantha, secondary experience of fronto-temporal dementia]

Self-understanding was a dominant theme within participant responses. This was in terms of regaining and embracing identity and self-recognition post mental health, and utilizing mental health to better understand self.

Mental health as a prompt for self-reflection, as a learning process in understanding self, and in some cases- allowing mental health experiences to inform identity and self-recognition- was common amongst many episodic participants. Some expressed this in a positive way- as an experience which had become a part of who they are:

> "…I kind of call my illness like an awakening process…" [Nicole, psychosis]
>
> "I am…learning me more, and…getting answers to who I am, I think they all [mental health experiences] [inform] a lot of why I behave why I do…" [Daria, Bipolar]
>
> "…I feel like I know myself now…" [Jill, Bipolar]

An example of how mental health itself can be utilized for better self-understanding can be seen in the responses of some episodic participants. Mental health can manifest itself for some as the voice of participant's own self-criticism. Therefore utilizing and listening to the voice of their mental health can not only help them manage the mental health, but can help address underlying issues:

> "Anthony: I mean the advice I was given was always to ignore [the voices] but once I started talking to them I could actually see…when I regain my rationality, that the things they are saying are things I do fundamentally believe about myself, sort bringing that to therapy, yeh…
> I: So embracing it, has helped you on your journey with understanding self?
> Anthony: Yeh, yeh definitely" [schizophrenia]

Nicole explains how she has conversations between herself and her mental health - 'the voices'- using notebooks as a form of therapy:

> "…I write things down…and most of the time I don't read my notebooks again because sometimes they have very difficult emotions and very difficult thoughts…so I tend to tear them off or burn them or throw them away, but yeh, writing has become something I do [laughs]…what I call inner dialogue, so writing, having a conversation with myself and all these different perspectives or voices as others would call them, on paper…helps" [Nicole, psychosis]

Self with mental health: a true self conception?

This section shall be evaluating findings to see whether participant perceptions of self with mental health pertain to a true self conception, including whether self changes to such a degree during a mental health experience that a new self is created, and whether self during mental health is a continuation of self or is periodic. This feeds into wider philosophical debate around the conditions under which "a life consists of stages of the same person and when a life instead is occupied by different persons over time."[375]

True self is a western concept around there being a 'most genuine' version of ourselves.[376] It is a widely used concept in western media in the context of self discovery and being 'who you truly are.'[377] Our 'true self' is therefore our most 'authentic' self. It can be juxtaposed with the idea of performance- acting differently depending on the environment and audience, in a way we would not behind closed doors.[378] Performance is synonymized with playing a role or wearing a mask- concealing 'who we really are' or our true self.

As mentioned in Chapter 1, true self has also been linked with the unimpaired self and is used to justify advance planning- privileging one version of self over another to protect

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[375] R. Dresser, 'Life, Death, And Incompetent Patients: Conceptual Infirmities And Hidden Values In The Law' (2021) 28 28 Ariz L Rev, 380.
[376] S Lawler, 'Masquerading As Ourselves: Self-Impersonation And Social Life', *Identity : Sociological Perspectives* (2nd edn, Polity Press 2021).
[377] Ibid 117-118.
[378] E. Goffman, *The Presentation Of Self In Everyday Life* (Penguin 1990).

the interests/wishes of the true self. E.R Saks provides an anecdote on the link between true self and the 'well' self:

> "Is the issue that the prior self is unimpaired or that it is the true self? Yet it is hard to say when a new self has come into being (rather than simply being a changed self) and when the new self has become the true self or is simply a temporary aberration. Most likely we identify the prior self as the true self because it is unimpaired. But if the status as unimpaired is what is important, we are simply flagrantly imposing our values as to what is better. I concede that this is true but do not find it altogether problematic. Surely a self that is unimpaired is in some sense "better" than a self that is impaired. It has more skills and more options. Impairments are limitations, and, all else being equal, it is better not to suffer limitations."[379]

Dworkin argues in favor of allowing the wishes of the true unimpaired self to bind a future uncapacious self, on the grounds that this protects their critical interests and an 'integrity view' of autonomy. The integrity view holds that the value of autonomy "derives from the capacity it protects: the capacity to protect one's own character."[380] Protecting character includes protecting a person's experiential and critical interests according to Dworkin. Experiential interests are those done for enjoyment, whereas critical interests are those values, beliefs and aspirations which bring core meaning to our lives.[381] Critical interests are superior to experiential interests according to Dworkin. Therefore in response to his fictional Margo case posed in Chapter 1, Dworkin argues that Margo's advance directive refusing life sustaining medical treatment should be adhered to, as this protects Margo's 'precedent' autonomy and allows her death to in some way reflect the critical interests most important to her in life.[382] Dworkin therefore allows one version of self to be privileged over another, dependent on the extent to which an individual retains the capacity to act in a way that protects one's own characters and critical interests.

Both Saks and Dworkin's perspectives conjure the idea of a periodic self, existing in different versions so as to allow one version of self to privilege another. These include the 'competent' and 'demented' versions of self which Dworkin believes are parts which

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[379] E. R. Saks, *Refusing Care* (1st edn, University of Chicago Press 2002) 204-205.
[380] R. Dworkin, *Life's Dominion* (HarperCollins 1995) 224.
[381] A. Ruck Keene, Rachel Cooper and Thomas Hobbs, 'When Past And Present Wishes Collide: The Theory, The Practice And The Future' [2017] Eld LJ, 134.
[382] R. Dworkin, *Life's Dominion* (HarperCollins 1995) 288, 211.

make up the whole person.[383] This pertains to a true self conception, whereby wishes made by the 'ill' self during a mental health experience can be overruled by the 'healthy' self - a different version of self, to protect the critical interests of the true 'healthy' self. Despite the true self being conceptually problematic for CRPD compatibility (discussed in Chapter 2,) it can be seen how this conception of self may be helpful for those participants who undergo drastic changes in self and make decisions they otherwise would not have made. This is particularly pertinent when an individual must 'return' to their life pre-mental health experience and face the potentially devastating consequences of their decisions. Therefore it can be seen how this conception could justify self-binding for those who experience episodes of mental health which have drastic impacts on self and decision making. However, when discussed in the context of more long-term mental health difference such as Alzheimer's and dementia, it can be seen how a periodic conception of self makes adhering to a self-binding provision unfair.

This is an argument put forward by Derek Parfit and Rebecca Dresser.
Derek Parfit's book 'Reasons and Persons' provides one of the most detailed accounts of personal identity.[384] He advocates for a Complex View Theory of personal identity. This posits that identity is made up, in part, of a mental entity which consists of continuity of memory and other psychological features including beliefs and desires. These features diminish over time, meaning there are different versions of self connected by chains of direct connections in memory and other psychological features. For example, we can say we are strongly connected to our self yesterday, and that self to the one the day before and so on, however we are not strongly connected now to a version of self twenty years ago. Therefore self exists in a string of successive but connected selves, and when speaking of our selves we refer to "only the part of our lives to which, when speaking, we have the strongest psychological connections. We assign the rest of our lives to what we call our "other selves."[385] A person can only therefore commit their present self to a decision, and our commitment to that decision weakens as direct psychological continuity diminishes.

Rebecca Dresser applies this theory to advance directives.[386] It can be seen how the psychological continuity needed for Parfit's account of personal identity can be lost during

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[383] Ibid 231.
[384] D. Parfit, *Reasons And Persons* (Clarendon Press 1984).
[385] D. Parfit, 'Later Selves And Moral Principles', *Philosophy and Personal Relations* (1st edn, Routledge and Kegan Paul 1973) 140-141.
[386] R. Dresser, 'Life, Death And Incompetent Patients: Conceptual Infirmities And Hidden Values In The Law' (1986) 28 Ariz. L. Rev.

mental health experiences when changes to memory, desires, values, behaviours and cognition can mean we are dealing with a very different self to the one who made the advance directive. This becomes particularly problematic when considering people with progressive mental health.

Dresser argues that on this basis it would be unfair to hold a future individual to the wishes contained in the advance directive as there exists little psychological continuity between these versions of self. Applying this to the Margo case therefore, Dresser would no doubt argue that Margo should be given treatment against the wishes of her contrary advance directive, as the version of Margo who made the directive no longer has dominion over the current Margo as they are not the same person.[387]

On the one hand therefore, Parfit's theory could be used to undermine the conceptual basis for self-binding as self during a mental health experience could be very different to the one who made the plan. If self is periodic in this way and is formed from connected versions of self, forbidding self-binding would protect the interests of the future incapacitous self. This is particularly important when considering those who will not regain a version of self similar to a version pre- mental health again, including Margo. Berghman notes that self-binding may be justified for those with progressive mental health depending on the degree of psychological connection between the self who made the advance plan and self during mental health experience.[388] Likely this connection would be stronger during the early stages of a progressive mental health difference, meaning self-binding would have limited effectiveness and may not apply when people most desire their will and preference to be overridden i.e. by a nominated support person during late stages.

On the other hand, a periodic conception of self like that of a true self model, has benefits for those whose mental health is characterised by episodes which cause drastic changes in self and decision making, and whose self prior to mental health will be regained to a much greater degree. The ability to dissociate versions of self is not only used by participants to allocate responsibility for negative behaviours and poor decision making to the 'ill' self but provides a conceptual basis for self-binding.

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[387] A. Ruck Keene, Rachel Cooper and Thomas Hobbs, 'When Past And Present Wishes Collide: The Theory, The Practice And The Future' [2017] Eld LJ, 134.

[388] R L P Berghmans, 'Advance Directives For Non-Therapeutic Dementia Research: Some Ethical And Policy Considerations.' (1998) 24 Journal of Medical Ethics, 34.

If self is continuous and there exists continuity between self pre, post and during a mental health experience, there exists no true self and no conceptual basis for privileging the will and preference of one self over another, effectively nullifying self-binding on these grounds. This is because these different versions of self are all the same self. It is likely therefore that a continuous conception of self would only justify self-binding where the individual was unable to communicate consistent will and preference or was about to make a decision which would result in serious direct harm to self and/or other (discussed more in Chapter 5).

Participant responses inform this conversation, including whether a different self or version of self are created during mental health experience; whether a true self conception is accurate in how participants perceive self with mental health; and whether self is continuous or periodic. This will inform whether some remaining conceptions around self with mental health remain and justify restrictions to legal capacity, according to participant responses, and therefore whether self-binding can be conceptually justified. It has already been outlined in Chapter 2 that a true self model which upholds a divide line in selves on the basis of mental health is considerably problematic in light of the CRPD. Therefore these responses could either re-enforce or further challenge this barrier to CRPD compatibility.

Are we dealing with a different self - a different person?

On the whole, the question as to whether self changes so much so that we are dealing with a different self or person during a mental health experience, received mixed responses.

The majority of participants who experienced episodes did not feel they became a different self during a mental health experience. While mental health may bring to the forefront elements of self they disliked, magnify elements of self and cause them to lose others, they still perceived this self to be their self- one and the same. It may not be a self they like nor strongly identify with, but it was them never-the-less. There were also participants who talked about mental health experiences being part of who they are- as recounted in ‘Change as Positive’ above.

Examples of this are as follows:

> “I think for me personally it’s a core that stays the same, you’re always gunna be who you are, I think, deep down, I still think I’m the same person I was, maybe 20 30 years ago…I do feel that you do change, [with MH]” [Klein, depression]

> “Daria: It’s still me I think it’s just, different elements of me…it’s a bit like, when somebody’s gone and had a few too many pints and…their inhibitions kinda go away and their reason and rationality and everything, they’re not necessarily thinking
> I: So it’s still you, just different elements of you come to the forefront
> Daria: Yeh” [bipolar and autism]

> “Well I think essentially what happens, and I can only speak with [Michelle] because obviously it’s the only experience I’ve had really with dealing with bipolar…I think there’s definitely a core of [Michelle]…that I would know, cause I’ve known you since you were a little girl… your personality traits [have] obviously developed as you’ve gotten [older]…but essentially you’re [Michelle]...if you gave me a bit more time, it’d be able to put bits of you together that are you, but what happens when you’re manic poorly, is that, they get, amplified, to, mega, mega doses of [Michelle]…and that’s everything, it isn’t selective it doesn’t amplify the, bad bits it amplifies everything, the bad bits the good bits the whole thing… the core of [Michelle] is still there, and that’s the bit, that…binds us together…” [Joseph - second-hand experience of bipolar with psychotic episodes]

> “Jessie: [discussing a close friend during psychosis] she really was another person but there were minutes when she’d say [Jessie] I’m still here and part of her knew, she knew, there was a core of her that could reach out and say [Jessie] I’m here, hang onto me…”

This idea of self being deeply rooted and developing over time with experience and mental health, whilst remaining largely the same and central to that person- runs through participant responses.

There were two participants with psychosis- one active (Simon) and one ‘recovered’ (Nicole) who felt mental health was external to self. Both communicated this as hearing voices from external sources. Nicole felt therefore that their self was the same during a mental health experience, and instead the environment their self was in had changed. She was therefore acting as her self would in this new environment:

> "…I was me, but I was interacting…with these beings or aliens…and they're communicating a lot and giving me information…so for me it was like I'm still me but the environment has changed…"
> I: Do you think self can completely change because of a mental health experience or [do you] think it can change with the experience but that largely it would remain the same?
> P#1: …I tend to think one can totally change into a new person…and just have your history because for me like the kind of person I was- some people would say I'm still similar because my personality probably doesn't change that much…then I think the way my mind, my being inside, I…feel, has changed…so I feel like, you don't really change, but your mind accessing certain parts of your brain [changes]…so I'm still me"

Simon felt the voices he heard were external to self and described them as 'someone else inside his head.'

> "Simon: There's 6 levels of hearing voices….first of all, there's your own conscious voice, you know when you're talking…or you've got a problem so you start talking to yourself in your head to try and work that problem out…
> then you've got the second voice, your subconscious, which can response back, they're interacting but they're still self, then you start going into the voices which are like intrusive thoughts, you get a thought that appears in your head but it's not something you're comfortable with, and you're like hmm where did that come from..
> I: Do you think that's still an element of self- of you?
> Simon: Not to me, it doesn't feel [like] an element of self, it feels like it's an element from outside…it actually feels like there's something else with me inside my head rather than just me...And, as I've sort of learned to live with it, I tend to ignore it"

Both participants therefore did not view these voices as the creation of a new self, but rather as something external.

While the majority of participants therefore do not feel they become a different self, there were far more instances of participants drawing on secondary experience of witnessing others with mental health difference and describing them as having become a new self or a different person.

The most common secondary account of a new self was in the case of late-stage progressive mental health. Steph, a participant with anxiety and PTSD recounts:

> "…my mother she just would not believe, that [herself in later stages of dementia] was the same person, so you are a different person…"

Peter, when discussing John's case study vignette with the group (see Chapter 3: Research Design,) draws parallels on how his girlfriend's father-in-law became a 'different person' during the late stages of dementia:

> "Peter: [John's] self has changed hasn't it, so he's not the man he was…he's never gunna get that other self back is he… cause he's a different, it's a different self…it's like, a situation that my girlfriends, father in law had, where, he didn't recognize his wife anymore, and...he made an association with another woman [in his nursing home]…and they had to accept that, because that was what was making him happy…"

Daria discussed her mother-in-law with dementia, having lucid moments in which she would become 'more herself.' This kind of language was common in most conversations around late-stage progressive mental health and creates the impression of a new self being created.

Molly and Samantha act as carers for their husbands with late-stage mental health difference. Both acknowledged their husbands as greatly changed or 'lost' because of mental health, while also talking about some retention of self including via their 'essence' and the concept of 'someone deep down.' Molly feels even this essence is gradually lost or changed because of dementia. However Samantha is more hesitant in her view. Understandably there may be a reluctance to confront the idea that their spouse and person they care for has become a different person, which may explain the lack of clarification in Samantha's response.

> "I think in the later stages of conditions like dementia, you've lost the person, you've lost them, you're not separating [the person from the condition] you've lost the person they were, [there's a new person]…I don't think there's a way back from dementia and I don't think the people, who have dementia would actually want to be the person they become…dementia is a loss, it's a loss, all the time, it's a loss of the, positive things in a person's essence of being, it's a loss, it's a bereavement...I'm grieving now…for losing the husband I've had for 52 years …" [Molly]

> "[A]lthough there is somebody deep down there, who's as he was, his characters changed so much, and his rational thinking has completely changed, his behaviour has changed, if I'm honest I'm looking after a toddler in a away, well maybe not a toddler, but a child…he's changed a lot…" [Samantha]

While secondary experience of a new self being generated was most common amongst conversations of progressive mental health, it was not exclusive to it. Some participants with secondary experiences of other types of mental health also believed it was possible for self to become a different person based on this experience.

Michelle felt that others in the secure mental health ward where she had stayed behaved so differently and their beliefs seemed so changed, they could be perceived as becoming a new person:

> "I think a good example, of this is...when I've been in hospital, and you were saying about people, if they're still themselves or if they've got a sense of self, there's been lots of times where I've seen other people, and when they've come back round to who they normally are- like there was one lady who was in hospital and…from what I gathered…I think she had schizophrenia or some kinda psychosis due to grief, and she was really racist…to the point she made a few staff members cry, but when she came back to being her normal self, she wasn't like that at all… but there's some people who just act completely bizarrely, and just

> some people, who…do lose a sense of self, I think it depends what condition they're struggling with…"

Lulu also comments on her brother with long-term psychosis being a different person:

> "Lulu: No but my brother will come out with stuff like that, and he'd say- oh well I've been talking to Hitler, and I just sit there and agree, cause I'm not gunna talk down to him
> I: But do you still see your brother?
> Lulu: No, he's just another person,
> Rebecca: Is his self like a permanent change or sort of in an episode? Does he have episodes of going back to himself?
> Lulu: No he doesn't have any no… there's just nothing there, he's just a shell, it's a shame"

Of course these accounts are based on second-hand experience and are therefore speculative as to whether the individual themselves would agree they become a new self during a mental health experience. Findings from this study show that the majority with first-hand experience would not perceive themselves to be a different person during a mental health experience, and with the exception of Joseph and Michelle, it is unknown whether their close family members would agree with that observation. Secondary accounts are never-the-less of value as any future trigger to restrict legal capacity using an assessor or support person will also have to rely on a secondary account of how that individual has been impacted by mental health. This is discussed in more detail in Chapter 6.

Overall therefore the majority of participants feel they remain the same self during a mental health experience despite sometimes drastic changes in elements of self. There were more secondary accounts of individuals becoming a new person based on external observations, particularly for progressive mental health.

A continuous or periodic self?

These findings on whether a new self/person exists during a mental health experience, provides insight into whether self is viewed as periodic or continuous.

Based on the findings presented above, it would appear that the majority of participants who experience mental health episodes, view self as continuous. This means that while time, experience and mental health changes self, there is a definite sense of continuity between self pre, post and during a mental health experience. Continuity could include continuity in the elements which make up a person's self or their 'core'- an idea which resonated with several participants.

Secondary accounts of progressive mental health however move away from self as continuous, as self is seen as drastically changed or lost with little recovery of elements of self as time goes on. It is possible therefore that self is more periodic for progressive conditions. Based on participant responses it cannot be said categorically whether this results in a new self, or whether self is comparably more periodic compared with those who experience episodes. Some sense of continuity may be retained via lucid moments, and because spousal carers described their partners as having retained an essence or self pre-mental health, or as being 'deep down.'

An example of this is offered by Jane:

> "…my dad had Alzheimer's, he didn't even know who he was- we'd took him down the pub…and this guy who hadn't seen my dad for donkey's years, used to work with him- 'hiya Steve!' My dad stands up shakes hands with him, 'god I've not seen you for ages, well that's my family, this is my brother Pete,' and we're all like- [opens mouth in awe] he hadn't recognized us for years, but this guy who he'd not seen in forever, triggered something in him, and well for that, 10 minutes at most, he became very lucid… he introduced us… for years, not recognised us …"

It appears therefore a distinction can be made dependent on the type of mental health difference, its severity, how drastically it impacts self and its duration.

A True Self?

Our understanding of 'true self,' which self is true, and how this relates to self during mental health experiences, plays a role in justifying which version of self's wishes we are protecting and therefore which selves wishes should be upheld.

If self is continuous, as the majority of participants convey, it seems unlikely that a ‘new’ self to rival the ‘true’ self is generated during a mental health experience. Therefore there is no ‘true’ self separated by impairment, because impairment does not separate selves. True self as a concept then, either does not exist for the majority of participants or encompasses the self pre, during and post mental health experience. As outlined in ‘participant perceptions of self,’ the majority of participants with first-hand experience of mental health episodes talk about self as encompassing mental health, as mental health being part of who they are. Mental health has also been described as part of a process of better self-understanding and self-reconstruction meaning mental health for some may be a process by which they can get closer to their true self. Mental health could also provide an outlet for, or a peephole into true self. This is because mental health can bring trauma normally suppressed to the surface which can prompt people to deal with its underlying cause; can bring normally suppressed feelings or thoughts to the surface; and can magnify certain characteristics or behaviours core to that person’s self.
In some ways then, self during mental health may be a part of true self or may be a truer version of self than the self they present normally. Self with mental health as a true self provides a new angle from which to challenge conceptions of ‘illness’ is social and legal theories of self and challenges the justification on which self-binding rests.

The themes of self-deconstruction and reconstruction also challenge a true self conception. This invokes a concept of self which changes and develops because of or to incorporate mental health. Some participants felt self changed daily and others expressed how ‘self’ did not mean much to them or was a conception they did not understand nor appreciate. There were also those who struggled greatly to communicate self and were open about the fact that they did not know what their identity was- some doubting they had one. In this regard then ‘true’ self was not a concept which seemed to resonate with some participants.

If self is changing and developing with mental health and does not resonate with a true self conception, the CRPDs approach to legal capacity seems necessary to ensure the voice of self with metal health is not lost.

Despite responses indicating the contrary, some participants with first-hand experience of episodes, and many with secondary experience of progressive mental health, still used divisionary language and discussed self in a way which resembled a ‘true self’ model, where the true self was self without impairment. Part of this discussion could be rooted in beliefs that a new self is created during a mental health experience, a common observation amongst those with secondary experience of dementia and Alzheimer’s. This could also be explained by the fact that participants are embedded in a society which portrays the idea of 'true self' in popular culture and in the media. Participants may therefore be using this language and these references because they are the ones with which they are familiar. They could therefore be expressing their feelings and opinions within the remits of societies already institutionalized beliefs on self. This true self narrative was particularly common for those who expressed dissociation or compartmentalisation of self. This language may therefore be used more so in reference to a wish to dissociate from thoughts or feelings they are uncomfortable with or feel ashamed of, as opposed to referencing a true self model.

It is worth noting that there exists a tension between wishing to dissociate from decisions and actions when unwell and the belief by the majority that this is still a part of the same self.

Findings do not explore on what basis these participants would justify self-binding. Likely self-binding would have to be justified on the basis of harm as opposed to a conceptual belief that a new self was generated, discussed in more detail in Chapter 6.

It is also possible that, if a new self is created during a mental health experience, this version of self could become the new 'true' self. This is provided there exists insufficient psychological continuity between these versions of self, in line with Dresser's interpretation of Parfit's view on personal identity.

Insight into the possibility of a new true self created by mental health is provided by Samantha in observation of her spouse with late-stage FTD, and how "he thinks he's always been this way":

> "[H]e's obsessed with dancing, which my old, he would be mortified, he'll jig along to anything!...in this world- the world he's in now, alongside this other world he can't see- if I said do you remember twenty thirty years ago you'd never get up and dance or whatever- that just goes out of his head cause he thinks he's always been this way…"

The CRPDs approach to legal capacity- in awarding the will and preference of this new 'true' self legal weight- also seems beneficial here to protect the voice of any new true self.

It is worth noting that this kind of comparison between selves, as Samantha demonstrates, could create tension between who the individual themselves considers the ‘true self’ and who their loved ones would consider ‘true self.’ For example, let us imagine an individual in the later stages of dementia, who is drastically changed and who does not experience many lucid moments. If their memory and cognitive abilities are significantly changed as a result of their mental health, they may not be able to compare or remember who they were pre-dementia with who they are now. Therefore their true self is the only one they currently know- their present self and the ‘new’ self experiencing mental health. This is reflected in Samantha’s insight above. This may not be the case however for family members who retain the memory and cognitive capacity to compare self pre and post mental health, and determine on Sak’s reasoning that the past self was the true self because it was not impaired by dementia. Family members with the ability for comparison therefore, may be in favor of self-binding to protect the version of self they deem ‘true.’ Given the CRPDs focus on supporting the *individual* in expressing their will and preference however, the individuals concept of self would likely be prioritized in this case.

Conclusion and implications for theories on self and self-binding

This Chapter has outlined findings which suggest that self with mental health does not align with the characteristics of the healthy self in social theory, confirming observations and criticisms made in Chapter 2. Whilst it is true that some participants during a mental health experience see a change or loss in the healthy self elements, and whilst some participants did use divisionary language, for example ‘my well self,’ and ‘my ill self;’ overall the healthy self conception was not reflective of how participants communicated self. While some groups had elements which placed consistently high or low, each response was unique. Self and how it was communicated was therefore highly individual. This therefore casts doubt over the validity of any theory which seeks to prescribe a model of self for all.

Participants chose to communicate self as a shape, by scrunching all the elements up into one pile, as a circle, as a hierarchy of elements, or not at all. The majority communicated them hierarchically. Mental health was also a dominant theme in all participant communications of self. Indeed many communicated self in direct reference to mental health. For example, one participant- Michelle- created two selves- a ‘well’ and ‘poorly’ self- with a category of elements they felt were impacted or lost because of psychosis. Others explained how some of the most hierarchically important elements of self had become important because they had previously been lost or changed by mental health difference, and they either feared losing them again or did not appreciate their importance until they were gone/changed. Self and mental health were therefore closely intertwined in perceptions of self.

All participants bar two, said that they changed during or because of mental health experiences- some drastically, some less so. There were enough commonalities in which elements changed to outline them. These changed elements included: independence (leading them to become more dependent,) ability to work, identity, self-recognition and mutual recognition, power (both loss of power and empowerment,) memory (and recollection and reflection as they relate to memory) beliefs, values, reason and rationality (both loss of, and heightened reliance on.) Therefore, participants reported that the majority of elements were impacted by mental health, even though this was not the case on an individual level.

While a minority dissented, the majority of participants felt they did not become a new self during a mental health experience. According to participants, although self changes- sometimes drastically- the majority believe there exists continuity between selves making self continuous as opposed to periodic. This is with the exception of those with secondary experience of progressive mental health. If there is continuity between selves therefore, it seems difficult to justify a true self conception. If there is such a thing as a 'true self' it is possible therefore that it includes rather than juxtaposes mental health difference. For the majority, versions of self are not separated by impairment, impairment is part of self. For those who view self as periodic, it is possible a new true self with mental health is created. Moving away from a concept of self which equates 'true self' with 'unimpaired' helps conceptually justify Article 12 and awarding self with mental impairment full legal capacity.

This Chapter also provides suggestions on how social and legal theories can be rethought to be more inclusive of mental health. Ways in which theories on self could develop include awarding more consideration of mental health and disability- more specifically by focusing on the deconstruction and reconstruction of self in light of mental health experience and by challenging self as a stable identity. While an in depth overview of how social theory could incorporate disability is not within the scope of this thesis- briefly it is worth highlighting that deconstruction is the focus of many social theories-previously Jacques Derrida,[389] and more recently Judith Butler.[390] However the concepts of deconstruction and reconciliation may benefit from being considered in a disability context, specifically in terms of mental health as a catalyst for these processes and how this deconstruction/reconstruction plays out in a mental health context. Butler along with Goffman also already criticize the idea of a stable identity- Butler focusing on gender and queer issues[391] and Goffman on presentation and self as performative.[392] An existing example of this would include gender fluidity which surpasses gender norms. However, there may also be scope to pose self with mental health as a challenge to the 'stable' identity given how frequently mental health as a process of self-unmaking was discussed.

In regard to self-binding and whose wishes we ought to protect, it would appear self-binding cannot be justified on the basis of protecting the unimpaired true self for the majority. This is because self for the majority is continuous meaning no new self arises and because true self may in fact include self with mental health. If this is the case Article 12 is correct in ensuring the will and preference of a future self with mental health is respected. This seems to preclude any form of self-binding. While there may be conceptual justifications for self-binding therefore, it seems unlikely any justification could be made on the basis that someone has mental health difference and therefore any wishes they express are not representative of their 'true self.' This supports academics who advocate for the removal of the diagnostic criterion in assessments to restrict legal capacity, discussed in Chapter 5. As we shall see in Chapter 6 however, a group of participants do desire self-binding provisions in advance planning. However this justification cannot rely on problematic conceptions of self, and instead relies on protecting self and others from harm and the effect mental health has on decision making ability. Concepts of true self therefore do not create a barrier to CRPD compatibility for advance planning provisions.

The highly individual nature of self with mental health and how it translates into law, policy and social theory is challenging. Chapter 6 builds on the findings of this chapter to

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[389] Derrida first used the term 'deconstruction' in Jacques Derrida and Alan Bass, *Writing And Difference* (Routledge 2001). Jacques Derrida, *Voice And Phenomenon* (1967). Jacques Derrida and Gayatri Chakravorty Spivak, *Of Grammatology* (1st edn, Johns Hopkins University Press 1997). All published in 1967.

[390] See for example J Butler, *Undoing Gender* (New York; London: Routledge, 2004).

[391] See for example Judith Butler, 'Gender as Performance' in Osbourne Peter, *A Critical Sense: Interviews with Intellectuals* (London: Routledge, 1996).

[392] Erving Goffman, *The Presentation of Self in Everyday Life* (Penguin Books 1959)

suggest an alternative to mental capacity assessments in the form of a user-led statement on change in self. This is an attempt to reflect the individuality of self with mental health and move away from the divide line in social and legal theory.

The next chapter explores awarding self during a mental health experience full legal capacity, and Chapter 6 explores how participant's views on self carry into decision making.

Chapter 5: Awarding Self with Mental Health Difference Full Legal Capacity and adherence to harmful, incapacitous will and preference

Introduction

So far Chapter 1 has outlined that the CRPD does not justify privileging one version of self over another on the grounds that an individual is assessed as lacking mental capacity. The previous chapter also outlined that self with mental health does not support a 'true' self conception for the majority of participants. If this is the case, there exist fewer conceptual grounds for privileging one version of self over another. If the conclusion drawn from findings so far suggest that will and preference during a mental health experience should be listened to full stop, and advance plans should therefore only trigger once an individual has lost the ability to communicate, awarding self with mental health difference full legal capacity with support must therefore be explored.

This Chapter outlines one of the 'hard cases' for legal capacity- when an individual expresses harmful will and preference during a mental health experience which may be contrary to those previously expressed in a valid advance plan. This relates to the question of whether participants would want all will and preference to be adhered to, or whether some may wish to use self-binding to overrule incapacitous will and preference to protect themselves and others from harm.

This chapter provides an overview of how the CRPD, UN Treaty bodies and academics have responded to this kind of 'hard case' and whether and how CRPD compatibility may be maintained.

It goes on to draw on participant responses to the case studies outlined in Chapter 3 on John, Mary and Ken, and participants own experiences of decision making during a mental health experience. These responses are used to assess whether participants want *all* decisions made during a mental health experience to be awarded full legal capacity and how harm impacts this decision. This is to see whether the barriers identified in Chapter 1- respecting incapacitous will and preference, and in this Chapter- whether to uphold harmful will and preference contrary to a valid advance plan, do in fact resonate with participants and their experiences to provide justifiable barriers to compatibility. If they do, this provides grounds for engaging with more interpretive analysis of the CRPD and general comment no.1, as opposed to adopting a more absolute interpretation. This Chapter reflects on how concepts of self with mental health discussed in the previous Chapter influence findings and the future of CRPD-compatible advance planning. It also provides potential ways to overcome any affirmed barriers and achieve or improve CRPD compatibility for advance plans.

Harmful will and preference and the CRPD

Will and preference which could lead to harm to self or others is often cited by academics as one of the 'hard cases' for legal capacity, alongside an individual simultaneously expressing two contrary wishes.[393] Advance planning has the potential to be helpful in resolving both type of hard case. In regard to conflicting will and preference, the wishes in an advance plan could help determine which conflicting decision to adhere to. However

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[393] C. Bhailís and E. Flynn, 'Recognising Legal Capacity: Commentary And Analysis Of Article 12 CRPD' (2017) 13 International Journal of Law in Context, 16.

for the purposes of this chapter, discussion will be limiting to the first type of hard case involving harmful will and preference.

The CRPD provides little clarification in regard to what consideration, if any, harmful decisions should be given. In lieu of a firm answer two dominant standpoints have arisen, with many academics now trying to strike a balance between CRPD compatibility and intervention to protect the individual from harm.[394] On the one hand the CRPD has been interpreted to mean that individuals are to be supported and deterred from harmful decisions, but ultimately their decision stands.[395] This has been termed by Szmukler as an 'absolutist interpretation' of the CRPD.[396] This position has been criticized however in that it does not address situations where a person who desires support refuses support during a mental health crisis,[397] where a person is in imminent harm or about to make a decision with serious adverse effect,[398] or where wishes during a mental health experience do not reflect what might be considered the persons 'true' wishes.[399] In light of this, others believe there are some situations in which legal capacity must be restricted to protect the individual and others from harm.

This raises the question of whether and under what circumstances a state may overrule will and preference, under the CRPD.

Depending on which will and preference constitute an exercise of legal agency- discussed in Chapter 1- this may impact which harmful will and preference may be overruled. For example if it is decided that only decisions with legal consequence are protected as an exercise of legal agency, a harmful decision with legal consequence documented in an

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[394] For example see E. Flynn and A. 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 and A. Nilsson, *Compulsory Mental Health Interventions And The CRPD: Minding Equality* (HART Publishing 2021).

[395] This position has been adopted by the CRPD Committee in their General Comment No.1 and T. Minkowitz, 'The United Nations Convention On The Rights Of Persons With Disabilities And The Right To Be Free From Nonconsensual Psychiatric Interventions' (2007) 34 Syracuse Journal of International Law and Commerce.

[396] G. Szmukler, '"Capacity", "Best Interests", "Will And Preferences" And The UN Convention On The Rights Of Persons With Disabilities' (2019) 18 World Psychiatry.

[397] See E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 96.

[398] See M. Bach and L. Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' (2010) prepared for the Law Commission of Ontario. Available <https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf> Accessed 26th January 2021; E. Flynn and A. 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.

[399] See E. R. Saks, *Refusing Care* (1st edn, University of Chicago Press 2002) 204-205; R. Dworkin, *Life's Dominion* (HarperCollins 1995) 211-288.

advance plan may prove harder or be impossible to overrule compared to harmful wishes which lack legal consequence. Saks example of eating too many cookies comes to mind.[400]

If harmful decisions, including those contrary to decisions contained in an advance plan, are to be adhered to at all times, self-binding becomes problematic. However if there exist some situations in which a person with mental health difference wants to be overruled to protect self and others from harm, self-binding is one such way this could be achieved while catering to the individual nature of self and without relying on a mental capacity assessment. This is discussed in more detail in Chapter 6.

Discussion on overruling harmful will and preference centers on forced treatment and involuntary detention, which are justified in many domestic legislations on the basis of treating mental disorder and protecting self and others from harm. This includes the Mental Capacity Act and its interrelation with the Mental Health Act as outlined above.

First, in terms of the Committees stance on harmful will and preference and whether it should be adhered to, there is no clear answer.

On a strict reading of general comment no.1 on Article 12, and the Committee's guidelines on Article 14- 'the right to liberty and security of persons'- both involuntary detention and forced treatment of persons with disabilities are prohibited:

> "The involuntary detention of persons with disabilities based on risk or dangerousness, alleged need of care or treatment or other reasons tied to impairment or health diagnosis is contrary to the right to liberty, and amounts to arbitrary deprivation of liberty."[401]

Overruling harmful will and preference via detention or forced treatment, even during crisis situations, where it may be presumed mental capacity is even more diminished, is prohibited under Article 12.[402] To allow so would create a breech in other convention rights according to the Committee:

> "Forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement of

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[400] E. R. Saks, *Refusing Care* (1st edn, University of Chicago Press 2002) 205-206.

[401] United Nations Commission, 'Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities: The right to liberty and security of persons with disabilities' (adopted during the Committee's 14th session, September 2015) para 13.

[402] United Nations Commission, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 40, 42, 46.

> the rights to personal integrity (art. 17); freedom from torture (art. 15); and freedom from violence, exploitation and abuse (art. 16). This practice denies the legal capacity of a person to choose medical treatment and is therefore a violation of article 12 of the Convention."[403]
>
> "Recognition of legal capacity is inextricably linked to the enjoyment of many other human rights provided for in the Convention on the Rights of Persons with Disabilities, including, but not limited to… right to be free from involuntary detention in a mental health facility and not to be forced to undergo mental health treatment (art. 14)"[404]

The guidelines on Article 14 by the Committee outline that "[l]ike persons without disabilities, persons with disabilities are not entitled to pose danger to others. Legal systems based on the rule of law have criminal and other laws in place to deal with those matters."[405] Therefore in regard to overruling will and preference to protect others, this is to be dealt with via criminal law in the same way it is dealt with for those without disabilities[406]. Nilsson conducts a non-discrimination analysis on the legitimate aims of involuntary treatment and argues that harm to others is not a legitimate aim if measures are targeted at persons with psycho-social disabilities.[407] This is on the basis that there are many equally relevant factors in predicting future violence. Justification of differential treatment is therefore lacking.

Based on a strict interpretation of the Committee's general comment no.1 and its guidelines on Article 14, it seems removing the diagnostic criterion from legal mechanisms which justify forced treatment and detention is insufficient. In line with legal capacity, neither disability nor perceived deficits in mental capacity are justifications for restricting an individual's legal capacity to make decisions regarding treatment and detention. Removing the diagnostic criteria alone therefore is arguably insufficient in creating the kind of structural change needed, given those affected will likely be disproportionately persons with mental health difference. While the CRPD is clear that

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[403] Ibid para 42.

[404] Ibid para 31.

[405] United Nations Commission, 'Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities: The right to liberty and security of persons with disabilities' (adopted during the Committee's 14th session, September 2015) para 14.

[406] T. Minkowitz, 'Rethinking criminal responsibility from a critical disability perspective: The abolition of insanity/incapacity acquittals and unfitness to plead, and beyond' (2014) 23 Griffith Law Review.

[407] A. Nilsson, *Compulsory Mental Health Interventions And The CRPD: Minding Equality* (HART Publishing 2021) 61, 130-131.

disability alone cannot be used to justify compulsion, there remains some debate as to whether disability in conjunction with other factors would provide justification. For example, disability in conjunction with risk of serious self harm.[408] The CRPD Committee guidelines on Article 14 (liberty and security) however say otherwise: "…legislation of several States parties, including mental health laws, still provide instances in which persons may be detained on the grounds of their actual or perceived impairment, provided there are other reasons for their detention, including that they are deemed dangerous to themselves or to others. This practice is incompatible with article 14 as interpreted by the jurisprudence of the CRPD committee. It is discriminatory in nature and amounts to arbitrary deprivation of liberty."[409]

Another possible insight into the Committee's stance on legal capacity and harm which moves away from an absolutist interpretation is provided in their concluding observations of the state report from Australia in September 2019. In their report the Committee recommends the state "implement a nationally consistent supported decision-making framework, as recommended in a 2014 report of the Australian Law Reform Commission [ALRC] titled *Equality, Capacity and Disability in Commonwealth Laws*."[410] The ALRC report is the most detailed law reform proposal on supported decision making and legal capacity to be advanced in the operationalisation of the CRPD. Therefore it provides crucial detail lacking in the general comment by which to gauge CRPD compatible law reform. The supported decision making framework recommended is part of a reform proposal based on four National Decision Making Principles. One of these concerns 'will, preferences and rights' and states that "[w]here a representative is appointed to make decisions for a person who requires decision-making support…. [a] representative may override the person's will and preferences only where necessary to prevent harm."[411] The ALRC proposal is therefore distinct from supported decision making under the general comment, as it allows will and preference to be overruled where decisions are harmful. Ruck Keene feels the endorsement of this proposal may reflect the changing

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[408] Ibid 45-49.

[409] United Nations Commission, 'Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities: The right to liberty and security of persons with disabilities' (adopted during the Committee's 14th session, September 2015) para 6.

[410] Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third periodic reports of Australia,* CRPD/C/AUS/CO/2-3 (15 October 2019) available at https://digitallibrary.un.org/record/3848618?ln=en para 24.

[411] Australian Law Reform Commission, 'Equality, Capacity And Disability In Commonwealth Laws (ALRC Report 124)' (2014) available at https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/3-national-decision-making-principles-2/will-preferences-and-rights-2/.

composition of the Committee which may have in turn changed their position since drafting General Comment No.1.[412]

The ALRC argue that overruling will and preference to prevent harm is consistent with a human rights-based approach and the CRPD- where will and preference conflicts with the right to physical and mental integrity.
The approval by the Committee of the AHRC’s proposal therefore, may provide proxy consent to overrule will and preference where necessary to prevent harm. This however is far from confirmation that will and preference may be legitimately restricted in scope under the CRPD.

Finally, it is worth noting the provisions of Article 12(4) appear to provide safeguards for the restriction of legal capacity. Article 12(4) reads "[s]uch safeguards shall ensure that measures relating to the exercise of legal capacity…apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.”
If there were no situations in which decision making could be restricted on the basis of incapacity, this begs the question of why 12(4) is worded in such a way as to seemingly go beyond support to discuss restrictions. It appears therefore that the CRPD foresaw some legitimate restrictions to legal capacity.

UN Treaty Body Interpretations of Article 12 and its Relation to Harm

In terms of how other UN treaty bodies set up to monitor human rights instruments have interpreted legal capacity in relation to harm, some support an absolutist ban on involuntary detention and forced treatment. There are others however who believe the CRPD did not mean for a total ban- but that disability *alone* could not be used to justify compulsion- whereas disability in conjunction with other factors, including harm, could be.

Interpretations supporting a more absolutist interpretation include the UN High Commissioner on Human Rights 2017 report ‘Mental Health and Human Rights’ which states that "[f[orced treatment and other harmful practices, such as solitary confinement, forced sterilization, the use of restraints, forced medication and

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[412] A. Ruck Keene, 'The CRPD Committee And Legal Capacity – A Step Forwards?' <https://www.mentalcapacitylawandpolicy.org.uk/the-crpd-committee-and-legal-capacity-a-step-forwards/> accessed 10 June 2021.

overmedication…not only violate the right to free and informed consent, but constitute ill-treatment and may amount to torture."[413]

In 2014 the former Special Rapporteur on Disability Mr Shuaib Chalklen, wrote an urgent request to amend the Human Rights Committee's draft version of General Comment No. 35 on Article 9 (Right to liberty and security of person) of the ICCPR, to bring it in line with the CRPD.[414] Mr Chlaklen states: "[m]ental health detention and compulsory treatment are serious human rights violations that cannot be condoned under any circumstances."[415]

The former Special Rapporteur on the Right of Persons with Disabilities - Ms Catalina Devandas-Aguilar, on her report on her mission to Republic of Moldova recommended Moldova "[i]mmediately halt any coercive intervention or treatment in mental health or any other settings without the free and informed consent of the persons concerned."[416]

The 2021 WHO report on 'Guidance on Community Mental Health Services' also takes a strict interpretation of the CRPD by promoting non-coercion and providing a set of actionable fronts alongside advocating for a change to law and policy.[417]

This position however has not been shared by all UN treaty bodies. The Human Rights Committee in General Comment (No. 35) on Article 9 of the International Covenant on Civil and Political Rights - the 'Liberty and Security of Persons,' state that:

> "The existence of a disability *shall not in itself justify a deprivation of liberty* but rather any deprivation of liberty must be necessary and proportionate, for the

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[413] UN OHCHR, 'Mental health and human rights: Report of the United Nations High Commissioner for Human Rights' (2017) A/HRC/34/32 para 33.

[414] UN Human Rights Committee, '*General comment no. 35, Article 9 (Liberty and security of person)*' (16 December 2014) CCPR/C/GC/35, available at: https://www.refworld.org/docid/553e0f984.html [accessed 16 May 2021]

[415] UN Special Rapporteur on Disability, 'Urgent request to amend the Human Rights Committee's draft version of General Comment No. 35 (CCPR/C/107/R.3) on Article 9 (Right to liberty and security of person) bringing it in line with the UN Convention on the Rights of Persons with Disabilities' (27 May 2014) available at: https://www.ohchr.org/Documents/HRBodies/CCPR/GConArticle9/Submissions/SRDisability.doc

[416] C. Devandas-Aguilar , 'Report of the Special Rapporteur on the rights of persons with disabilities on her mission to the Republic of Moldova' (2 February 2016) A/HRC/31/62/Add.2 para 67(b).

[417] WHO, 'Guidance On Community Mental Health Services: Promoting Person-Centred And Rights-Based Approaches' (2021) <https://www.who.int/publications/i/item/9789240025707> accessed 7 January 2022, 7-9.

> purpose of protecting the individual in question from serious harm or preventing injury to others."[418]

This interpretation is echoed by the Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, who state that:

> "Any deprivation of liberty must be necessary and proportionate, for the purpose of protecting the person in question from harm or preventing injury to others." [419]

Both approaches recommend detention be the least restrictive option and be accompanied by procedural and substantive safeguards.

Signatory states to the CRPD also support this position and say as much in declarations and reservations made upon ratification. The majority of domestic mental health law permits compulsory intervention where a person with psychosocial disability is refusing treatment professionals believe they require, and the person either lacks decision making ability, or there is a risk of a serious deterioration in health, self harm, the harming of others or a combination of these factors.[420] Harm therefore plays a dominant role in overruling will and preference.

There are currently twelve declarations or reservations concerning the lawfulness of compulsory care under the CRPD from Australia, Canada, Egypt, Estonia, France, Norway, Georgia, Kuwait, Netherlands, Poland, the Syrian Arab Republic and Venezuela. For example, Australia, Norway, Ireland and the Netherlands "declares its understanding that the Convention allows for compulsory assistance or treatment of persons, including measures taken for the treatment of mental disability, where such treatment is necessary, as a last resort and subject to safeguards."[421]

While there is disagreement therefore, there does seem to be more support amongst UN Treaty Bodies that disability alone is insufficient to justify compulsion; however some

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[418] United Nations Human Rights Committee, 'General Comment No. 35 - Article 9: Liberty and Security of Person' (16 December 2014) CCPR/C/GC/35, para 19.

[419] Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment , 'Approach of the Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment regarding the rights of persons institutionalized and treated medically without informed consent,' (26 January 2016) CAT/OP/27/2 para 11.

[420] A. Nilsson, *Compulsory Mental Health Interventions And The CRPD: Minding Equality* (HART Publishing 2021) 45-49.

[421] 'UN Treaty Collection' (*Treaties.un.org*, 2021) <https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-15&chapter=4&clang=_en> accessed 10 June 2021.

compulsion may be justified to pursue other legitimate aims, including protecting the individual from harm.

Academic Interpretations of Article 12 and its Relation to Harm

Scholarly interpretations, as is the case with the scope of legal agency, also vary. It varies in regard to what circumstances legal capacity may be restricted and the level of intervention which may be justified.

Flynn and Bhailis believe Article 12 would not prohibit all forms of state intervention which could lead to denials of legal capacity, so long as they are "applied on an equal basis, and do not constitute direct or indirect discrimination against people with disabilities."[422] They build on Gooding and Flynn's previous article on expanding the doctrine of necessity to legitimately restrict legal capacity,[423] and argue that a state actor has a duty to intervene where there is 'imminent and grave harm to life, health of safety.'[424] By 'state actors' they are here referring to "an agent of the state acting with powers or protection from liability guaranteed by the state including social services, law enforcement and public health professionals."[425] They highlight how state intervention may be needed to enable the state to offer support[426] and that risk of imminent harm is a necessary but not always a sufficient criterion to justify intervention.[427] They also provide examples of the kinds of interventions which can be justified against the individuals will and preference, including the power to enter a person's home where a risk of imminent and grave harm is identified; the removal of a dangerous object from an individual in immediate danger; and the physical removal of an individual in imminent danger i.e. preventing a person from jumping off a roof.[428] In determining when intervention may be justified, the state should rely on the proportionality test to establish that 1. their aim is legitimate and 2. the intervention is proportional i.e. the least intrusive option. Nilsson

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[422] C. Bhailís and E.Flynn, 'Recognising Legal Capacity: Commentary And Analysis Of Article 12 CRPD' (2017) 13 International Journal of Law in Context, 16.

[423] P. Gooding and E. Flynn, 'Querying The Call To Introduce Mental Capacity Testing To Mental Health Law: Does The Doctrine Of Necessity Provide An Alternative?' (2015) 4 Laws.

[424] E. Flynn and A. 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, 49.

[425] Ibid 49.

[426] Ibid 42.

[427] Ibid8 50.

[428] Ibid.

goes on to develop this proportionality test to provide states with practical guidance on when a coercive measure retains compatibility with the CRPD.[429]

Flynn and Arstein-Kerslake permit detention but prohibit forced treatment, due to the wealth of literature on its negative impacts from service users and survivors. They also discuss the potential for support persons to remove an individual from a harmful situation, against their express will and preference, in order to assist the individual in getting to a place where they can better communicate their 'true' will and preference.[430] This only applies to emergency situations or when adhering to will and preference would constitute criminal or civil negligence. Indeed Flynn and Arstein-Kerslake acknowledge that supporters should be allowed and even expected to make the baseline assumption that an individual would not choose to be in a situation in which they were being harmed.[431]

Bach and Kerzner also propose a restriction to legal capacity based on pre-emptive intervention to prevent 'serious adverse effects.' This includes admitting the individual to a psychiatric facility for assessment and/or treatment, against their will and reference, where a person has facilitator status and is engaging in decisions, or is in a situation which engages, serious adverse effect.[432] This is subject to a tribunal hearing to challenge facilitator status.

Serious adverse effects include "when a person, as a result of his/her actions or those of others:

> a) Experiences loss of a significant part of a person's property, or a person's failure to provide necessities of life for himself or herself or for dependants; or
> b) Experiences serious illness or injury, and deprivation of liberty or personal security; or
> c) Has threatened or attempted or is threatening or attempting to cause physical and/or psychological harm to himself or herself; or

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[429] A. Nilsson, *Compulsory Mental Health Interventions And The CRPD: Minding Equality* (HART Publishing 2021).
[430] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 99.
[431] Ibid 98.
[432] L. Kerzner and M. Bach, 'A New Paradigm For Protecting Autonomy and the Right to Legal Capacity' (Law Commission of Ontario 2010) 140.

> d) Has behaved or is behaving violently towards another person or has caused or is causing another person to fear physical and/or psychological harm from him or her."[433]

Facilitator status means "others facilitate the making of needed decisions" and is awarded when an individual is unable to act legally independently.[434] This means they 'lack the ability by themselves or with assistance, to understand information that is relevant to making a decision and to appreciate the reasonably foreseeable consequences of a decision;'[435] and there are no others with personal knowledge of that individual "to understand their ways of communicating their will and/or intentions as a basis for decision-making (as in a supported status)."[436] It also applies to people who lack legally independent status and have created an advance planning document and to those who do have others in their life, but these others are unable to determine their will and preference sufficiently to guide decision making.[437]

Bach and Kerzner's model differs from Arstein-Kerslake and Flynn's in that it permits treatment against will and preference in some situations where a person has facilitator status, and allows for pre-emptive action to prevent harm.

Other academics retain a mental capacity assessment minus the diagnostic requirement. Dawson and Szmukler believe that having a disproportionate effect on one group of people does not amount to indirect discrimination so long as 1) the aim is legitimate 2) the criteria are objective and 3) the criteria are reasonable in light of the aim.[438] They use the example of people with cognitive disabilities being disproportionately impacted by the training requirements needed to become a doctor, without this constituting indirect discrimination.[439] Dawson and Szmukler also widens the scope of intervention beyond imminent risk of direct harm, to include any 'preferences' made during an episode which contradict a person's previously expressed 'will.' They draw a distinction between the meanings of the two words to justify self binding.

'Will' is the "manifestation of a person's deeply held, reasonably stable and coherent personal beliefs, values, commitments and conception of the good," and characterizes

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[433] Ibid 133.
[434] Ibid 91.
[435] Ibid 97.
[436] Ibid 91.
[437] Ibid.
[438] George Szmukler, '"Capacity", "Best Interests", "Will And Preferences" And The UN Convention On The Rights Of Persons With Disabilities' (2019) 18 World Psychiatry, 37.
[439] Ibid.

personal autonomy; compared with ‘preferences’ which include desires and inclinations.[440] An advance plan upholds ‘will’ and therefore can be used to overrule contrary ‘preference’ during a mental health experience. This is reminiscent of the position adopted by Dworkin on critical versus experiential interests and a true self conception, as outlined in the previous chapter. The conception of self with mental health this adopts may be representative for some but not all. Therefore an advance plan risks binding someone’s new ‘will’ formed during mental health by mistaking it for ‘preference.’ The CRPD Committee also do not draw a distinction between ‘will’ and ‘preference’ and instead always refer to ‘will and preference’ as a single phrase.

Scholars are also concerned that adhering to will and preference regardless of harmful consequence could lead to violations of other core human rights, including the right to life and the highest attainable standard of health.[441] How to balance competing rights under the CRPD is ultimately unclear.[442]

There is also the question of whether Article 16 of the CRPD - ‘freedom from exploitation violence and abuse’ - would limit the scope of legal capacity under Article 12 if it were interpreted to include freedom from self-inflicted violence. Keeling advises against using Article 16 to curtail the rights of Article 12 stating “safeguarding mechanisms which disempower the individual do not work to prevent future harm; in order to be effective, protective mechanisms must work towards enhancing and supporting individuals legal capacity.”[443] Public interest may also bear relevance on whether serious self harm and suicide should be permitted. There is recognition of the principle of public interest in criminal cases concerning consensual harm, and whether the level of consensual harm undertaken exceeds that which should be allowed for the sake of public interest.[444] Therefore, it is not a stretch to imagine that allowing someone to engage in serious self-harm or suicide where support has failed under an absolutist interpretation of the CRPD, may go against public interest.

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[440] Ibid 38.

[441] Melvyn Colin Freeman and others, 'Reversing Hard Won Victories In The Name Of Human Rights: A Critique Of The General Comment On Article 12 Of The UN Convention On The Rights Of Persons With Disabilities' (2015) 2 The Lancet Psychiatry.

[442] This is also the case with existing law, for example reasonableness tests, where there are many textual considerations which can conflict and must largely be resolved by the individual decision-maker.
F. Schauer, 'Balancing, Subsumption, And The Constraining Role Of Legal Text', *Institutionalized Reason* (Oxford University Press 2012).

[443] A. Keeling, 'Article 16: Freedom From Exploitation, Violence And Abuse', *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (1st edn, Oxford University Press 2018) 489.

[444] See for example *R v Brown* [1993] UKHL 19; *Attorney General’s Reference* [I9921 2 All ER and *Re v Donovan* [1934] 2 KB 498.

There is also the question of morality. As stated by Szmukler in his submission to general comment No.1 "…this goes against a widely held moral intuition that sometimes others ought to step in when a person who is clearly unable to make a judgment about their predicament is faced with a serious threat to his or her well-being."[445] A wealth of literature exists around the morality of suicide and the (ir)rationality of self harm and suicide. This ranges from a libertarian approach which believes in a right to suicide and non-interference,[446] to approaches which believes suicide to be morally wrong, including the deontological or 'sanctity of life' account, the Thomistic natural law position, and various role-based arguments- that the individual must stay alive to repay society socially and economically. Minkowitz defends the absolutist interpretation of Article 12 as non-libertarian, as rather than leaving people to die it advocates for non-coercive support to deter people from harmful decisions.[447] However this does not address the issue of how to distinguish between rational and irrational harm under the CRPD.

If a person experiencing psychosis believes they have to refuse life saving medicine because medical professionals are trying to poison them, Article 12 offers no solution if support is rejected or fails to change the individual's opinion. This is despite this harm being based on false or delusional realities. As stated by Emily Jackson "[i]t will also often be necessary to distinguish between wishes which reflect a person's core values, and wishes which instead are the result of delusions, phobias or addictions. Not 'all statements about "what I want"' are, in fact, 'meaningful acts of "will".'[448] According to Callaghan and Ryan "[e]quating autonomy with a bare expression of will gives rise to serious practical and ethical concerns, that currently at least, the theory has no response to."[449] Many theories on rational suicide therefore either exclude mental health expressly, or include indicators to this effect.[450] Allowing potentially irrational suicide where mental health is impacting reasoning therefore, is theoretically and morally problematic.

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[445] George Szmukler, 'Submission to Committee on the Rights of Persons with Disabilities on the Draft General Comment on Article 12' (19 Feb 2014).

[446] See for example T. Szasz, '*Fatal Freedom: The Ethics and Politics of Suicide*' (2002) Syracuse University Press.

[447] T. Minkowitz, 'CRPD And Transformative Equality' (2017) 13 International Journal of Law in Context, 82, 85.

[448] E. Jackson, 'From 'Doctor Knows Best' To Dignity: Placing Adults Who Lack Capacity At The Centre Of Decisions About Their Medical Treatment' (2018) 81 The Modern Law Review, 270 paraphrasing S. M Callaghan and C. Ryan, 'Is There A Future For Involuntary Treatment In Rights-Based Mental Health Law?' (2014) 21 Psychiatry, Psychology and Law, 755.

[449] S. M. Callaghan and C. Ryan, 'Is There A Future For Involuntary Treatment In Rights-Based Mental Health Law?' (2014) 21 Psychiatry, Psychology and Law, 755.

[450] For example the impact of mental health difference on the decision to commit suicide is used by Brandt to morally excuse an objectively wrong suicide in R. Brandt, 'The Morality And Rationality Of Suicide', *A Handbook for the Study of Suicide* (1st edn, Oxford University Press 1975) 317.

To summarise, there is a lack of any explicit determination in the CRPD itself on which decisions fall within the scope of legal agency and whether harm constitutes a legitimate restriction to legal capacity. Interpretations from the Committee, other UN Human Rights bodies, states and scholars also differ. In light of there being no firm conclusion therefore, participant feedback based on their own experiences of decision making during a mental health experience will prove invaluable to gaining a new perspective on these questions. The next section explores the responses of participants with first and second-hand experience of a variety of mental health experiences, on decision making during this period. Specifically, it will outline whether participants want decisions made during a mental health experience to be awarded legal capacity and how harm impacts that decision.

Findings: Do Participants want all Decisions Made During a Mental Health Experience to be Enforced at Law?

Based on the discussion of will and preference in Chapter 1, it would appear the CRPD is in favor of adhering to will and preference expressed during a mental health experience including during crisis. This seems to render any self-binding properties in an advance plan ineffective, given any wish made contrary to those contained in an advance plan are to be adhered to. There may however be some situations in which an individual would want their advance plan to be adhered to over their current will and preference.

Participants were therefore asked to reflect on whether they would want will and preference made during a mental health experience to be legally enforceable based on their own experience.

This is to affirm whether participants desire for some form of self-binding provision and whether there is therefore some tension therefore between how the CRPD envisages advance plans to operate versus how participants would like them to work as a method of support. If self-binding is desired and this request is justified based on participant experiences, it becomes harder to justify an absolutist application of the CRPD at the expense of desired and quality support. More interpretive analysis of the CRPD may need to be engaged. The vignettes used to facilitate discussion specifically focused on individuals during mental health experiences, making decisions which were contrary to those in a previously stated advance plan. These vignettes feature John, Mary and Ken and are referenced in full in Chapter 3.

Case study vignettes of situational decision making during mental health difference were read to participants in an attempt to draw out reflection on their own experiences of decision making during a mental health experience. The case studies were hypothetical but based on potential real-life occurrences. The case studies purposefully included several factors which may influence participant views on whether a decision should or should not be adhered to. These included the type of decision, the impact of mental health on change in self, the role of others, undue influence and different types of possible harm. It is the responses from these case studies which have informed this chapter.

Participant Responses to the Case Studies

During analysis, the responses of those who shared similar experiences/diagnosis with the vignettes subject were privileged. This was because of their shared experience with the case study subject, because they could provide unique insight into the mind of self during that experience, and how self would feel after that experience had ended (where applicable.)

First, all 25 participants interview provided some feedback to John's vignette. John's case study involved an elderly man with late-stage dementia who had created an advance care plan to refuse non-kosher food products, including pork, in line with his religious beliefs of fifty plus years. One day when asked what he wanted for breakfast, John replies that he would like a bacon sandwich. John says he wants to know what bacon tastes like and remembers making an advance plan. The question posed to participants was whether they would give John the bacon sandwich. Not only does this case study therefore involve contrary wishes to those contained in an advance plan, but also questions of John's beliefs and identity. Of those 25, 4 had shared experienced with John in that they were in the early stages of a progressive mental health difference. This included Olive and Betty who had early-stage dementia, Sandra who had progressive memory loss caused by a stroke, and Robert who had undiagnosed memory loss suspected to be Alzheimer's. There were also two spousal carers- Samantha and Molly, who cared full time for husbands with FTD and dementia respectively, and therefore had second-hand experience of change in self and decision making during a mental health experience. 3 of the 25 also had experience helping care for family members with progressive mental health difference including Klein, Daria and Steph. 11 of the 25 participants who provided responses answered in the affirmative- that they would adhere to John's contrary wish and give him the bacon sandwich. This is despite this being opposed to his previously held religious beliefs. This included 3 of the 4 participants with shared experience, with the exception of Sandra who felt the advance plan should overrule his current wishes. 6 of the 25 said they would not go against the advance plan and therefore would not give John the bacon sandwich. 4 were unable to decide one way or the other including Samantha who placed decision making onerous on John's family. 2 participants- Jessie and Molly- sought alternatives to bacon including turkey and veggie bacon in the hope that both John's wishes (in part) and the advance plan would both be appeased; and 2 sought to try John with an alternative, which if he refused would be replaced with the originally requested bacon sandwich. In this way support in decision making was framed as a test of mental capacity. The majority therefore felt that John's advance plan should be overruled and his current contrary wish upheld. Whilst not unanimous, this majority does seem to uphold a more CRPD compatible view of decision making during a mental health experience.

Mary's case study involved an elderly woman who had memory loss. Mary wished to remove grandchildren from her will who she no longer recognised, and instead wished to spend that money on buying costly figurines. Mary has begun collecting these figurines as they bring her happiness. If she continues to spend the amount of money she currently does however she may have to move to another more affordable residential care home, which is considered not as nice as the one Mary has resided in for the past seven years. The questions posed to participants therefore were whether Mary's will should be changed as per her request, and whether she should be allowed to continue buying figurines. Of the 7 participants who provided responses, 4 had shared experience with Mary (Olive, Betty, Sandra and Robert,) 2 were carers for those with late-stage dementia (Samantha and Molly) and 1 had no shared experience (Nicole.) Olive, Betty, Sandra and Robert all felt Mary's will and preference in both cases should be upheld- she should be able to change her will and continue buying figurines. However it was not clear from their conversation whether this group made changes to her will contingent on mental capacity:

> "Sandra:...if I go by what it says here, and she does have a lack, but when she's on one of her good sessions, she should be, it's her, you can change your will."

They wanted more information on whether those who saw her regularly thought she was on a 'good day,' so the contingency of capacity may depend on what they mean by 'having a good day.' Of the remaining participants, Molly wanted to encourage Mary to buy cheaper figurines as an alternative, to appease Mary, her advance plan and her family. Both Molly and Samantha did not think Mary should be allowed to change her will; and Nicole was ultimately unable to decide whether her current will and preference should be adhered to.

The final case study concerned Ken, a man with psychosis who experiences delusions in which he believes himself to be a messenger of God. Ken has an advance directive refusing treatment Y and an advance plan requesting he receive any mental health treatment at home. During an episode Ken has a tendency to self-harm and Ken's relevant clinician wants to treat Ken with treatment Y in hospital where he believes risk of harm to Ken will be minimized. The questions posed to participants were whether Ken should be given treatment Y and whether he should be treated at home as per his advance plan. 10 participants responded to Ken's case study. Of those 10, 2 had the same diagnosis as Ken (Simon and Nicole); 1 had very similar experience to Ken via psychotic episodes during manic bipolar (Michelle); 1 had diagnosis' characteristic of having distinctive episodes like Ken's (Peter (schizophrenia)); 2 had secondary experience of caring for a family member with episodic mental health difference (Michelle's dad Joseph and Lulu); and the remaining 4 had no/little shared experience with Ken.

Regarding whether Ken's wish to be treated at home should be upheld, Simon, Nicole and Peter thought his wish should be overruled and he should be treated in hospital as per the clinician's recommendation; those with secondary experience- Lulu and Joseph- agreed. Michelle thought Ken's will and preference should be upheld; and of the 4 with no shared experience, 3 felt it was Ken's wife's decision and 1 was unable to come to a decision. The majority therefore wanted to overrule Ken's wish to be treated at home.[451]

Regarding Kens advance directive to refuse treatment Y, Nicole thought that in lieu of an alternative, his advance directive should be overruled and he should be given treatment Y; this view was echoed by Lulu and 1 of the four with no shared experience; Simon, Peter and Michelle felt his advance directive should be upheld, as did Joseph; 2 of those with no shared experience felt his directive should be upheld and 1 was unable to provide an answer due to time constraints. A majority were therefore in favor of upholding Ken's advance directive. If Ken is being treated under the Mental Health Act participant responses reflect a stricter position than that currently adopted by the Mental Capacity Act- which allows advance directives to be overruled. The government white paper on the

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[451] Something to note is the loose use of the word 'majority' when discussing these findings. None of the responses demonstrate a particularly strong majority as there are many different factors which go into individual decision making, including their own experience of mental health. There is no 'right' answer as the question of contrary wishes operates within a morally grey area of law, one of the reasons this area is so challenging.

proposed reform of the Mental Health Act introduced Advance Choice Documents.[452] These Advance Choice Documents can contain decisions about treatment refusal like advance directives but create a higher threshold to overrule refusals compared with advance directives and how they currently interact with the Mental Health Act. More on these proposals is discussed in Chapter 7. Participant responses therefore support the introduction of this higher threshold.

Overall then, the majority of participants were in favor of adhering to the will and preference of those with progressive mental health difference.

Some of the dominant reasons given by participants as to why decisions during a mental health experience should be adhered to include that people should retain the right to change their mind and may be unequipped to bind a decision for a future, and in some cases, unfamiliar situation. This is a well documented concern around advance directives in literature, as discussed in Chapters 1 and 4. As stated by Dresser: "[d]decisions about the future health care that will advance their interests are inextricably intertwined with their current conceptions of the good. But people experiencing various life events, including set-backs in their physical and mental functioning, may revise their goals, values, and definitions of personal wellbeing. As a consequence, their notions of a life worth living can be modified as well. As long as individuals remain competent, they can incorporate their transformed ideas into the decisions they make. But incompetent patients lose this opportunity."[453] Examples of people adjusting their will and preference away from more long-standing decisions are provided in decision making literature.

Christensen-Szalanski's study examined the attitudes of 18 pregnant woman on the use of anesthesia during active labor, one month prior to, during and one month post labor. Findings show a drastic change in preference at the start of hard labor in favor of receiving the anesthetic to avoid pain. During pre and post-partum however, many women wanted to avoid the use of anesthesia. According to Christensen-Szalanski, this "…implies that a patient's preference varies with the passage of time, and that during certain periods of time a patient's values may not be representative of his or her long-term preference."[454]

For this reason, many participants were concerned that advance planning provisions could be more harmful than helpful and expressed concerns about decisions being 'set in

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[452] Department of Health and Social Care, Reforming the Mental Health Act (Cm 355, 2021).

[453] R Dresser, 'Life, Death And Incompetent Patients: Conceptual Infirmities And Hidden Values In The Law' (1986) 28 Ariz. L. Rev. 379.

[454] J. J. Christensen-Szalanski, 'Discount Functions And The Measurement Of Patients' Values' (1984) 4 Medical Decision Making, 47.

stone.' They discussed the importance of listening to the individual at the time a decision is being made:

> "If it was me making the advance plan, I'd be really super careful to the point of not doing it, because I'd want people to make that decision at the point, rather than…when things were totally different, and…a lot of things can change, well in 6 months a lot of things can change… I can't see why- if you've got the right team around you, why the decision can't be made at that point rather than have it set in stone" [Joseph]

> "I think an advance plan is best used as a guide…I think the patient should always come first over any type of advance plan" [Simon]

This seems to support a strict interpretation of the CRPD in that advance plans should only be used when the individual is unable to make any expression of will and preference.

Participants also felt that self during a mental health experience should still be accorded the same rights and same 'decency' in their decision making as others:

> "…if that's what he wants, it's just a level of dignity you've got to give people regardless of whether they're ill or not" [Michelle, bipolar with psychotic episodes]

> "…it's down to human rights as well, that's what the argument is in the care sector, it's their right and choice to change their mind, whether they're of sound mind or not" [Ella, bipolar]

> "…you have to respect his wishes, okay I know there's a religious aspect to it, and probably a family aspect to it, but, I think your taking away, his liberty …and I think you still have to treat- although he might have Alzheimer's and Dementia- he's still a person, he's still John no matter what…" [Klein, depression]

This idea of respecting will and preference equating to respect for the person is reminiscent of a continuous self discussed in Chapter 4- that even during crisis the person remains, and their will and preference should be respected.

A desire for self-binding?

There were therefore compelling reasons provided by participants as to why will and preference made by self during a mental health experience should be respected in line with a CRPD compatible model of decision making. That being said there were participants who dissented. The strongest voice of dissent came from those with secondary experience of progressive mental health difference including dementia and Alzheimer's, and those who experienced the most drastic changes in self because of mental health. Notably these include participants who have a diagnosis of psychosis and bipolar characterized by manic episodes.

Regarding the former, carers for persons with mental health which could be characterized as progressing over time, stressed the value of substitute decision making which currently comes in the form of a lasting power of attorney. This was mainly discussed in the context of financial decisions, but also included welfare decisions. Carers felt their loved ones were simply no longer capable of making many of these decisions for themselves. They also discussed the difference between more individual versus collective decisions which involved people other than the individual. For example lasting powers of attorneys for financial decisions were also discussed as being necessary to protect not just the individual but the individual's family- for example to protect against unwise financial decisions involving jointly owned homes, joint bank accounts or where family make up the shortfall in residential care costs. Lasting powers of attorney were therefore considered necessary to protect both the individual and their family from emotional and financial harm.

A minority of participants, including many of those who related their own experiences to Ken's vignette, acknowledged situations where they would want their decision making during a mental health experience to be overruled. This was based not on a hypothetical formulation of what they *might* want, but of what they do want based on past experience. This group of participants were the same group identified in Chapter 4 as experiencing drastic changes in self because of mental health. These participants provided several reasons for this. Mainly these reasons related to how self changed with mental health difference and how those changes impacted decision making. Participants discussed self during crisis becoming short-sighted and basing decisions on short term pleasure and satisfaction. They also discussed self losing reason and rationality, therefore becoming less able to weigh up the long-term consequences of a decision and making decisions uncharacteristic of self pre-mental health experience. Finally, they spoke about having to deal with the aftermath of a decision once the episode had ended including the confrontation and management of harmful consequences. Indeed, some of this damage is irreparable. These changes make their self during a mental health experience less capable of making some decisions, or more likely to make decisions they would not otherwise have made and which they consider unwise or harmful. These participants therefore desired some form of self-binding provision.

> "Yeh, so I remember during hospital, the things I did- I'm glad somebody stopped me…from doing what I was doing, cause looking back I'm like oh god I'm so happy the person was forceful enough to tell me no! [talk laughs] because at that moment I was very angry about her…you...don't care about the future anymore, you just want happiness now, and the whole concept of well I have a future to plan for, you're like- well why can't I be happy today, yeh there was that whole thing with me as well where I lived in the moment and I didn't really think about the future" [Nicole, psychosis]

> "[S]ome of the decisions I've made over the past when being manic, [sighs] it's something that helped diagnose [me] with bipolar because they're so out of character…some of the things I've done I wouldn't even [nervous laugh] necessarily like to bring up…in terms of sexual partners and things, and like, actually cheating on people, things I'd never dream of doing normally, and, me not really understanding afterwards, why I brought myself to do it… I think when I'm manic, reason and rationality goes completely out of the window.. when I'm not manic, I'll control like my behaviours and how I [make] decisions…but when I'm manic…completely [goes out of the window], does not matter what I believe in or, what I've been taught right or wrong, and if, it makes sense to do it or if it's wise, if it's going to get me in stupid amounts of debt.. none of that matters [laughs] I do it anyway…" [Daria, bipolar]

Other participants also shared experiences of harmful or unwise decision making which could be described as self-harmful, during a mental health experience. This was discussed in one of the themes in how self changes with mental health discussed in Chapter 4- namely 'dissociation and compartmentalization.' An example of this provided by other participants with experiences of episodes include Jessie's experience of being more likely to make decisions which fuel addictive behaviours:

> "…addictive behaviours, inappropriate relationships- not in the last 10 years but certainly looking back, choosing violent partners, addictive shopping, you name it I've done it and I'm aware that person lives inside me…"

In relation to advance planning provisions then, both Nicole and Daria expressed views that they would want to be able to self-bind some decisions:

> “I think some demands if you’re in that episode, can be overruled and allow the person to be frustrated through it, because the episode will come to an end and the person will be like ‘oh what happened what did I say,’ and picking up your actions and consequences later is more painful than actually the frustration during the episode, so I think yeh, just hold on for them to let it all out, so for example if you had someone with letters they wanted to post, let them post them but keep them maybe, and then ask them towards the end, are you sure you want these posted…things like that” [Nicole, psychosis]

> “For me [I would listen to] the one who you knew was of sound mind, as long as you make sure they’re of sound mind when they put that plan in place, for me you listen to that because that’s their, I mean if you’re not, in, a proper sound mind, and you’re not fully in control of, what you’re doing, the plans in place so that they don’t make decisions that they wouldn’t normally do when they’re in that state” [Daria, bipolar]

These findings - that a minority of participants, particularly those who experience drastic changes in self because of mental health and their decision making, desire some form of self-binding – is supported by other research findings. In Gergel et al’s 2021 study 82% of the 565 participants who completed an online survey through Bipolar UK, endorsed self-binding directives.[455] 89% justified this on the basis of an adverse change in decision making ability towards distorted thinking.[456] Stephenson et al’s systematic review of 11 eligible studies also found 69% of participants were in favor of having a “self-binding” component in their advance plan, which would “support an advance request for compulsory treatment whilst acknowledging that at the time treatment was required they would be likely to refuse.”[457] When relating to their experiences of decision-making during mental health, participants who could be characterized as experiencing mental health episodes displayed no common standpoint in where they situated themselves in the case study scenario. Other participants tended to situate themselves in the position of the case study subject they had most in common with. For example, those with secondary experience of mental health situated themselves more so with the family or carer. Those with previous experience as professional carers or medical professionals situated themselves with the medical professional, and those with early-stage

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[455] T. Gergel and others, 'Reasons For Endorsing Or Rejecting Self-Binding Directives In Bipolar Disorder: A Qualitative Study Of Survey Responses From UK Service Users' (2021) 8 The Lancet Psychiatry, 603.

[456] Ibid.

[457] L. A. Stephenson and others, 'Advance Decision Making In Bipolar: A Systematic Review' (2020) 11 Frontiers in Psychiatry, 4.

progressive mental health were more likely to situate themselves with the case study subject- in this case John or Mary. Instead, participants with more episodic mental health seemed to adopt both a subjective and objective standpoint.

This was not expected. Given their shared experience, it was presumed that there would be a tendency for these participants to put themselves in Ken's shoes. However, while these participants retained a good degree of subjectivity and understanding of Ken's feelings and experiences, they retained objectivity and voiced both roles. Nicole, Simon and Daria in particular comment on how during an episode they wanted their will and preference to be upheld, but with the benefit of hindsight they are grateful their decision was overruled. It may be the case therefore that because of their experience and unique standpoint, this group are in the privileged position of being able to conduct an internal conversation for both sides of the decision making argument with greater insight than those who lack first hand mental health experience.[458] Their retrospective view of decision making during crisis may make for a more informed and therefore superior internal dialogue, compared with someone who lacks their experience. This ability to adopt both a subjective and objective standpoint for the internal conversation may also be fuelled by the desire to dissociate from Ken thereby dissociating from their self with mental health. This theme of a desire to dissociate was also discussed in Chapter 4.

This phenomenon is supported by the research of Owen and David et al regarding retrospective decision making.[459] This study consisted of 94 people who lacked capacity to make treatment decisions and who were admitted both involuntarily and informally to a psychiatric hospital. These participants were interviewed at the point of discharge or one month after being released (whichever came sooner). Results show that 83% of those who regained capacity gave retrospective approval of the treatment options which were made on their behalf.

Something emphasized by all participants responses and from all case studies, was the need to offer support before overruling will and preference, including during crisis. Michelle, who has similar experiences to Ken, had a dissenting opinion to Nicole and Daria and believed will and preference during crisis should not be overruled.

Michelle discussed experiencing an internal conflict during psychotic episodes where she simultaneously wished to both seek treatment and call her dad (who supports Michelle in accessing treatment,) whilst also wishing to avoid treatment and continue to enjoy the

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[458] A good example of an 'internal conversation' is provided by Carol Gilligan, *In A Different Voice* (Harvard University Press Cambridge, Massachusetts, and London 1982).

[459] Gareth S. Owen and others, 'Retrospective Views Of Psychiatric In-Patients Regaining Mental Capacity' (2009) 195 British Journal of Psychiatry.

‘high’ of mania. This shows that Michelle makes decisions during mental health experiences which are contrary to those she would have made before the episode. Eventually however, Michelle arrives at her decision to seek help by herself, with support:

> “Michelle: …all my friends have my dad’s number, and I say when I’m poorly, when I’m manic and psychotic, you’ve got to call my dad...but obviously when I’m poorly I’m like- ‘don’t call my dad, I’m fine! Let’s all go out for drinks!’ [laugh voice]
>
> I: Can I ask you a question about that? Why do you ask your friends not to call your dad when you’re unwell?
>
> Michelle: I think it’s because I know that he’s going to section me, and I don’t want to be sectioned, I remember, I specifically said to everyone not to call my dad, so I knew, I knew I was ill and I knew it was happening again, [sighs]…I was trying to get help but I wasn’t, I mean, when I’m poorly no offence dad, but he just takes me to A&E and I get sectioned and obviously I don’t like being sectioned…
>
> Joseph:…I think there’s a part of you that wants help, and there’s another part of you that thinks way hey this is great!
>
> Michelle: Yeh I’m having a great time! [laughs]
>
> Joseph: it always filled me with fear when [Michelle] said- oh I really enjoy my manic episodes, and I can see it, I can see why because, at the time, you’d prefer to be really happy and flying high rather than being in the depths of low depression”

Michelle also has experience of being coerced into taking treatment that made her ‘poorly’ and has negative experiences of being sectioned. Michelle communicated her negative reaction to clapixol to her relevant clinician and was coerced into continuing with that same treatment regardless. These experiences likely eroded her trust in the support offered by medical professionals and are likely one of the reasons Michelle is firmly against overruling decisions made during a mental health experience. This connection between a willingness to self-bind and trust in medical professionals was also a finding of Stephenson et al’s systematic review.[460] This shows the importance of not

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[460] L. A. Stephenson and others, 'Advance Decision Making In Bipolar: A Systematic Review' (2020)

only support during decision making, but of non-coercive, quality mental health treatment which does not give people cause for excessive apprehension in their decision to seek support.

Episodic Versus Progressive Patterns of Mental Health Experience and how the 'Regaining' of Self Impacts Self-binding

One finding which has not previously been discussed at length in literature is the bearing mental health has on whether self-binding should be permitted and whether contrary wishes should be adhered to.

In previous chapters two broad typologies of mental health have been alluded to. These include mental health characterized by episodes, and mental health which progresses and changes self to a greater extent over time i.e. dementia and Alzheimer's. This distinction is broad and not an exact science. Indeed mental health is highly individual (as we have seen in Chapter 4) and participants correctly outlined that some diagnosis which could be considered as occurring in episodes can go on for long periods of time (Simon and Lulu's brother both have long-term psychosis) and persons in late-stages of progressive conditions can experience lucid moments.

That being said, it is recognized that "'[t]here are certain mental illnesses that have periodic features. The most prominent are bipolar disorder and schizophrenia."[461] These periodic features of mental health, mean that for some, a version of self which shares many of the elements of self pre-mental health experience can be regained.[462] Once diagnosed, a person with bipolar can expect ten recurrences of symptoms over the course of their life, and each episode tends to manifest the same early warning signs in the weeks leading up to a full relapse.[463] This provides a level of predictability and consistency that could be drawn on for self-binding provisions, to ensure the person has insight into what they want to happen during an episode. For Widdershoven and

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11 Frontiers in Psychiatry, 4.

[461] G. Widdershoven and R. Berghmans, 'Advance Directives In Psychiatric Care: A Narrative Approach' (2001) 27 Journal of Medical Ethics, 92.

[462] P. Mackin and A. H. Young, 'Bipolar Disorders', *Core 10 Psychiatry* (1st edn, Elsevier Saunders 2005) and K. R. Merikangas and others, 'Lifetime And 12-Month Prevalence Of Bipolar Spectrum Disorder In The National Comorbidity Survey Replication' (2007) 64 Archives of General Psychiatry.

[463] A. Jackson, J. Cavanagh and J. Scott, 'A Systematic Review Of Manic And Depressive Prodromes' (2003) 74 Journal of Affective Disorders.

Berghman ""[u]lysses contracts would be permitted only when the individual's illness were recurrent, interspersed with periods during which behaviour was relatively symptom-free."[464]

Prior experience and this ability to 'regain' self, as we shall see, had a big impact on participants opinions on self-binding, who should be able to self-bind and which kinds of decisions a person could bind.

First, this ability to regain self has practical implications. There is likely more opportunity for a person whose mental health is characterized by episodes to 'regain' self and be assessed as having mental capacity, thereby enabling them to draw on experiences to update any advance plan to be more reflective of their will and preference if they change their mind. This is less likely for people with progressive mental health who cannot draw on prior experience and would likely not retain a lucid moment long enough to be deemed to have mental capacity and to update the advance plan. "While a person making planning in anticipation of dementia, for example, will have to speculate as to how he or she will feel at the time the decision is acted upon, after the first episode, a person with bipolar disorder making an advance decision will have direct experience of the condition and therefore what he or she will or will not want"[465] This is likely one of the reasons why the Mental Capacity Act Code of Practice allows the length of time which has passed between the making of an advance directive and its possible application, to be taken into consideration when determining its validity.[466] The more time has passed the higher the likelihood the plan has become outdated and unrepresentative of the individuals will and preference, which may be the case particularly for progressive conditions.[467]

In terms of how the mental health typology impacted participant responses to the case studies, there were thematic difference in the way participants discussed upholding incapacitous wishes contrary to an advance plan. These included finality - how long a person has left to live, experience new things and see their wishes fulfilled; and happiness - making the present self with mental health happy. These themes were recurrent in participant discussion of John and Mary's case studies on progressive mental health but were almost absent from discussion in reference to Ken's case study

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[464] G. Widdershoven and R. Berghmans, 'Advance Directives In Psychiatric Care: A Narrative Approach' (2001) 27 Journal of Medical Ethics, 95.

[465] P. Bartlett and others, 'Planning For Incapacity By People With Bipolar Disorder Under The Mental Capacity Act 2005' (2016) 38 Journal of Social Welfare and Family Law, 264.

[466] Office of the Public Guardian, 'Mental Capacity Act Code Of Practice' (2007) 9.29–9.30, available: https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice

[467] Ibid 9.30.

concerning psychotic episodes. Where discussed, these themes were not discussed to nearly the same extent.

After noticing this pattern in discussion participants were asked whether and how the type of mental health difference and how it was characterized impacted whether the advance plan should be upheld or overruled according to current will and preference. Participants said the following:

> "I think with dementia its different, *you don't go back*,[emphasis] talking about a transient episodic altered state, its different cause you then go back, I think dementia is actually quite different because you don't experience that, people just become more advanced in their dementia so I think that's different…" [Jessie]

> "It's like you know dementia, it changes to its own beat doesn't it, you're not the same person, you only get little twinkles of that person coming through now and again," [Daria, bipolar]

> "…so someone who comes in and out, it is different, because [they] could maybe add something in [to their advance plan]…that lets someone off the hook a bit really because obviously they've been able to rationalise that when they're like that…whereas if you're going down down down if you were down here, you'd have no idea what you'd be like up here, and you won't come out of it, it'll just carry on, so they're two different types of care plan…" [Samantha, carer for husband with FTD]

> "[for progressive] once they probably lost the capacity of who they are before, they're a new person, frustrating this new person- are you frustrating the person they'll be going forward or are you frustrating the person they were that they're letting go of?...Yeh, I think that both should be treated slightly different cause you're dealing with a new person and this other one your dealing is a temporary person…I think the consequences of the temporary one are more important, because they're going to come out…but if this other person is going to be someone who probably won't be recognised in a few months or a few years to come, I think that would be dealt with differently…and maybe [don't] ask them to

> make too many decisions about how they should be treated in the future because you're putting pressure on not only themselves but the carer, the family…cause their going to be a whole new person, so decisions, I don't think they should be the ones to make the decisions about how they're treated in the future…if you're telling this person whose become a new person no you can't do that because you told us last year that- don't do this- I think it will cause them so much harm because it will remind them of what they're losing, yeh, I think there should be a difference between the two" [Nicole, psychosis]

> "Definitely, definitely, because they're two different things…[b]ecause, it's not that…ones more or less than another, it's that somebody goes through…psychosis, they've still got, [they] are still able to retain and learn from what's happened, whereas someone with dementia…it's parts of the cells being destroyed, so what, if those cells were still there, that person wouldn't, have, or wouldn't want to be doing some of the things they're doing, but in the case of the guy who wanted a bacon sandwich, it might be that he's always wanted a bacon sandwich, and the only thing that stopped him is his belief, and or how other people would see him" [Steph, PTSD and experience caring for her mother with dementia]

The potential to 'come out' of, or 'go back to' a self similar to self pre-mental health experience was therefore a key concept for participants and impacted how they formed decisions. Participants also considered the fact that upon 'coming out' of an episode there may be a breach of trust between the individual and care team upon realising their advance plan had been overruled. When asked if they would be more likely to uphold will and preference for one type of mental health over another, participants said the following:

> "Yeh, I'd more likely let the person with dementia do whatever they want, that's how I'd want it, if I had dementia and if I was vegan now, but when I got dementia I wanted to eat meat and I wanted to, tattoo my whole body or, do whatever, I'd just be like, look guys I'm going to be poorly and I've got dementia, and these are the last years of my life… as long as I'm not causing harm to other people just let me do it…
>
> I: So you think you'd be more inclined depending on background information to listen to the [Advance Plan of a] person with more episodic mental health?

> Yeh cause they’re going to come back” [Michelle]

> “I think it’s easier in a way if someone has care wishes of someone with psychotic episodes, cause they can come out of it and they know what they were saying back here…like…that scenario where…John wanted…bacon…if he was in like a psychotic episode, I would probably not give [it to] him…because he’s going to come out of it…and it would be like- oh I’ve eaten pork and God will punish me! But because he’s becoming a new person, probably that’s why I’d be more lenient…or maybe, give him something [else]…yeh so I feel like psychosis and dementia are very different…” [Nicole, psychosis]

Some participants wanted to adhere to the advance plan regardless of the way mental health was characterised, as they maintained a true self model and believe that for those with progressive the advance plan contained the wishes of a ‘truer’ self.

> “I:…would the type of mental health difference impact whether you’d listen to the person sat in front of you now- the person experiencing the mental health, or the person who wrote the advance plan?
>
> M:…[Y]es because, the nature of…the mental health conditions are very different, so therefore I think you can’t ignore that fact, but I do think that…the self that made the plan, would have had more truth about it, in that that person really thought about the plan and the person that made the will, knew that she had some lovely grandchildren and that she did want to provide for them, so I think you’re always looking, back to the self that made the plan, and trying as hard as you can to, enable that, person, to, have the best treatment or quality of life that they can do, as their mental health changes, or as it deteriorates” [Molly, carer for spouse with late-stage dementia]

Debbie argued that regardless of the type of mental health, if there was an advance plan in place, the individual had clearly given enough thought and consideration into the contents of the plan that it should be followed in the event of contrary wishes. Debbie’s decision therefore was not based on the potential to ‘regain’ self pre-mental health, but on the fact that advance planning represents an embodiment of advance thought which the individual, regardless of mental health typology, intended to be binding. It should not therefore be overruled.

While there was disagreement therefore, the majority of participants allowed the way mental health interacted with self- specifically the potential to 'regain' self- to impact whether contrary will and preference should be upheld or overruled in favour of an advance plan. Many participants said they would treat the same scenario differently on this basis. The majority of participants were more likely to overrule an advance plan in favour of contrary will and preference made by someone with progressive mental health as opposed to someone who experienced episodes.

Experiences of different types of mental health difference therefore seems to be a factor influencing self-binding and when to uphold or overrule decisions contrary to an advance plan. This is in the sense that participants whose mental health could be characterised by episodes were the group who expressed a desire to self-bind, and participants were more likely to uphold contrary wishes for those with progressive mental health.

It is likely therefore that how mental health impacts self and the broad typology of mental health should be taken into consideration when looking at self-binding provisions under the CRPD. This requires further academic attention.

While mental health typology is one factor for consideration, there are other factors also at play. These include the type of decision being bound and the severity of harm incurred directly or as a consequence of a decision.

Findings: The Impact of Harm on Legal Capacity

It has already been outlined in Chapter 1 that one of the most dominant justifications for restricting legal capacity is to prevent harm. The majority of domestic mental health law permits compulsory intervention where a person with psychosocial disability is refusing treatment professionals believe they require, and the person either lacks decision making ability, or there is a risk of a serious deterioration in health, self-harm, harm to others or a combination of these factors.[468] Mental capacity law restricts legal capacity when an individual is assessed as lacking the mental capacity to make a certain decision and the will and preference they are expressing is opposed to what is deemed in their best interests. In regard to scholarly attempts to provide a CRPD compatible justification for limiting legal capacity, these include decisions which pose imminent harm, serious

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[468] A. Nilsson, *Compulsory Mental Health Interventions And The CRPD: Minding Equality* (HART Publishing 2021) 45-49.

adverse effect or situations in which a person needs to be removed against their will and preference from a harmful situation to establish their 'true' will and preference.

Only decisions which cause direct harm to the individual are considered here, as the CRPD Committee outline that criminal acts of harm towards others can be dealt with using existing criminal law.[469]

There were many instances of harm presented to participants in the case studies. These include risk of direct physical harm (Ken) harm to religious beliefs (John) financial harm and harm to individual welfare (Mary.) They also include harm to different 'versions' of self. This includes harm to self pre-mental health experience by potentially overruling the will and preference contained in an advance plan, harm to the present self with mental health by overruling their current will and preference in favor of an advance plan, and harm to self post-mental health experience if a decision made during a mental health experience has harmful consequences.

These case studies encouraged participants to reflect on how harm impacted whether will and preference during a mental health experience or a valid advance plan should be adhered to. Participants provided information based on their experience on where a cut-off point to legal capacity may lie, how different types of harm factored into decision making and how harmful decisions should be handled. Participants also drew some assertions about how the type of mental health difference should impact the types of decisions which could be self-bound using an advance plan.

First, regardless of the type and level of harm and mental health type, the majority of participants first sought to ascertain the individual's reasoning behind the decision in order to provide support and offer suitable alternatives. This was because overruling will and preference in itself was perceived as a form of harm.

This therefore firmly supports the CRPDs emphasis on support in decision making first and foremost:

> "[F]irst of all I'd want to know the details of self-harm- what lead him up to that, what kind of psychosis has he got, is it something that can be applied with the

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[469] United Nations Committee on the Rights of Persons with Disabilities, 'Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities: The right to liberty and security of persons with disabilities' (adopted during the Committee's 14th session, September 2015) para 14.

> therapy, does he just need someone to talk to for example, what is it he wants to share first of all" [Simon, psychosis]

> "[W]hat you said about people making their own decisions, it's got to be taken in context…and it's how it's viewed and how it's backed up –it's not saying let them commit suicide, it's saying, look… you've got a decision to make here- you'll be saying- why, reflect [on] yourself, why [are] you doing it and do you want some support?" [Diego, anxiety and depression]

> "Yeh and…also reasoning out to the patient as well sometimes…as much as it can be hard-…with a family member…say look, we've tried everything, if we don't do this the situations going to get worse and what do you think we should do?" [Nicole, psychosis]

Participants also regularly stressed the importance of negotiation. In John's case study this involved offering him a turkey or veggie bacon sandwich, and for Mary involved encouraging her to buy more inexpensive figurines. This negotiation is key as it is not always possible to prevent someone from engaging in harm. A prime example of confronting the reality of harmful behaviour whilst negotiating to minimize harm was demonstrated by Joe- a mental health nurse on a secure facility employed for over ten years. She provides the following example in which she negotiated persistent, harmful will and preference, to prevent the individual from committing more serious self-harm:

> "[y]ou need to be flexible, to work with that persons needs from day to day, you're talking about self-harming…and yes there are ways around it- we had a guy who used to cut himself, we gave him an elastic band, and he got hurt every time he [flicked] it, but there's no lasting damage, you know and we'd try and word things like that, it was just a case of okay right, if we leave him alone he'll do everything from sharpen his toothbrush to you know prying a bit of plastic, even off a food box he'd get, and cut himself, he found the most bizarre things to actually use to cut himself, but if he wanted to do it, he'd even use [the hook off his pants]…straighten one of them out…if they want to do it they'll find ways of doing it …we always had to try and find a way around the situation, while still giving them their choices, their option, that they want to do, we even had those pens that you click on yourself, like a shock, but it didn't do any lasting damage…I mean there's loads of things that people could do to hurt themselves… if you're locked in a medium secure unit, you're basically screwed, so you take the choices out completely anyway, and even with diabetes, that's another one, 'I want to eat

> sweet things,' well I'm sorry you're not, you're diabetic, 'but I want them,' well we'll compromise, you'll have one dessert a day, cause if you allow it and they die, you're going to have a massive big [sounds like human cry] all you can do is work within what you've got and just be there basically, build that respect, get to know the person, and then let the person be able to talk to you" [Joe, depression]

Throughout her interview Jo emphasized the importance of building a trusting support relationship between medical professionals and patients receiving mental health treatment. Trust is of great importance given another participant with very negative experiences of detention in a mental health facility, believes hospital can destroy sense of self, causing the individual to have to rebuild self 'from scratch.' This likely made recovery more arduous and therefore mental health treatment which aims to retain a sense of self is important. Communication, trust, and negotiation to retain legal capacity are likely a large part of that.

Participants did identify what they believed to be a cut-off point to legal capacity. The majority aligned themselves with scholars who took a non-absolutist approach to the CRPD. In a mental health context, participants felt a decision which would result in serious self-harm causing loss of life or the decision to end life should be the cut-off point to adhering to will and preference. Any will and preference contrary to an advance plan which would result in loss of life was therefore to be overruled. This therefore provided a legitimate restriction to legal capacity according to participants.

In terms of the reasons why participants felt this cut off point was justified, this largely centered round the individual not being in the 'right frame of mind' to make such an irreversible decision. The idea of heightened emotional distress was mentioned as was the tendency to change one's mind. The capacity narrative was relied upon, as demonstrated by comments like 'they're just not in the right frame of mind,' although this could also be reflected in earlier discussions on change in self- and how for some, their self with mental health changes in such a way that they become less capable of making decisions. Protectionism also played a role. This idea of changing one's mind is also echoed in suicide literature- in the sense that suicide may only be rational when it can be known for certain that the next day and the days after that will be worse than today. Since in many cases this cannot be known with any certainty, the rational choice would be to postpone suicide, given the situation may improve and the individual may change their mind.[470]

I also believe public interest in terms of what it is morally permissible for society to allow, played an underlying role in participant responses. Examples of this reasoning include the following extracts:

> "[T]hey're just not in the right frame of mind to make that decision are they, if they're fully with it you can see the argument for that although still, I just think if someone's suicidal they aren't in the right frame of mind, so I just wouldn't go for that at all" [Debbie, personality disorder]

> "Daria: I think ultimately if you're a danger to yourself or other people, somebody needs to step in, whether you like it or not,
>
> I: Yeh
>
> Ella: Like my stepdaughter- we found out last year that she was self-harming, and she'd been cutting herself…I'd like to think if...they knew she was actually harming herself and like you say she'd gone to doctors and got new cuts and one of them had been quite sever, and she's making herself properly at risk, they'd step in
>
> I: So if they're sat here going 'well I want to self harm because I think that helps my recover'..
>
> Daria: yeh it's like- 'but look at state of you and it's getting infected and you're not looking after the cuts'
>
> I: So you think there are some types of decisions which are particularly harmful [where someone should step in?]
>
> Both- Yeh" [Daria and Ella]

> "[I]t's the thing with suicide though isn't it, the next day you might not feel like that [way]…" [Layla, Borderline Personality Disorder]

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[470] R. Brandt, 'The Morality And Rationality Of Suicide', *A Handbook for the Study of Suicide* (1st edn, Oxford University Press 1975) 327.

> "I: Is that sort of a view that's shared then? So if it involved suicide or self, harm, you…think that [should be prevented]?
>
> Lulu: Yeh
>
> Jill: Yeh just to protect the person isn't it" [Lulu, depression and Jill, undisclosed]

The majority of participants felt these decisions justified detention- including in a mental health facility, despite the CRPDs specific prohibition of detention against the individuals will in a mental health facility:

> "Simon: …they need putting in somewhere for their own safety
>
> I: Yeh? So in that case they shouldn't be listened to, so there's a cap?
>
> Simon: If someone planning on harming themselves they should be put in...yeh" [Simon, active psychosis]

> [On Ken being admitted to a MH facility against his wishes] "I think it's for his own safety" [Lynn]

> [On their own reflection of being detained against their will and preference] "Nicole: I can also appreciate that being in hospital was the best place for me, as much I didn't want to be in hospital…I look back and I'm like- actually that was the best place for me, because if I went home I probably would have hurt myself, I don't think I would have been better" [Nicole, psychosis]

A good example of the kind of imminent harm which justifies detention according to Flynn and Arstein-Kerslake was provided by Jessie, who recalled a time when they had to detain a friend to prevent them from jumping off a balcony:

> "[T]his colleague of mine who orbits to another planet… I've had some very intense experiences with her- for example having to sit on her to stop her throwing herself over the balcony, I mean it was physical, I was with her 24 hours a day [Jessie]

For around a third of participants, serious self-harm or suicide even justified forced treatment against will and preference- including in the case of Ken’s advance directive.

This was justified by reasoning that the sooner the episode ends, the sooner Ken’s decision to commit harm will subside. This was likely influenced by the case studies wording, that ‘*[d]uring these episodes [Ken] has a tendency to self harm. Treatment for his psychosis to prevent this self harm involves treatment Y.’* This poses an over simplified account where the doctor recommended treatment for psychosis involves something refused by the individual. Whilst oversimplified, this case study was trying to outline a ‘worst case scenario’ to try and judge how far participants would go in upholding will and preference. This was done by making the treatment for the episode and therefore the possible end of an ‘increased tendency to commit self harm,’ the very medication Ken had refused. In reality, and as many of my participants pointed out, there may be alternative treatments and courses of action without needing to overrule Ken’s advance directive. The aim of this was to see how willing people were to allow involuntary treatment to prevent harm.

While participants were under no obligation to disclose whether they had been in receipt of forced treatment before, this means it is possible that the minority who would use serious harm and suicide to justify forced treatment may lack first-hand experience. Michelle, the only participant who openly disclosed that they had been subject to forced psychiatric treatment, was adamantly opposed to it, as was her dad Joseph who bore witness. Academics such as Flynn and Arstein-Kerslake are also opposed to justifying forced medical and psychiatric treatment under the CRPD based on service user accounts.[471] This does not however provide answers to what should happen in a scenario where a person during crisis is refusing life-saving medical treatment for reasons based on delusion. This is clearly an area which requires further academic attention.

Many participants rightly pointed out that a ‘tendency’ to commit harm did not equate to certainty, and therefore any decision which overrules will and preference would be justified based on a *risk* of self-harm alone, which some thought was problematic. This is a problem with maintaining a cut-off point to legal capacity which is serious self-harm and suicide. There are many criticisms around the accuracy of dangerousness evaluations. Large et al’s systematic review of the clinical factors associated with psychiatric in-patient suicide calculates that for every 100 people detained 98 would pose

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[471] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 99.

no threat to their own life.[472] She therefore asks whether detention and forced treatment based on risk- which is incredibly hard to accurately predict, is justified, but concludes it to be a legitimate aim for the two lives saved.[473] This tendency to err on the side of caution seems to be reflected in participant responses.

In summary therefore, participant responses have offered support to existing scholars and legal reformers who do not adopt an absolutist interpretation to Article 12, where will and preference is harmful. Instead participants justify restrictions to legal capacity in a mental health context, where a person's decision would lead to suicide or serious self harm which could result in loss of life, and where support has failed. Therefore they support a 'cut-off' point to legal capacity which creates a barrier to an absolutist interpretation of CRPD compatibility.

The Scope of Decisions Participants want to Self-bind

As outlined in the previous section a group of participants who experience mental health in episodes and experience drastic changes in elements of self, did want to retain the ability to self-bind. This would mean overruling will and preference during an episode, where support has failed, when they make a decision contrary to a decision in their advance plan. This would expand the scope of justified interference beyond serious self-harm and suicide to other harmful decisions. This support would likely come in the form of continuing to provide support to an individual, despite that individual verbally refusing support during a mental health experience, or allowing an elected support person to take over certain decisions listed in the advance plan.

The majority of discussion amongst participants centered around self-binding decisions they were more inclined or had a higher tendency to make during an episode, based on their past experiences. The main reason for wanting to self-bind these decisions was to avoid harm to self and others or harmful consequences. The decisions they wanted to bind extended beyond the scope of serious self-harm or suicide, and therefore the point at which the majority felt legal capacity should be restricted. Instead participants wanted to bind both objectively and subjectively important decisions. 'Objectively important' decisions is a term being used to describe those decisions currently recognized by legally

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[472] M. Large et al, 'Systematic Analysis and Meta-analysis of the Clinical Factors Associated with the Suicide of Psychiatric Inpatients' (2011)124 Acta Psychiatrica Scandinavica, 26.

[473] There is a wealth of literature on the accuracy of dangerousness and risk predictions in mental health care, however this does not need to be expanded on here for my purposes.

binding advance plans and for which there exists societal consensus that these decisions are important. Participants mainly discussed a desire to self-bind financial decisions to avoid debt and large purchases.

'Subjective decisions' is a term being to include those decisions which are of great importance to the individual but which lack societal consensus over their importance and are not currently protected by legally binding advance plans. Participants discussed subjective decisions relating to the maintenance of relationships, including on sex and sexual partners and decisions required to uphold beliefs. These decisions can therefore be devoid of legal consequence which - depending on the scope of legal agency - may mean these decisions are not protected under Article 12 and may be overruled.

Participants felt they should be able to self-bind whichever decisions were of great importance to them, regardless of whether that decision was considered objectively or subjectively important/harmful. This is because harm can take many forms, including social and relational harm. Whilst direct harm is no doubt serious, this kind of indirect harm can be just as harmful.

As we have already seen however, consideration of subjective harm to the individual was recently given by Mr Lord Justice Hayden in Barnsley Hospital v MSP, in which MSP's physical appearance- which was of great importance to him- was considered as part of the best interests hearing.[474] If consideration of more subjective harm is being awarded under current mental capacity law, as well as consideration of what the individual considers important, it is not much of a stretch to see how subjectively important decisions could be awarded legal weight under a reformed advance planning mechanism.

Permitting self-binding to prevent other harmful decisions, would also allow harm to others to be taken into account. This form of harm was a source of concern to many participants, either in recounts of their own experiences or in discussion of the role of the family in case studies. The harm a decision during a mental health experience could have on others and their relationship with others, was one of the main reasons participants desired self-binding. It is demonstrated in Chapter 4 that changes caused by mental health can result in feelings of isolation and a loss of relationship with others. This seems to be something participants would want to use self-binding to protect against. The desire to protect relationships lends support to relational autonomy and the concept of individuals as socially embedded and dependent on relations to strengthen individual autonomy.[475] Maintaining 'group belonging' as Anthony put it in his elements of self

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[474] *Barnsley Hospital NHS Foundation Trust v MSP* [2020] EWCOP 26.

[475] J Nedelsky, 'Reconceiving Autonomy: Sources, Thoughts And Possibilities' (1989) 1 Yale Journal

activity, likely goes some way towards achieving self-reconstruction following a mental health experience. The implication of this finding is that participants would wish to self-bind for the sake of others as well as themselves. While concerns could arise about whether a person is self binding purely in their own interest or for the sake of another, this phenomenon is nothing new. People make decisions in the interests of others all the time, sometimes at great personal cost. Likely the scenario in which this becomes problematic is when undue influence is suspected.

Of course, practical consideration must be given to the scope of decisions an individual can bind, beyond those decisions currently available under current mental capacity law. Regard must be had for whether these decisions are realistic, practicable, and whether they impose a positive obligation on a support person beyond a reasonable scope of what the support person can be expected to do. Widening the scope of decisions which can be self-bound after all, does frame advance planning as a potential source of positive and active support- requiring support persons to play an active role in mental health care. This is opposed to its current scope, which is concerned with negative obligations i.e. treatment refusal. It is likely therefore that these wishes would need to comply with some form of reasonableness test.

Ultimately it would likely be beneficial to widen the scope of decisions which could be self-bound using an advance plan, to avoid prescribing a set model of self and which decisions that self should consider of importance, and in order to give that person as much control as possible over their mental healthcare with the aim of avoiding harm. Provided the creation of this advance plan was accompanied by accessible education and the legal nature of self-binding was made clear, existing research supports that individual would be highly unlikely to problematically self-bind a large number of subjective decisions. This behaviour is already evidenced by the current use of advance plans, where sections relating to ‘preferences and instructions’ are often left blank. This is likely where subjective decisions, which are outside the scope of current advance planning provisions, would go. There are many reasons why this section may be left blank, however this is never-the-less a good indicator that individuals are hesitant to express legally significant wishes unless they are well thought out and viewed by the individual as key to their care. This was also the impression received during interviews with participants.

The nature of the mental health difference and the extent to which an individual could ‘regain’ self also impacted which decisions participants believed a person should self-

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bind. The majority of participants were uncomfortable with the idea of a person with progressive mental health i.e. dementia and Alzheimer's self-binding subjectively important decisions. Because participants viewed those who experience episodes to have a greater chance of regaining self, they believed it more important to uphold their subjective wishes during mental health experiences, compared with those who experience progressive mental health. Examples offered by participants included beliefs and diet i.e. veganism. Overall, this was because subjective decisions were not considered to be as harmful compared with objective decisions, because subjective decisions were thought of as being more susceptible to change- especially when self can be so changed with mental health that another person with new preference is created.

The content of advance planning provisions, in terms of which decisions a person can self-bind, may also need to consider the impact of mental health difference on self.

The Right to Take Risks and Make Mistakes

While many participants did wish to have the option to self-bind, many also recognized that harmful decision making should not always be prevented. This supports the CRPD Committees position that persons with mental health difference retain 'the right to take risks and make mistakes.'[476] First this is for the obvious reason that not all harmful decisions can be prevented, including decisions made by people *without* disabilities. It is also because a knee-jerk reaction to discussions of self-harm and unwise decisions can hinder an individual from seeking support. As we have seen this can include challenges to mental capacity and being sectioned under the Mental Health Act. This position has already been outlined by academics who worked closely on the CRPD and by service user organizations, who believe support is sufficient to handle harmful will and preference.[477]

Therefore a person during a mental health experience who makes a harmful decision which falls short of suicide or serious self-harm, should not be prevented from making that decision and should not have their legal capacity restricted according to the majority of participants. Instead participants emphasize the importance of quality support, communication and negotiation in dealing with harmful decisions.

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[476] United Nations Commission, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 22.

[477] T. Minkowitz, 'The United Nations Convention On The Rights Of Persons With Disabilities And The Right To Be Free From Nonconsensual Psychiatric Interventions' (2007) 34 Syracuse Journal of International Law and Commerce.

To further participant views, one underlying presumption needs to be rebutted. This is that mental health difference and self are divisible, mental health difference creates harmful decisions, therefore harmful decisions are not a product of self and what self wants but a product of the mental health difference. Therefore harmful will and preference is disingenuous. The convergence of mental health and harmful decision making is problematic if legal capacity is to be awarded to decisions made by self during a mental health experience and times of crisis.

While mental health is not the only recognized reason for self-harm and harmful decision making, the two remain linked.

Under the Mental Health Act the presence of a 'mental disorder' and harmful behaviour is sufficient to detain and treat the individual (when urgent) against will and preference, regardless of whether they have mental capacity.[478] Local authorities often challenge capacity when an individual with a known mental health difference has made an objectively harmful decision. This is a value judgment which occurs despite the fact that people are not to be considered to lack capacity because of unwise decisions. This can include the refusal of life sustaining treatment - for example the inquest into Kerry Wooltorton,[479] *Re T*[480] *Re C (adult: refusal of medical treatment)*[481] *and Wye Valley NHS Trust v RB.*[482] More recently this includes *A Local Authority v RS (Capacity)* where a social worker used evidence of repetitive risky behaviour to challenge capacity.[483] Capacity is also frequently challenged when an individual with mental health difference wants to continue to reside in, or move to a residence considered harmful by the local authority, or considered insufficient to meet care needs. This was the case in *RB v Brighton and Hove City Council,*[484] *PH v (A local authority*)[485] and *Re F (Mental Health Act Guardianship*).[486]

This tendency to challenge capacity when an objectively harmful decision is made, suggests there is a doubt around whether a harmful decision can be made by a person free from mental health difference and in full capacity. Indeed, people with mental health

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[478] Mental Health Act 1983, part 2 and 4.
[479] Summary of Evidence' presented by Mr W. Armstrong (HM Coroner Greater Norfolk District) at the Inquest into the death of Kerrie Wooltorton held on 28 September 2009.
[480] *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649 (CA). Refusal of treatment overridden because of suspected undue influence from Ps mother who was a Jehovah witness.
[481] *Re C (adult: refusal of medical treatment)* [1994] 1 All ER 819 (QBD)
[482] *Wye Valley NHS Trust v B* [2015] EWCOP 60.
[483] *A Local Authority v RS (Capacity)* [2020] EWCOP 29.
[484] *RB v Brighton and Hove City Council* [2014] EWCA Civ 561.
[485] *PH v A Local Authority & Z Limited* [2011] EWHC 1704 (Fam).
[486] [2000] 1 FLR 192.

difference wanting to make an objectively harmful decision may be in a 'catch 22 situation' in the eyes of the law, in the sense that in expressing a harmful decision they are considered to lack capacity. This is expressly drawn to attention by Mr Justice Peter Jackson in *Re E (Medical Treatment Anorexia,)* which involved a woman with Anorexia Nervosa refusing life sustaining medical treatment.[487] On capacity and decision making he states: "I acknowledge that a person with severe anorexia may be in a Catch 22 situation regarding capacity: namely, that by deciding not to eat, she proves that she lacks capacity to decide at all."[488] This creates a presumption that an objectively harmful decision is not voluntary but a result of mental health difference and a lack of capacity. The two may go hand in hand.

The majority of participants however do not view self as separate or divisible from mental health (as seen in Chapter 4), instead viewing both self and mental health as interconnected. If self and mental health are intertwined, it becomes impossible to separate out the wishes of self from the decision caused by the mental health in relation to self-harm. This could mean that the decision to engage in self harm or harmful decisions cannot be said categorically to be the voice of mental health, but that of an interconnected self with mental health.

If participants view self with mental health as indivisible and interconnected, harmful decisions should not be dismissed as something generated from mental health as a divisible and isolated entity. As such will and preference should be listened to, to uphold that person's legal capacity, and should not provoke an immediate knee-jerk reaction resulting in the control of the individual via detention or by having their decisions overruled. This goes some way in answering the question of to what extent it is helpful to separate mental health from the person. In short it depends on how the individual perceives self and mental health. If the individual views them as connected, then trying to separate the two is not helpful.

There were three themes present in participant discussions on the reasoning behind self-harm. These include self-harm as a form of self-control, as a learned behaviour to deal with trauma and a way to deal with emotional distress. This is reminiscent of the theme 'mental health as a process of recovery' discussed in Chapter 4.

First, self-harm was discussed as a way to retain control over self where there exist many factors they lack power over. This rings true with some of the justifications provided for rational suicide- making the choice between controlled, certain demise and

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[487] *Re E (Medical treatment: Anorexia) [*2012] EWHC 1639 (COP)

[488] Ibid [53].

an uncertain future world which cannot be controlled.[489] Participants advise that trying to control those decisions and overrule will and preference can in fact be harmful:

> “[Y]ou go to self-harm groups where you talk about depression, but to talk about the fact you self-harm- anything about that oo! It’s still taboo …[I use it to]… kinda control part of me… I sometimes get very low and wish I could die, and that goes in my mind, and it’s an escape, and if I told a professional about that they’d try to stop, they’d try to take control, the only way out I can see is suicide, so it can be counterproductive trying to control…because it can actually cause problems…so my feelings are, if you see somebody on a high building you go up there, you don’t rush up and try and stop them cause they’re more likely to throw themselves off, you know there’s some negotiations” [Diego, anxiety and depression]

Here Diego outlines that detaining or controlling someone to prevent harmful behaviour may in fact make them feel trapped, less in control and make them more likely to commit harm. This approach is also advocated for by the NICE guidelines on self-harm, which advise against forceful intervention.[490]

Simon who has long term psychosis also disclosed that he had suicidal thoughts, but actually uses the decision to die as a way of controlling and offsetting harm. This is done by offsetting the date to a future point in time, to allow Simon to seek more support and take each day at a time to allow him to change his mind.

An example of participants equating self-harm with a learned behaviour to deal with trauma and sever emotional distress was given by Jessie.

> “…my adopted daughter who comes from Africa, and…has a very very destructive mother who burnt her feet as punishment- that’s now her behaviour of choice- to burn herself, and I think it’d be very easy for a clinician to look and say that’s adverse behaviour…but actually that’s perfectly logical- she learnt at a young age that she’s unlovable and that therefore she must punish herself- her mother burns her so now she burns herself, and I think sometimes you’re told it’s a symptom of something and I think ‘no it’s not a symptom it’s a logical reaction to all the pain

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[489] R. Brandt, 'The Morality And Rationality Of Suicide', *A Handbook for the Study of Suicide* (1st edn, Oxford University Press 1975) 324-325.

[490] National Collaborating Centre for Mental Health, 'The Short-Term Physical And Psychological Management And Secondary Prevention Of Self-Harm In Primary And Secondary Care' (National Institute for Clinical Excellence 2004) <https://www.ncbi.nlm.nih.gov/books/NBK56385/pdf/Bookshelf_NBK56385.pdf> accessed 10 June 2021.

> and distress that I’m feeling at this moment, my behaviour is logical, cutting myself is the only thing I can do, the only place I can go, to get the pain out, and I think for me that’s why I’m getting more comfortable with myself, cause I can hang on ‘what I’m doing’s logical, and I won’t have it defined as a symptom.’”

Other research indicates that self-harming is used to avoid feelings of suicide and may be used as a coping mechanism to temper more dangerous tendencies.[491] In this way, removing harmful decisions may therefore strip people of a coping mechanism used until that individual can acquire more support.

Therefore removing legal capacity from other harmful decisions- beyond those elected by the individual and self-bound using their advance plan- may be counterproductive.

Summary

This Chapter has provided insight into two main research questions. These are whether will and preference made during a mental health experience or in crisis which is contrary to that contained in an advance plan should be awarded full legal capacity, and how harm influences that decision. To answer these research questions Chapter 1 outlined the weight awarded to will and preference by the Mental Capacity Act and in best interest rulings at the Court of Protection. Chapter 5 outlines the risk and level of possible harm incurred plays a large role in deciding when will and preference is overruled. This also applies to the will and preference contained in advance directives which can be overruled under s 63 of the Mental Health Act or where the relevant clinician is not satisfied the validity requirements of the directive have been met. This is at odds with the CRPD Committee who believe will and preference are to be adhered to at all times including in crisis situations, and that persons with mental health difference retain the right to take risks and make mistakes.

In this Chapter participant responses to case studies on situational decision making during a mental health experience were analyzed, to discover whether they would want all decisions made during a mental health experience to be awarded full legal capacity, based on their own experience. Responses were varied and participants foremost concentrated on support, communication and in some cases, negotiation. The majority of participants agreed with dominant literature on harm and legal capacity and believed

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[491] Ibid 73.

there to be a cut-off to legal capacity when a person was making the decision to suicide or cause serious self-harm.

A slim majority were happy for decisions made during a mental health experience/crisis and contrary to a previously made advance plan to be adhered to. A small group of participants who experience drastic changes in self which negatively impacted their decision making, did want to self-bind some decisions to protect themselves and others from harm. This was also an opinion shared by carers and family members of those with progressive mental health difference, who felt self-binding similar to lasting power of attorney was essential as their loved ones were unable to make some decisions for themselves.

The type of mental health difference and how it impacted the ability to 'regain' self impacted participant views on whether to uphold or overrule wishes contrary to an advance plan, and the contents of the advance plan itself. Participants were more likely to uphold the advance plan for individuals who experience mental health in episodes and therefore 'regain' self. They were less comfortable however with adhering to the advance plan for progressive types of mental health difference however, where the person becomes very changed and is unable to 'regain' self to the same extent. For this same reason, participants were also more comfortable with people who experience mental health in episodes to self-bind more subjectively important decisions- those outside of finance and welfare- compared with progressive mental health. Subjectively important decisions were thought to be more subject to change as the individual changed, compared to objectively important decisions on finances and welfare. The scope of wishes which can be included in an advance plan and protected under Article 12 depends on the definition of legal agency, as outlined in Chapter 1.

If a minority of individuals would like some decisions made during a mental health experience to be overruled, there needs to be a way of determining when that individual is in an episode to determine which will and preference should be adhered to. Advance plans however currently come into force once an individual is assessed as lacking mental capacity, and mental capacity assessments are incompatible with the CRPD according to the CRPD Committee. Therefore an alternative trigger for advance plans is required. The next Chapter provides one such alternative based on a user-led statement on change in self.

Chapter 6: Generating New Thinking: A User-led Written Statement on Change in Self because of Mental Health Difference as a Potential Alternative to Mental Capacity Assessments

Introduction

So far, this thesis has explored barriers to compatibility with the UNCRPD for advance plans. This includes problematic conceptions of self with mental health difference, harmful decision making and the difference in weight awarded to will and preference in the Mental Capacity Act compared to the CRPD. This chapter draws on this discussion, particularly Chapter 4 on understanding self with mental health difference, to discuss one of the biggest barriers to compatibility- mental capacity assessments. Mental capacity assessments are currently used to determine when a person lacks the decision-making capabilities to decide for themselves. They are also currently used to trigger advance plans. In Chapter 6 a group of participants described experiencing drastic changes in self because of mental health, which cause them to make decisions they would not normally make. This group confirmed that for some, the very draw of advance plans is to self-bind future decisions to protect self and others from harm, and safeguard deeply held values and beliefs. This confirms other empirical studies discussed in Chapter 1 on the benefits of self-binding directives, including the control and empowerment they award persons with psychosocial disabilities.

If self-binding provisions are desired in advance planning, the question then becomes how to determine when self has changed because of mental health difference, and therefore how to know when to restrict legal capacity for the decisions contained in the advance plan. The CRPD Committee is clear in prohibiting mental capacity assessments and a functional approach- whereby decision-making capacity is assessed and legal capacity denied accordingly. As stated by Szmukler and Bach, the problem then becomes "[h]ow [to] distinguish between acts that should command the respect of others, and acts violating a person's dignity and causing substantial harm."[492] We are therefore in need of a CRPD compatible trigger which does not rely on an assessment of an individual's mental capacity, which can be used to trigger a self-binding advance plan.

So far attempts to create an alternative based on a supported decision-making framework have retained some element of a functional approach. This includes the combined supported decision-making model outlined by Scholten et al,[493] Bach and Kerzner's use of a functional approach to establish a person's legal status and the level of support they require,[494] the Australian Law Reform Commission's use of a functional approach to determine when an individual is exempt from compulsory voting due to lack of decision-making ability,[495] and Szmukler, Daw and Callard's use of a 'decision making capability assessment' in their Fusion Law Proposal.[496] This chapter attempts to use participant responses and a re-conceptualized understanding of self with mental health to create new thinking on an alternative trigger. This is with the aim of moving away from a capacity based functional approach. This Chapter explores whether the concept of a user-led written statement on change in self could prove a CRPD compatible alternative to mental capacity assessments, for the purposes of triggering a self-binding provision in an advance plan. This is no means a fully fleshed out reform proposal and as shall be highlighted, there remain problems with this approach. However this has the potential to contribute new thinking on how to achieve CRPD compatibility while offering a way for

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[492] G. Szmukler and M. Bach, 'Mental Health Disabilities And Human Rights Protections' (2015) 2 Global Mental Health, 6.

[493] M. Scholten, A. Gieselmann, J. Gather and J. Vollmann, 'Psychiatric Advance Directives Under The Convention On The Rights Of Persons With Disabilities: Why Advance Instructions Should Be Able To Override Current Preferences' (2019) 10 Psychiatry.

[494] M. Bach and L. Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' (2010) prepared for the Law Commission of Ontario. Available <https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf> Accessed 26th January 2021, 98-101.

[495] Australian Law Reform Commission, 'Equality, Capacity And Disability In Commonwealth Laws (ALRC Report 124)' (2014) available at https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/3-national-decision-making-principles-2/will-preferences-and-rights-2/ para 1.27

[496] G. Szmukler, R. Dawb and F. Callard, 'Mental Health Law And The UN Convention On The Rights Of Persons With Disabilities' (2014) 37 International Journal of Law and Psychiatry, 248.

persons with mental health difference to opt-into state intervention and self-bind to protect themselves and others from harm. This alternative also has the potential to strike a balance between safeguarding disabled people while respecting their right to take risks and make mistakes.

This chapter begins by outlining academic criticisms of mental capacity assessments and the reasons why the CRPD Committee prohibit them. Participants who have been the subject of, witnessed or conducted mental capacity assessments, are asked to share their experiences, and whether they feel mental capacity assessments can be improved upon. A user-led written statement on change in self because of mental health difference is outlined and participant feedback discussed, specifically on whether they feel capable creating such a statement, who they would nominate to interpret the statement and trigger the self-binding provision, and any constructive feedback they have on how this idea could be further developed. Whether and how this alternative marks an improvement on mental capacity assessments in achieving CRPD compatibility and overcoming the criticisms outlined by academics, the Committee and participants, is discussed.

Mental Capacity Assessments: Room for Improvement?

There exists a wealth of literature concerning mental capacity assessments and how legitimate they are as a way of restricting legal capacity. These concerns are advanced by both academics and the CRPD Committee.

A critique of mental capacity assessments has already been offered with the help of participant responses based on conceptions of self with mental health difference, in Chapters 2 and 4. Mental capacity assessments are strongly cognitive and based on rationalist criteria. In Chapter 2 it is argued that they act as a divide line between the autonomous 'healthy' self capable of making rational, genuine decisions, and a non-autonomous 'ill' self who is not. This divide is based on the presence of a 'disturbance of the mind or brain' which adversely impacts people with psychosocial disabilities. The criteria of mental capacity assessments - that an individual must be able to understand, weigh and retain relevant information to a decision and communicate that decision to others independently, also assumes certain cognitive capabilities those with psychosocial disabilities may not possess. Chapter 4 outlined that the concept of self with mental health difference put forward by the 'healthy' social and philosophical self and the autonomous legal self are not representative of how participants conceive of self. What is more, these models of personhood centered round a 'rational man' seem at odds with our own everyday experiences.[497] They are therefore unlikely to be an accurate representation of self for the majority, disability or no. The CRPD would not uphold this divide line between selves and instead conveys a more universal conception of self. In order to distance from problematic conceptions of self in mental capacity law therefore, and in order to award self with decision making deficits legal capacity, an alternative to mental capacity assessments is required.

There also exist more practical concerns on the validity of mental capacity assessments. These include concerns about the fluctuating nature of capacity and how this can impact the accuracy of assessments. Ruck Keene is concerned that capacity is in the 'eye of the beholder', in the sense that the preconceptions and beliefs of the assessor and how they interact with the assessment criteria, can result in an incorrect outcome.[498] There are also concerns that the weighing of relevant information is being conflated with an outcome approach – where the ends justify the means - in cases involving unwise decisions.[499] Banner highlights that assessments of the use and weigh criteria are often not just objective measures of a person's decision making process, but are impacted by normative dimensions including values, beliefs and emotion.[500] This point is demonstrated by Mr Justice Jackson who highlights the 'catch 22' nature of mental capacity, whereby in the case of *Re E (Medical treatment: Anorexia)*, the decision not to eat meant she could not weigh the relevant information in a meaningful way.[501] The concern that assessors adopt an outcome driven approach to mental capacity assessments also gives rise to concerns around protectionism. As acknowledged by Mr Justice Baker "in cases of vulnerable adults, there is a risk that all professionals involved with treating and helping that person – including, of course, a judge in the Court of Protection – may feel drawn towards an outcome that is more protective of the adult and thus, in certain circumstances, fail to carry out an assessment of capacity that is detached and objective."[502] Mr Justice Hedley makes it clear however in *A NHS Trust v P*

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[497] G. Quinn and A. Arstein-Kerslake, 'Restoring The 'Human' In Human Rights – Personhood And Doctrinal Innovation In The UN Disability Convention', *The Cambridge Companion to Human Rights Law* (1st edn, The Cambridge University Press 2013) 37.

[498] A. Ruck Keene, 'Is Mental Capacity In The Eye Of The Beholder?' (2017) 11, 2 Advances in Mental Health and Intellectual Disabilities.

[499] D. Gibson, 'Conceptual And Ethical Problems In The Mental Capacity Act 2005: An Interrogation Of The Assessment Process' (2015) 4 Laws, 232-238 and C. Kong and others, 'Judging Values And Participation In Mental Capacity Law' (2019) 8 Laws.

[500] N. F. Banner, 'Unreasonable Reasons: Normative Judgements In The Assessment Of Mental Capacity' (2012) 18 Journal of Evaluation in Clinical Practice.

[501] *Re E (Medical treatment: Anorexia) (Rev 1)* [2012] EWCOP 1639 [49-53].

[502] *PH v A Local Authority* [2011] EWCOP 1704 [16xiii].

& Anor that a person is not to be treated as lacking mental capacity because they make an unwise decision: "[t]he intention of the Act is not to dress an incapacitous person in forensic cotton wool but to allow them as far as possible to make the same mistakes that all other human beings are at liberty to make and not infrequently do."[503]

Regarding the weighing of relevant information to a decision, there are concerns about the unrealistic level of subjective insight it would require for the assessor to know whether an individual was disregarding what others would consider 'relevant' information for legitimate reasons or whether their disregard reveals or reflects a disturbance of the mind. This is particularly problematic for cases where the assessee holds strong religious beliefs which tread the line between religious zeal and delusion.[504] Decisions may also seem unwise or to disregard relevant information where the assessor has a very different social, cultural and economic background to the assessee.[505]

There is also a lack of clarity over what it means to 'understand' relevant information. Various interpretations of this term have been offered. Lady Justice Mancur in *LBL v RYJ & Anor* interprets 'understanding' to mean that P understands the salient details of a decision which are case specific.[506] Bartlett and Sandland interpret 'understanding' as having tacit knowledge of the information, which someone can understand without having to believe in.[507] This is contrary to an interpretation offered by Sir James Munby *in Local Authority X v MM & KM* (2007) whereby believing in something is a precondition to understanding, and therefore understanding requires subjective endorsement.[508] What exactly is meant by this criterion therefore is unclear.

Finally, Ruck Keene argues that mental capacity assessments do not take into account that a person may be able to make decision but may lack the executive function to carry these decisions into practice.[509] For example, while a person may be able to answer questions related to a specific decision, their capacity to actually enact that decision may be impacted.

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[503] *A NHS Trust v P & Anor* [2013] EWHC 50 (COP) [10].

[504] *A County Council vs MS and RS* [2014] EWHC B14 (COP) [2014] W.T.L.R. 931 [85].

[505] A. Ruck Keene, 'Is Mental Capacity In The Eye Of The Beholder?' (2017) 11, 2 Advances in Mental Health and Intellectual Disabilities, 34.

[506] [2010] EWCOP 2665 [58]

[507] P. Bartlett and R. Sandland, Mental Health Law: Policy And Practice (4th edn, Oxford University Press 2014), 180.

[508] [2007] EWHC 2003 (Fam) [81]

[509] A. Ruck Keene, 'Is Mental Capacity In The Eye Of The Beholder?' (2017) 11, 2 Advances in Mental Health and Intellectual Disabilities, 31.

Given the difficulty in assessing capacity therefore, these factors have led to medical professionals differing in their opinion of whether P has or lacks mental capacity in case law, including medical professionals differing from the judge’s ruling.[510] The latter is evidenced by *WBC v Z*[511] and *King's College Hospital NHS Foundation Trust v C and V.*[512] These cases confirm concerns around the legitimacy of mental capacity assessments to limit legal capacity.

The CRPD Committee have also made it clear that they prohibit the use of mental capacity assessments as a way of restricting legal capacity. The Committee believes the functional approach present in the Mental Capacity Act - whereby mental capacity is assessed and legal capacity is denied accordingly- is flawed for two key reasons. First they are discriminatorily applied to disabled people and second, they presume to accurately assess the inner workings of the mind or brain.[513] If a person fails the assessment they are denied a core human right- equal recognition before the law. As stated by the Committee *"…unsoundness of mind" and other discriminatory labels are not legitimate reasons for the denial of legal capacity (both legal standing and legal agency.) Under Article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity*."[514] The Committee go on to say that "[*m]ental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon…[it] is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity*."[515]

Regarding functional assessments, they go on to say "[i*]n all of these approaches a person’s disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but, rather, requires that support be provided in the exercise of legal capacity*."[516]

One avenue which has been pursued in an attempt to achieve CRPD compatibility and formal equality for persons with disabilities is to restrict legal capacity on the basis of disability-neutral criteria. Chapter 5 outlined attempts to justify restrictions to legal

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[510] A. Ruck Keene and others, 'Taking Capacity Seriously? Ten Years Of Mental Capacity Disputes Before England's Court Of Protection' (2019) 62 International Journal of Law and Psychiatry, 65.
[511] [2016] EWCOP 4.
[512] [2015] EWCOP 80.
[513] Committee on the Rights of Persons with Disabilities, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 15.
[514] Ibid para 13.
[515] Ibid para 14.
[516] Ibid para 15.

capacity on the basis of harm. This included Flynn and Arstein-Kerslake's 'imminent harm,' Bach and Kerzner's 'serious adverse effect' and the ALRC's proposals allowing a representative to overrule will and preference where 'necessary to prevent harm.' Risk or dangerousness are also criteria currently used in the majority of domestic mental health laws of those signatory to the CRPD, to justify compulsion.

Others argue that decision making assessments or the functional component of mental capacity assessments, decoupled from a diagnostic criterion, provide a disability neutral way to legitimately restrict legal capacity.[517] For example Szmukler, Dawson and Dawb propose a fusion law which assesses decision making capacity on disability neutral criteria to restrict legal capacity for certain time-specific decisions.[518] This applies to situations where support is insufficient to assist the individual in making a decision or where support has been refused.[519] Szmukler et al argue that this approach would apply equally to all regardless of disability according to the definition of disability offered by the CRPD. He uses the example of a young person suffering a head injury during a motorcycle accident, and how the decision-making assessment would apply equally to this person regarding treatment refusals, as it would to someone with a diagnosis of schizophrenia.[520] This approach is currently used by the Mental Capacity Bill (Northern Ireland) 2016 and uses only deficits in decision-making decoupled from a diagnostic criterion.[521]

Nilsson also argues that "[i]f certain skills are deemed vital to health care decision-making, this should arguably apply to every health care user."[522] This argument is made on the basis that there is a lack of empirical evidence linking diminished decision-making capacity with presence of a psychosocial disability. There is therefore insufficient evidence justifying the targeting of those with psychosocial disabilities in current mental health law. Instead everyone, including those with somatic conditions, ought to be

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[517] See G. Szmukler, R. Dawb and F. Callard, 'Mental Health Law And The UN Convention On The Rights Of Persons With Disabilities' (2014) 37 International Journal of Law and Psychiatry; G. Szmukler and M. Bach, 'Mental Health Disabilities And Human Rights Protections' (2015) 2 Global Mental Health; W. Martin, 'Consensus Emerges In Consultation Roundtables: The MCA Is Not Compliant With The CRPD' (ThirtyNine Essex Street 2014) <http://repository.essex.ac.uk/14227/1/UNCRPD-MCA-Compatibility-Discussion-Paper-Final-5-8-14.pdf> accessed 21 July 2021; A. Nilsson, *Compulsory Mental Health Interventions And The CRPD: Minding Equality* (HART Publishing 2021).

[518] G. Szmukler, R. Dawb and F. Callard, 'Mental Health Law And The UN Convention On The Rights Of Persons With Disabilities' (2014) 37 International Journal of Law and Psychiatry

[519] Ibid, 250.

[520] Ibid 249.

[521] s 3(3).

[522] A. Nilsson, 'Objective And Reasonable? Scrutinising Compulsory Mental Health Interventions From A Non-Discrimination Perspective' (2014) 14 Human Rights Law Review, 484.

subject to compulsion where certain decision making criteria are not met, in order to achieve disability neutrality.

Bartlett expresses concern that a loss of decision-making ability caused by impairment of mental functioning would in effect constitute a 'disability,' meaning restrictions made on the basis of a functional approach would still not achieve disability neutrality.[523] As put by Bartlett "the fact that the statute is neutral on its face will not address [the problem of discrimination in mental capacity law] if a prohibited criterion – disability, in this case – is still relevant to the decision taken. Express discrimination has merely become implied discrimination."[524] This reflects concerns that formal equality via the functional approach fails to account for indirect discrimination and create real change. Indeed, achieving substantive equality for disabled people according to Kayess and French, requires consideration of difference, structural and institutional change.[525]

Minkowitz outlines that a change of language would do nothing to combat inequality and discrimination, while power relations go untransformed.[526] This is because the functional approach would no doubt have a disparate impact on disabled people resulting in indirect discrimination. Disabled people are more likely to be targeted for assessments because of prejudice. Indeed Arstein-Kerslake and Flynn believe the presence of disability plays a 'major role' in the determination of functional capacity.[527] Targeting is also likely because the choices and actions of disabled people are more visible to third parties from whom they receive care and support.[528] Incapacitous decisions by someone without a disability are therefore less likely to be flagged for intervention in the same way.[529] The level of intervention is also likely to be much greater for disabled people compared with others. The comparable examples provided for non-disabled people i.e. a person in a road traffic accident or someone who has had too much to drink, are likely to incur low levels of short-term interference with individual rights.[530] This is in contrast to the kinds of

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[523] P. Bartlett, 'The United Nations Convention On The Rights Of Persons With Disabilities And Mental Health Law' (2012) 75 The Modern Law Review, 763.

[524] Ibid.

[525] R. Kayess and P. French, 'Out Of Darkness Into Light? Introducing The Convention On The Rights Of Persons With Disabilities' (2008) 8 Human Rights Law Review, 8-9.

[526] T. Minkowitz, 'CRPD And Transformative Equality' (2017) 13 International Journal of Law in Context, 84.

[527] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 87.

[528] L. Series and A. Nilsson, 'Article 12 CRPD: Equal Recognition Before The Law', rom: The UN Convention on the Rights of Persons with Disabilities: A Commentary Edited By: Ilias Bantekas, Michael Ashley Stein, Dimitris Anastasiou (1st edn, Oxford University Press 2021), 358.

[529] Ibid.

[530] Department of Constitutional Affairs, 'Mental Capacity Act 2005 Code of Practice' (London: TSO, 2005) para 4.9 and 4.12; also W. Martin, 'Consensus Emerges In Consultation Roundtables: The

interferences disabled people are more likely to face, including "institutionalisation, forced psychiatric treatments, entry into guardianship, involuntary sterilisation, loss of rights to marry and found a family or engage in sexual relationships."[531] There are very few instances in which these measures are taken in regards to someone without a disability, and therefore to compare them seems inappropriate. Appelbaum and Grisso also believe the criteria for competence assessments determines the identity and proportion of individuals deemed to lack capacity.[532] Therefore capacity assessments create a characterization of persons who are incompetent. Capacity assessments are therefore designed to pick out characteristics which are more common in clinical groups than in the general population, meaning indirect discrimination is almost inevitable because of the very nature of the assessments design.

Criticisms made in Chapter 2 and 4 would also not be addressed by retaining a functional approach minus the diagnostic criteria. Both the conception of self contained in capacity assessments - and the divide assessments draw between the autonomous 'healthy' self from the 'ill' non-autonomous self, need to be removed to achieve CRPD compatibility. The functional approaches decoupled from psychosocial disability, retains both.

If both mental capacity assessments and functional assessments are lacking then in regards to achieving CRPD compatibility, the problem becomes on what basis an individual's legal capacity can be restricted. This problem is best encapsulated by Szmukler, Daw and Callard, who state that "while there is practical work still to be done on impaired [decision-making capacity]…we see no other ethical basis for potentially intervening in a person's life when their wellbeing appears to be seriously threatened by what appears, at first sight at least, to be a seriously imprudent decision or an inability to make a decision at all."[533] Others who critique decision making assessments "argue that a fundamentally new approach is required – a "new paradigm" that will provide support to persons with disabilities to give effect to their own will and preferences, rather than stepping in to make decisions on their behalf where decision-making capacity is deemed

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MCA Is Not Compliant With The CRPD' (ThirtyNine Essex Street 2014) <http://repository.essex.ac.uk/14227/1/UNCRPD-MCA-Compatibility-Discussion-Paper-Final-5-8-14.pdf> accessed 21 July 2021, para 14.

[531] L. Series and A. Nilsson, 'Article 12 CRPD: Equal Recognition Before The Law', rom: The UN Convention on the Rights of Persons with Disabilities: A Commentary Edited By: Ilias Bantekas, Michael Ashley Stein, Dimitris Anastasiou (1st edn, Oxford University Press 2021) 357.

[532] P. S. Applebaum and T. Grisso, 'Comparison Of Standards For Assessing Patients' Capacities To Make Treatment Decisions' (1995) 152 American Journal of Psychiatry, 1033.

[533] G. Szmukler, R. Dawb and F. Callard, 'Mental Health Law And The UN Convention On The Rights Of Persons With Disabilities' (2014) 37 International Journal of Law and Psychiatry, 248.

to be lacking."[534] Attempts have been made to create a supported decision making approach compatible with the CRPD.[535] It has already been outlined however that these alternatives retain reliance on some form of functional/decision-making assessment.[536] In this chapter it is argued that advance plans could provide this 'new paradigm' which does not rely on a state-enforced functional test of decision making capacity, to legitimately restrict legal capacity.

Participant Experiences of Mental Capacity Assessments

Participants who had been the subject of, witnessed or conducted a mental capacity assessment were asked what they thought of them and whether they had room for improvement. This was to see whether participants agree with the CRPD Committee that mental capacity assessments need significant reform. Participant responses offered two additional critiques of mental capacity assessments. These include the time specific nature of assessments and the lack of relationship between the assessor and assessee. Currently assessments are decision and time specific. Participant responses however would indicate a departure from the latter to reflect the more holistic and individual nature of self and mental health difference over time, as opposed to a 'snapshot'. There is also no requirement for assessors to know or have previously cared for the assessee. Participants believe this provides another area for improvement. Participant responses also provide insight into the nature of professional support in decision making.

When asked for their opinion of mental capacity assessments, responses varied. Some believed mental capacity assessments were necessary. When asked why, participants on the whole responded that an objective assessment conducted by a healthcare professional provides an authority other professionals could trust, authority which would not be present if the individual themselves or an elected support person conducted the assessment. This perspective portrays part of a healthcare professional's role as

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[534] W. Martin, 'Consensus Emerges In Consultation Roundtables: The MCA Is Not Compliant With The CRPD' (ThirtyNine Essex Street 2014) <http://repository.essex.ac.uk/14227/1/UNCRPD-MCA-Compatibility-Discussion-Paper-Final-5-8-14.pdf> accessed 21 July 2021 para 21.

[535] See for example L. Kerzner and M. Bach, 'A New Paradigm For Protecting Autonomy and the Right to Legal Capacity' (Law Commission of Ontario 2010) and Australian Law Reform Commission, 'Equality, Capacity And Disability In Commonwealth Laws (ALRC Report 124)' (2014) available at https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/3-national-decision-making-principles-2/will-preferences-and-rights-2/.

[536] Supra note 2-5.

validating and legitimizing intervention, something an individual or support person alone cannot currently do with any real enforceability.

Power over intervention therefore, resides for many participants, with the relevant clinician. This does not however appear to be the role of medical power proposed in the CRPD.

The role of medical professionals in the CRPD seems to be primarily one of support. More specifically the role seems to focus on facilitating informed consent which involves direct engagement, providing information on medical and non-medical treatment options,[537] and providing quality treatment on an equal basis with others.[538] Medical professionals also seem to be guardians of 'true' will and preference under the CRPD. As stated by the Committee *"[a]ll health and medical personnel should ensure appropriate consultation that directly engages the person with disabilities. They should also ensure, to the best of their ability, that assistants or support persons do not substitute or have undue influence over the decisions of persons with disabilities."*[539] The Committee also make it clear that a medical professional is not permitted to make a substituted judgment on behalf of an individual with disabilities.[540] Power over intervention and treatment therefore seem to reside firmly with the individual as opposed to medical professionals. Only where the will and preference of the individual cannot be obtained does it seem medical professionals could play a role in making treatment decisions by helping ascertain a 'best interpretation' of the individuals wishes, based on any relevant prior conversations. The majority of participants supported a more CRPD-aligned conception of medical power as well as a move away from medical power.

Regarding mental capacity assessments, other participants talked about them as a source of embarrassment, likely because they confront a person's self-constructed identity and how they portray themselves to others. Peter reflects: "I thought it was...well, quite embarrassing for me mum…that she had to do it, because she's always been independent and stuff..." Assessments are also designed to pick up on lack as opposed to using a capabilities approach to identify areas where an individual requires additional decision-making support.[541]

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[537] Committee on the Rights of Persons with Disabilities 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 42.

[538] United Nations Convention on the Rights of Persons with Disabilities, Article 25(d).

[539] Committee on the Rights of Persons with Disabilities 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 42.

[540] Ibid para 3, 17, 27, 28, 40, 41.

[541] Bach and Kerzner's approach for example draws on Amartyr Sen's capabilities approach, acknowledged in L. Kerzner and M. Bach, 'A New Paradigm For Protecting Autonomy and the Right

Participants also talk about them being frustrated by and fearful of assessments, because they know that if failed their decision-making enforceability could be taken away:

> "…you're thinking, I need to be careful to make sure I don't get locked up for a while [laughs] last thing you want is to end up with a hospital stay…" [Daria, bipolar]
>
> "I get annoyed by assessments…I get really frustrated…because, [exhales] it's horrible having, like, three people that you don't know trying to make a decision about your life, it's really frustrating, but it is a necessity at the same time…" [Michelle, bipolar with psychotic episodes]

A couple of participants described having covert assessments which were done by medical professionals without their knowledge. This includes Anthony who is diagnosed with schizophrenia and Molly's mother who had dementia.

> "Anthony: For me it was covert...retrospectively I look back in horror actually- like how on earth could they have done that!? But I do think part of it is paternalism- it's about their thinking, you don't have insight and…therefore we need to take as much charge- we don't want to cause distress…whereas I think if they'd been more upfront about it I would've been fine with it…"
>
> "Molly: [i]t was a very cursory visit…[the social worker] was really I suppose just there to confirm what the mental health nurse, thought… as much as anything, it had a practical purpose…
>
> I: [Did your mum have] an awareness of why they were there and that they were doing an assessment of?
>
> Molly: Well I think she was suspicious, and she was very scared! Cause she knew the implications…"

This paternalistic approach of leaving an individual out of decisions about their mental health status and decision-making capabilities, to supposedly prevent them from becoming distressed, goes against both the CRPD and a standard view of human rights. Participants who had experienced covert assessments therefore supported the Committee's emphasis on consultation which directly engages disabled people.[542]

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to Legal Capacity' (Law Commission of Ontario 2010) 21-22, 68-71.

[542] Committee on the Rights of Persons with Disabilities 'Article 12: Equal Recognition Before The

When asked how they felt mental capacity assessments could be improved upon, all felt capacity assessments could be more tailored to the individual. This was to reflect the highly individual nature of self, how mental health impacts self and how this fluctuates over time and with new experiences. Some participants felt the questions asked to gauge capacity were not always relevant to the individual being assessed and therefore should be made more contextual according with the individual's life and relevant knowledge. For example 'who is the prime minister' was a question raised separately by a number of participants as having been asked, which might have been outside the remits of the assessee's knowledge.

Another highlighted area for improvement was the frequent lack of relationship between the assessor and assessee. Participants feel this infringes an assessor's understanding of the individual and how mental health impacts their self, both of which are highly individual. Emphasis was therefore placed on time and the building over time of a more holistic understanding of the individual on a continuum, by the assessor. This is in contrast with an assessor having no prior relationship with the individual and getting a 'snapshot' of their capacity in a very short time frame, as is currently the case for many capacity assessments. This was important to participants because of the fluctuating nature of capacity, meaning a 'snapshot' is not representative of capabilities which may change day to day and with medication, the side effects from which can be difficult to separate from the effects of mental disorders.[543]

For the reasons given, participants also felt close family and friends who have known them for a prolonged period of time and have witnessed them before during and post mental health difference, are in a better position to assess decision-making capacity. They are also able to draw an informed comparison of self before and during a mental health experience to assess whether and by how much decision-making capacity has diminished, a comparison many assessors would be unable to draw. Participants therefore suggested drawing on the insight of an elected support person to assess capacity.

The problem of a 'snapshot' assessment was raised by Jessie who was a volunteer advocate for disabled people for several years and identified many occasions where an individual was overmedicated immediately before a mental capacity assessment. She felt this unduly impacted the outcome of the assessment. A prolonged period of assessment

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Law General Comment No 1'(2014) para 41.

[543] P. Bartlett, 'The United Nations Convention On The Rights Of Persons With Disabilities And Mental Health Law' (2012) 75 The Modern Law Review, 763.

or prior relationship with an assessor would therefore have been beneficial to take these factors into consideration.

> "I: [What is your experience of mental capacity assessments?]
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> Jessie: Appalling! This is a woman I've fostered who had down syndrome because she had early onset dementia, for a start the questions weren't relevant to her, to her existence, and second I found it was contextual and didn't take into account that tomorrow she'd be quite different, so it just made no sense…this...small snapshot, and I actually worked with her over a continued two weeks to demonstrate she did have capacity, whilst we were being told she didn't
>
> I: So you think there's maybe a need for a better understanding of her whole self and not just the person on the day?
>
> Jessie: Yes, exactly, the holistic continuum over a period of time, and also where she'd be losing- she was growing in other areas…and I think it should be based on things that are relevant to your world and your experience because we're all very different"

Having established that mental capacity assessments contain room for improvement according to academic literature and responses from participants, the next section moves on to discuss a written statement on change in self as an alternative. This approach moves away from a functional approach to create new thinking on a user-led alternative. How this alternative achieves CRPD compatibility and improves upon the criticisms outlined above is discussed.

Change in Self Caused by Mental Health Difference as a User-Led Alternative: Opting into State Intervention

An overview

The following section discusses a user-led written statement on change in self with mental health difference, based on past experience. This statement is specifically to trigger self-binding provisions in an advance plan, which come into effect before an individual has lost the ability to communicate will and preference.

It is worth reiterating that this is by no means a full theory on proposed statutory reform. Instead, this idea is the product of findings and participant responses from Chapters 2, 4 and 6 in an attempt to create some new thinking on a mental capacity / functional approach alternative. This approach is being used as a framework for participant responses and to provide a starting position on a way forward. Its purpose is to frame data and prompt discussions, not to propose legislative reform.

The user-led statement on change in self during mental health difference, was put to participants in a basic format. It was conceptualized as a written statement created by them, prompted by the elements of self activity outlined in Chapters 3 and 4 where individuals were asked to communicate self and how self changed during a mental health experience. The trigger would therefore be the individual communicating in written form, how they felt their self or their elements of self, changed during mental health difference. This would be with a focus on perceivable changes others could notice. We have already seen examples in Chapter 4 of these changes and how they could be communicated. The group who desired self-binding provisions are the ones who likely demonstrate the most perceivable changes in self because of how drastic there are. These changes are individual, as outlined in Chapter 4, but included behavioural changes, asking strange questions, elements of their self becoming magnified or shrunk and becoming comparatively more fearful and paranoid, to name a few examples. It is also worth noting that this kind of self-awareness of mental health is already utilized in recovery planning- usually in the form of 'early warning signs,' and is therefore a concept some participants were already familiar with.[544] When these changes begin to manifest and decisions contrary to those in the statement are being made, this statement could then be used to trigger the advance plan to enforce the will and preference contained within. This model was not put to participants in detail, but as a basic principle to gain feedback on the idea.

This approach could make a number of improvements to mental capacity assessments in regard to achieving CRPD compatibility and overcoming the criticisms outlined in the previous sections.

First, the concept of 'self' - specifically a user-led perspective of change in self, has the potential to create some new thinking on an alternative to mental capacity by moving away from autonomy and mental capacity, to a more fundamental concept which has yet to be considered in this context. Whilst the concept of 'self' has not yet been considered in discussions of an alternative to mental capacity assessments- indeed theories have yet to incorporate self with mental health in a fully inclusive way- self is non-the-less at the heart of both autonomy and mental capacity. Legal personhood and what it means to be

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[544] See for example Wellness Recovery Action Plans (WRAP) and the 'This is me' statement for dementia and Alzheimer's care.

human are questions central to the rights discourse and who can accumulate rights.[545] Removing the autonomous legal self from the equation means certain capabilities or elements of self people are *supposed* to have, are not forced on individuals with mental health difference to restrict legal capacity. This fundamentally removes a benchmark decided by others of what characteristics the autonomous self should have, and instead allows the individual to decide their own benchmark. We have already seen in Chapter 4 that the elements of the autonomous self are not reflected in participants view of self. If the power of self-construction and capabilities is placed with the individual, this allows for a more tailored process which respects the highly individual nature of self as outlined in Chapter 4. Individuals would be able to describe how mental health impacts their self and decision-making abilities, rather than having these things prescribed for them. It therefore overcomes the barrier to CRPD compatibility outlined in Chapter 2- by detaching from problematic conceptions of self via the autonomous legal self and 'healthy' social theory self and moving toward a more CRPD compatible model of universal self.

Drawing on past experience of mental health difference also avoids the current problem of people making decisions about future unfamiliar situations where they are unlikely to accurately predict what they will want.[546] This would avoid the problem presented in Dworkin's hypothetical Margo case, where Margo refused life sustaining treatment years previous when she was a very different version of self.[547] This approach also echoes Berghman's observations that self-binding advance plans for those with progressive conditions should be contingent on how recently they were made and should become less relevant as the condition progresses and the persons self and wishes change.[548]

Second, this is not a functional approach. It replaces a mental capacity assessment with triggers decided by the individual based on past experience. It is therefore not a blanket assessment and does not impose a problematic concept of self nor a standard of decision making that self ought to be capable of. These triggers can be individual to reflect the individual nature of self and how mental health impacts self. This also adheres to the

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[545] For example, the Universal Declaration of Human Rights applies to all persons by virtue of being human in Universal Declaration of Human Rights (UDHR) 1948, (resolution 217 A), adopted 10 December 1948 preamble.

[546] R. Dresser, 'Life, Death And Incompetent Patients: Conceptual Infirmities And Hidden Values In The Law' (1986) 28 Ariz. L. Rev.

[547] R. Dworkin, Life's Dominion: An Argument About Abortion, Euthanasia and Individual Freedom (Harper Collins, London, 1993) 220-226.

[548] R L Berghmans, 'Advance Directives For Non-Therapeutic Dementia Research: Some Ethical And Policy Considerations.' (1998) 24 Journal of Medical Ethics, 35.

CRPD Committee’s statement that perceived or actual deficits in mental capacity should not be used to justify restrictions to legal capacity,[549] and matches the guidance offered by the Committee on when advance directives should trigger. Advance Directives- presumably meaning treatment refusals- are described by the Committee as entering into force and ceasing to have effect at a point “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.”[550] A written statement on change in self meets these criteria. By moving away from a functional approach, the divide line between different versions of self, outlined in Chapter 2, is removed, and instead we can begin to envisage a self with mental health difference capable of full legal capacity.

Removing this divide line also aids in moving toward a more CRPD-aligned conception of universal self as opposed to dividing versions of self on the basis of ‘lack’ ‘illness’ and cognition. It could aid in moving away from a blanket, problematic ‘true’ self conception in advance planning. While there remains some semblance of a division between versions of self or a different class of will and preference, this divide is drawn by the individual and not the state. By allowing individuals to decide their own indicators this divide is also not necessarily based on cognition and what a ‘healthy’ autonomous self ought to be capable of, unless the individual so chooses. A ‘true’ self conception is therefore not upheld by this formulation of self-binding to anywhere near the extent as it is currently.

Third, by allowing a statement on change in self to trigger the plan *before* an individual has lost the ability to communicate will and preference, this allows people to self-bind and opt-into state intervention as opposed to having intervention forced upon them. This offers protection to the group of individuals identified in Chapter 6 - who communicate disingenuous or harmful will and preference during a mental health experience. It also respects the right to take risks and make mistakes for individuals with psychosocial disability who do not desire state intervention. This therefore marks an improvement to current mental capacity assessments, where, if an individual is found to lack mental capacity, intervention follows. This addresses one of the most contested elements of CRPD compatibility – how to safeguard vulnerable persons with disabilities while upholding a right to legal capacity. The ability to opt-into restrictions of one’s own legal capacity is likely one of the most CRPD compatible ways this can be done, without falling back into substitute decision making. For this reason, and because advance plans

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[549] Committee on the Rights of Persons with Disabilities 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 13.
[550] Ibid para 17.

document will and preference, advance planning has the potential to play a crucial role in protecting legal capacity under Article 12 of the CRPD.

Everyone can engage on an equal basis with others, regardless of disability, in creating an advance plan to document will and preference for a future point in time when they are unable to communicate wishes. The introduction of self-binding using a statement on change in self and its focus on experience however, does mean the target audience for this provision are people with psychosocial disabilities. In this sense, people with psychosocial disabilities have more provisions for advance planning and can utilize advance planning more widely than people without disabilities. Self-binding provisions within advance planning would therefore apply disproportionately to persons with psychosocial disabilities. This however should not be considered indirect discrimination but accommodation of difference, and acknowledgment that those who tend to plan in advance are those who expect their self and decision-making capabilities to change.[551] 'Respect of difference' is also a general principle in Article 3(d) of the Convention. This accommodation of difference creates positive steps to acknowledge the needs of disabled people - in this case the need for support in restricting legal capacity.

Finally, the statement on change in self was conceptualized as a written document to avoid the practical issues which can currently be foreseen with verbal advance plans. Judges and relevant clinicians are more likely to be swayed in their decision making by written statements which formally document will and preference, as opposed to oral statements which may have been informal, had less thought given to them and which could be more subject to external influence.

Now that a written statement on change in self has been outlined, including how it was presented to participants, how it achieves CRPD compatibility and improves upon the criticisms of mental capacity assessments, the next section outlines a case for self-binding provisions in advance plans and how they can retain CRPD compatibility.

A Case for Self-binding under the CRPD

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[551] R. Kayess and P. French, 'Out Of Darkness Into Light? Introducing The Convention On The Rights Of Persons With Disabilities' (2008) 8 Human Rights Law Review, 8.

Overall, it is unclear whether the CRPD would permit or prohibit self-binding, and therefore whether self-binding is a restriction or an exercise of legal capacity. However, the CRPD recognizes the possibility to restrict legal capacity and overrule some will and preference. It could also be argued that self-binding in the formulation it is presented here, can in fact be an exercise of legal capacity as opposed to a restriction of it.

A strict reading of general comment no.1 may have us believe that will and preference must be adhered to at all times, including in emergency situations, in order for the right to legal capacity to be upheld. Therefore, will and preference during a mental health experience cannot be overruled even in respect of a single decision. This would seem to preclude self-binding which allows the individual to document wishes to overrule their own will and preference at a future point in time, when certain conditions (in this case observable changes in self because of mental health difference) are met. However I am of the opinion that respecting legal capacity is not as simple as adhering to everything a person says during a mental health crisis. I believe it possible, provided the right conditions are met, that self-binding using advance planning could in fact be an extension as opposed to a restriction of legal capacity. By 'the right conditions being met' I am referring to striking a balance between the right to protect self and others from harm using self-binding on the one hand and using self-binding to inadvertently cause harm on the other. The way this proposed alternative uses self-binding makes considerable advancements in achieving compatibility with the CRPD. First, it is possible to interpret the CRPD as permitting some will and preference to be overruled, thereby justifying restrictions to legal capacity. Article 12(4) details safeguards to "ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, *apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests* [emphasis added]." While the Committee explain that these safeguards refer to systems of support, the italicized section of this paragraph is where the CRPD strays from safeguarding support to safeguarding scenarios in which legal capacity is restricted.[552] After all, why would it be desirable for support to apply for the shortest time possible and in what ways would decision-making support which respects will and preference affect a person's rights and interests? This indicates that the drafters of the CRPD must have anticipated situations in which will and preference can be overruled, thereby restricting legal capacity. Richardson

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[552] Committee on the Rights of Persons with Disabilities 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 20.

suggests that this could extend to substitute decision making in some extreme cases, and for our purposes this could also include self-binding provisions.[553] This sentiment is also echoed by the Committee in their discussion of advance directives. Allowing directives to trigger 'at a point decided by the individual and included in the text of the directive' infers that the advance plan can come into effect at a point before an inability to communicate will and preference.[554] It is possible therefore that advance directives may have some self-binding properties, and this principle could be extended to other forms of advance planning.

It has been shown from participant responses in Chapter 6 that self-binding provides a way for people to safeguard themselves and others from harm. In Chapter 1 it was highlighted that the very draw of advance planning for some people with psychosocial disability is the ability to overrule will and preference during a mental health crisis. In Chapter 6 participants discussed wanting to self-bind to protect self from harm. This distinction of there being different classes or categories of will and preference has been picked up by a number of academics to justify why not every will and preference has to be listened to, to uphold legal capacity. This includes Flynn and Arstein-Kerslake's discussion of a support person removing a person from a situation against their will in order to gather and understand their 'true' will and preference in emergency situations.[555] Szmukler separates 'will' from 'preference' in order to justify overruling harmful preferences which are not thought to reflect that individual's will. This approach was adapted from Dworkin's critical and experiential interests which again differentiates between different categories of will and preference and justifies the use of advance plans, which contain critical interests, to overrule experiential interests made during a mental health episode. Not all will and preference therefore may have to be adhered to, to retain legal capacity. If an individual can identify different categories or classes of will and preference, based on past mental health experience, as we have seen one group do in Chapter 6, self-binding is one way to prevent one class of will and preference from overruling or harming a more important class of interests. Adhering to the will and preference contained in an advance plan instead of the will and preference expressed by that same person during a mental health experience therefore, can in some situations aid in exercising the right to legal capacity.

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[553] G. Richardson, 'Mental Disabilities And The Law: From Substitute To Supported Decision-Making?' (2012) 65 Current Legal Problems, 346.

[554] Committee on the Rights of Persons with Disabilities 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 17.

[555] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context.

Therefore, provided self-binding is formulated to address these criticisms, is careful to support individuals in opting into restrictions of will and preference during a mental health experience, and does not unduly restrict will and preference, self-binding can be a tool to extend legal capacity as opposed to restrict it.

Participant Responses

Overall, when asked whether a written statement on change in self due to mental health difference was a viable alternative to mental capacity assessment, responses varied. The majority felt in its current state it was not a viable alternative, others believed the approach was an improvement on mental capacity assessments but that it needed further development. Participants shared concerns and offered constructive feedback on how this approach could be developed.

Those who liked the approach, did so because it supported a power shift away from medical power towards the individual and reframed the role of medical professionals as one of support. It gives the individual control over their mental health treatment and intervention. Control is a theme discussed in Chapter 4 as one way self changes with mental health difference and is discussed again in Chapter 6 in regards to self-harm being a way to regain control. If control is returned to the individual this may diminish feelings of powerlessness which have a negative impact on that person's outlook and behaviours. Were this statement to work, it would therefore have to be part of a wider movement to shift power away from medical professionals and toward the individual. This is in line with the CRPD's shift away from the medical model to the social model, discussed in Chapter 1. We have already seen a movement towards more individual participation regarding the future direction of mental capacity law, for example in the Wessely report[556] and the white paper on 'Reforming the Mental Health Act.'[557] The CRPD general comment on Article 12 also outlines how states must take steps to "[c]losely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations, in the development and implementation of legislation, policies and other decision-making processes that give

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[556] S. Wessley, 'Modernising The Mental Health Act Increasing Choice, Reducing Compulsion Final Report Of The Independent Review Of The Mental Health Act 1983' (2018) <https://www.gov.uk/government/groups/independent-review-of-the-mental-health-act#governance> accessed 14 January 2021

[557] Department of Health and Social Care, Reforming the Mental Health Act (Cm 355, 2021)

effect to Article 12."[558] The importance of this power re-balance is a core principle of the CRPD and cannot be understated.

Participants who thought the concept was not a viable alternative did so because of concerns over the statement's formation and practicality.

There were concerns among some participants that they would be unable to communicate, with support, a coherent statement on self and how self changed with mental health difference.

When asked if they felt able to create a statement on self there were several issues raised, including issues observed during the earlier elements of self activity, discussed in Chapters 3 and 4. First, spousal carers and relatives of those with progressive mental health difference, expressed that their relatives would be unable to communicate a change in self, as they lacked both the self-awareness and predictability to know how their self would change. By the time their self had changed they would likely lack the self awareness and the cognitive ability to create a written statement on change in self. It has already been discussed in Chapter 6 how the impact of mental health on self, specifically the ability to regain self following an episode, impacted participants opinions on who should be able to self-bind. Because people who experience mental health for the first time or who have mental health characterized as progressive have no prior experiences to draw on to inform change in self, this group may either be excluded from self-binding under this approach or would have to rely on alternate triggers. I personally favor the former. More on how this approach is better suited for some groups as opposed to others is discussed in the section 'reflecting on this approach.'

Second, some participants felt unable to communicate self using a written statement, because they did not feel they currently had a sense of self. It may be difficult therefore for the purposes of this alternative to create a statement on how self changes with mental health, given the baseline of 'self' is unclear. This linked with participant discussion in Chapter 4 of mental health experience as a process of self-rediscovery or self-making/unmaking, and how the experience challenged previously held conceptions of self. Some participants therefore felt they were unable to communicate self, and indeed many could not do so or struggled to do so, during the elements of self activity.

Others felt their self changed daily, meaning they would be unable to communicate a coherent concept of self. As stated by Sandra, "if you put them in a row today you could ask us again next month and we'd put them in a different row…they're [the elements of

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[558] Committee on the Rights of Persons with Disabilities 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 50(c).

self prompt cards] all part of who I am." This was an issue noted during the elements of self activity, during which participants would regularly include, dis-include, reorder elements, and continuously change their mind as others were talking. If self is an ongoing and fluctuating concept this does indeed make any reliable communication of self difficult, especially if this communication is to play a role in a legally binding advance plan. This relates to concerns that 'self' and the factors which go into making up self are abstract and can mean different things to different people. This feedback is what gave rise to a focus on observable triggers which could be perceived by others, and participants suggested accompanying the triggers on how self changes with descriptions, examples and explanations in an attempt to understand the individual's intent as clearly as possible.

Another concern around the practicality of a user-led statement was that medical professionals would not trust individuals to make the decision of when an advance plan with self-binding provisions should trigger. If medical professionals are not on board with the proposed reform, it is unlikely to work in practice. There exists a tension between the perceived role of clinicians to make treatment decisions they believe to be in the best interests of the patient, and the principle of allowing patients to make their own treatment decisions and plan in advance, especially when these two conflict.[559] In order to have a user-led trigger therefore, there would have to be a shift in the role of clinicians from a paternal substitute decision maker role with comparably more power than the patient, to one focused on providing sufficient information for informed consent, building a trusting and supportive relationship with the individual, and where the individual is in a greater position of power.

Participants suggested that one way a compromise could be met was by involving a trusted medical professional in the creation of the statement. Perceivable changes in self could therefore be formed collaboratively to encompass different subjective and objective perspectives by drawing on support persons secondary experience and the medical professionals expertise. This input could aid in getting medical professionals on board with the idea. In terms of format, this process could possibly replicate a circle of support, where everyone participates equally in discussion and contribution, but the individual is ultimately the one who decides which triggers to include in the statement.[560] This would

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[559] P. Bartlett, 'PACT Advance Decision-Making Template: Is Another Form Really The Answer?' <https://www.nationalelfservice.net/treatment/systems/pact-advance-decision-making-template-is-another-form-really-the-answer/> accessed 22 July 2021.

[560] For authority on the use of circles of support see World Health Organization, Supported decision-making and advance planning: WHO Quality Rights specialized training (Geneva: World

also overcome a problem identified by Verekamp about what to do if the medical professional who can judge whether the advance plan is activated is not there during a moment of crisis.[561]

It is possible that participants only suggested including a medical professional in this process because of the perceived power professionals have, which could help assure the document would be taken seriously. As stated by Lulu "no one would ever question the GPs letter really [laughs]." However this may be a possible compromise in order to make this alternative workable in practice and to ensure the individual has access to a range of support, including professional support, during the formulation of their statement. Some participants discussed not having a trusting and enduring relationship with a medical professional, and so preferred creating the statement with only the help of a close family member. This again emphasizes the shift in the role of medical professionals which would need to take place were this alternative to work- towards building an enduring a trusting support relationship.

Regarding other constructive feedback, some participants who felt they could complete a statement on change in self felt they would struggle to do so because of cognitive difference or diagnosis such as attention deficit disorder. They would therefore need assistance because of the written nature of the statement and its formality. Participants gave the comparable example of Personal Independence Payment forms, which they required support to fill out.

Participants also offered some helpful insight into who they would want to interpret the statement to decide when the perceived changes in self had been met- a question many participants immediately jumped to. For example, if a plan contained information about how an individual's self changed with mental health difference, and these included becoming withdrawn, spending time alone, aspects of their personality shrinking of becoming magnified, making decisions considered out of character (with details on the kinds of decisions they consider out of character;) who would be charged with deciding these conditions have in fact been met?

In the Committees statement on how advance directives should come into force and cease to have effect there exists no requirement that the individual must interpret the triggers themselves, although this possibility is also not excluded. Voluntary admissions

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Health Organization, 2019). Available at https://apps.who.int/iris/bitstream/handle/10665/329609/9789241516761-eng.pdf?sequence=1&isAllowed=y, 32.

[561] I. Varekamp, 'Ulysses Directives In The Netherlands: Opinions Of Psychiatrists And Clients' (2004) 70 Health Policy, 296.

to mental health facilities show that maintaining a level of self awareness to trigger an advance plan is not outside the realms of possibility. Indeed we have already seen this level of self-awareness in Michelle's simultaneous desire to get help and avoid being sectioned- eventually attending a medical practice of her own free will to obtain medication during a manic-psychotic episode.

When asked if they felt able to trigger this statement themselves, the majority felt this was something they would be unable to do. Some lacked the self-awareness to realise they had changed, others would not want to willingly relinquish decision making capabilities and some feared the consequences of relinquishing decision-making control. While the group of individuals who experienced drastic changes in self, identified in Chapter 5, did retain a level of self-awareness, they did describe either ignoring this self-awareness of their declining mental health or actively using this awareness to deceive those around them to retain decision making enforceability for as long as possible.

An example of this is provided by Nicole who describes altering her behaviour to deceive those around her and retain legal capacity for as long as possible, because the voices wanted her to keep them a secret:

> "Nicole: the voices…didn't want to me to talk about them, it was meant to be a secret…they felt very, very intense…they had a lot of power over me…as a patient, we used to try and work out how we can get away as soon as possible, and…you kind of play mind games with the doctors and nurses because you're like- oh they ask me that- more medication, if I say no- less medication…so for me, if I knew that what I say will determine, whether I get power of something…I will play the game…
>
> I: okay so if you put something in the advance plan like- if I start asking unusual questions or if I start doing this behaviour- something like that- if you were aware of that during your mental health experience, you would either deliberately not do those things, so you could manipulate and maintain decision making for as long as you could?
>
> Nicole: Yeh, definitely"

For many this question was inextricably bound with the statement's formation. If a medical professional or support person helped create the trigger, they should interpret them. Likewise, if the statement was formed collaboratively, it should be triggered collaboratively. This method also provides some form of check and balance to aid in preventing one person from having undue influence over the decision. However it could also lead to conflict if for example the medical professional believes the triggers have been met but the elected family member disagrees. It may be that the individual can plan for this in their statement and give guidance on how to resolve any conflicts.

The majority of participants expressed a desire to have an elected support person (often a family member) involved in interpreting the statement. This finding is reflective of research by Morrissey that found 51.4% of the 109 service users involved wanted a family member or trusted friend to determine decision making capacity for the purposes of activating an advance directive.[562] The Committee awards legal recognition to an individual's chosen support person(s) and create a mechanism for third parties to challenge a support person if they believe they are not acting in accordance with the will and preference of the individual.[563] Using an elected support person to overrule will and preference to uphold an individual's legal capacity has also found favour in other support-based alternatives, which attempt to retain CRPD compatibility. Bach and Kerzner for example argue that an observer who knows the person well can help characterise the level of 'decision-making capability' that, with support, would allow an a person to exercise legal capacity.[564] Arstein-Kerslake and Flynn discuss the potential for support persons in emergency situations or where failure to act could constitute criminal or civil negligence, to remove an individual from a harmful situation, against their express will and preference, in order to assist the individual in getting to a place where they can better communicate their 'true' will and preference.[565] Minkowitz advocates for lasting powers of attorney "to allow another person wide scope to take action in a situation where one is not able to manage responsibilities of everyday life or needs advocacy to make one's wishes known effectively," provided they are adapted from an incapacity context.[566] Provided appropriate measures are taken to ensure supported decision making is guided by the individuals will and preference and does not become substitute

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[562] F.E. Morrissey, 'The Introduction Of A Legal Framework For Advance Directives In The UN CRPD Era: The Views Of Irish Service Users And Consultant Psychiatrists' (2015) 1 Ethics, Medicine and Public Health.

[563] Committee on the Rights of Persons with Disabilities 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 29(d).

[564] M. Bach and L. Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' (2010) prepared for the Law Commission of Ontario. Available <https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf> Accessed 26th January 2021, 66.

[565] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 99.

[566] T. Minkowitz, 'CRPD Article 12 And The Alternative To Functional Capacity: Preliminary Thoughts Towards Transformation' [2013] SSRN Electronic Journal <https://www.researchgate.net/publication/272241633_CRPD_Article_12_and_the_Alternative_to_Functional_Capacity_Preliminary_Thoughts_Towards_Transformation> accessed 18 January 2021, 9.

decision making, it seems a support person could be elected to interpret a statement on change in self while retaining CRPD compatibility.

Some participants with secondary experience however were hesitant about to what extent family members/friends should be involved. Joseph, Michelle's dad, felt as though his input as a close family member could lead to an inaccurate interpretation of the triggers. He bases this on a past decision in which he fought to prevent Michelle from being sectioned and admitted to hospital. In hindsight he believes this was the wrong decision, driven by his emotion, and which ultimately caused more distress for everyone involved. Consideration may have to be given therefore to how experienced the elected support person is regarding the individual's mental health, and therefore how learned and tempered their emotions are in reaching an accurate decision.

An important point to note here is whether a user-led statement on change in self, if triggered by a third party- be it an elected support person or medical professional, is different from substituted decision making.

Substitute decision-making regimes are defined by the Committee as "systems 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 his or her will; or (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective "best interests" of the person concerned, as opposed to being based on the person's own will and preferences."[567] Self-binding in the format it is presented here does not meet these criteria of substitute decision making. I have already presented an argument that this first criteria may not apply to self-binding in the formulation I have presented here, as it is not a restriction of legal capacity but an extension of it. The second criteria is also absent because the individual is permitted to elect whomever they choose as their support person for the purpose of interpreting their statement and triggering the self-binding aspect of their advance plan. This is not done against the individuals will. Finally, the decision to trigger the plan and overrule legal capacity for some decisions is not based on an objective best interests ruling, but on the will and preference of the individual.[568] Any elected support person would be making their decision based on the

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[567] United Nations Commission, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 27. As amended by the corrigendum found here: 1https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1/Corr.1&Lang=en

[568] A similar observation was made by Szmukler et al when discussing Bach and Kerzner's supported decision-making approach- specifically how facilitated decision-making which gives effect to will and preference is, for this reason, distinct from substituted decision making. They state "within their schema, one could argue that the facilitated decision is not a 'substituted' one in an

observable changes in self detailed by the individual and contained in the wording of the plan, and not on an assessment of when they believe an individual requires state intervention. The support person is therefore making the decision from the persons worldview and their unique subjectivity as opposed to being disconnected from, and substituted for, the interpreter's worldview.[569] There are some major differences therefore between this approach and substitute decision-making, even where a support person is elected to trigger the statement and overrule select will and preference.

Finally, a point raised by Rachael is what would happen if an individual who feels unable to trigger the statement themselves has no trusted friends, family or medical professionals to elect. Simon is one such person who identifies as being in this situation. She suggests a 'volunteer advocate' who would build a relationship with the individual in order to interpret their triggers. This idea of building a trusting relationship with a support person to trigger the statement on change in self is reminiscent of the kind of role currently played by Independent Mental Capacity Advocates (IMCA) under the Mental Capacity Act, and is also reminiscent of the Personal Ombudsman Service, which is seeing great success in Sweden. There is room for this kind of advocate role within a mental capacity alternative therefore. Potentially this role could be subsumed by medical professionals in their new role under the CRPD or undertaken by whatever role is adapted from or replaces IMCAs under the CRPD.

All participants agreed that the decision of who should interpret the statement should be decided by the individual and included in the statement. A one-size-fits all approach should therefore be avoided.

Reflecting on this Approach and a Way Forward

While a user-led statement on change in self could therefore offer some improvements to mental capacity in regard to CRPD compatibility, it is not without its problems. This section briefly highlights some of the immediate limitations of this approach and highlight areas where more research is needed.

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important sense, since it gives expression to the 'person's ascertained 'will and preferences'' in . Szmukler, R. Dawb and F. Callard, 'Mental Health Law And The UN Convention On The Rights Of Persons With Disabilities' (2014) 37 International Journal of Law and Psychiatry, 249.

[569] T. Minkowitz, 'CRPD Article 12 And The Alternative To Functional Capacity: Preliminary Thoughts Towards Transformation' [2013] SSRN Electronic Journal, 7.

First, the emphasis this alternative places on past experience of how self changes with mental health, means that those with no prior experience to draw on are potentially excluded from self-binding provisions. This includes those with progressive mental health i.e. dementia and Alzheimer's and those experiencing mental health for the first time. This approach is therefore better suited to people who experience mental health episodes, where there exists sufficient similarity between episodes for this experience to retain some relevance for future episodes.

While some may argue that those with no past experience of mental health, how they will feel, what they will want etc. should not be a candidate for self-binding provisions, it is reasonable that people with no prior experience may wish to self-bind a provision similar to a lasting power of attorney, to elect a support person(s) to take over for certain decisions when that individual can still make some expression of will and preference.

The value of a lasting power of attorney was emphasised by every participant who had secondary experience of a progressive mental health condition. It has also been acknowledged in literature that a provision similar to a lasting power of attorney would be CRPD compatible provided it was decoupled from a capacity/incapacity approach.[570] The question then becomes how a change in self statement can be made to work for this group. This is reminiscent of findings discussed in Chapter 6, that the availability and content of self-binding provisions may benefit from working differently depending on how mental health impacts self.

One potential solution would be to allow those with no prior experience to create a statement of self, as opposed to a statement on change in self. This would allow people to document their values, beliefs and any other elements of self they so choose and would trigger the LPA-style provision once a person was making decisions inconsistent with this concept of self. This would provide a way for people with no experience of mental health to instead use their longevity of self and character to trigger a self-binding provision. This kind of reflection on whether a decision reflects or goes against a person's long held values and character is something best practise in the court of protection is already engaging with. The case of *Kings College Hospital NHS Foundation Trust v C and Another* is a good example of this.[571] Mr Justice MacDonald took into consideration C's life

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[570] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 96 and T. Minkowitz, 'Legal Capacity From A Psychosocial Disability Perspective: A Discussion Paper' <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2374733> accessed 14 January 2021, para 9.

[571] [2015] EWCOP 80.

characterised by 'impulsive and self-centred decision making without guilt or regret'[572] and held her decision to refuse treatment was in keeping with "the things that are important to her, in keeping with her own personality and system of values and without conforming to society's expectation of what constitutes the 'normal' decision in this situation."[573]

This approach however is not without its challenges. Participants have already outlined how difficult and potentially insurmountable it would be to create a statement communicating their self, particularly where that communication would be relied on with legal effect. Self can change daily, with experience and mental health difference. Others struggled to communicate self because they felt they were going through a process of self-unmaking or self-remaking. This may therefore prove too great an ask and was the reason perceivable changes in self were focused upon.

Data in this thesis is limited in this regard, but if those with progressive mental health difference and no prior experience wish to self-bind certain decisions, it seems difficult to justify this without recourse to some form of decision making/capacity assessment. In Srebnik et al's study 47% of the 106 community mental health centre outpatients wanted to activate their self-binding directive at the point of incapacity, thereby self-electing a mental capacity assessment.[574] It is unclear whether this would retain CRPD compatibility, although there is something to be said for an individual choosing to undergo a mental capacity assessment as opposed to having one forced upon them. This risks however missing out on the kind of substantive change the CRPD set out to create. It risks putting the trigger for self-binding artificially in the hands of the individual while creating no real change if the trigger itself- an assessment of mental capacity- remains the same. Also while many of my own participants felt mental capacity assessments were necessary, it is worth remembering that they are all participants have known and the only provision they have any experience of. They are therefore working within the constraints of pre-existing thought and that does not mean something better is not out there.

At this stage it seems difficult to justify self-binding provisions for those with no prior mental health experience without recourse to some form of functional approach which is not CRPD compatible according to the Committee's interpretation. More research is therefore needed on this area.

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[572] Ibid para 8.
[573] Ibid para 97.
[574] D. S. Srebnik and others, 'The Content And Clinical Utility Of Psychiatric Advance Directives' (2005) 56 Psychiatric Services, 596.

Concerns may also arise as to how an individual can be proven to be in their right mind when they create a statement on change in self, if not by reference to a decision-making assessment. This again would require more academic attention, however it should be noted that the process of creating a statement itself may suffice to settle any concerns and people without a mental health diagnosis are not subject to mental capacity assessments when they create wills, take out mortgages etc. The answer to this question may depend on to what extent consideration of difference can tread on the toes of disability neutrality. In terms of at what stage an individual could revoke a self-binding provision, the same problem may be seen to arise. This process could be the same as the one used to trigger the statement- that an individual cannot revoke the plan until elected support persons and any medical professionals agree that the changes to self no longer apply and the individual is no longer making the harmful decisions contained in the statement.

This approach, in removing capacity assessments in favour of a statement on change in self, also presumes that everyone who may need to restrict legal capacity has access to this provision. In terms of resources and practicality, this cannot be guaranteed. Therefore this approach does not aid in situations where a person is presenting with no statement on change in self, who is making harmful decisions which fall short of suicide, and whose family and friends say have lost the capability to make these decisions and that they would not otherwise have made these decisions.

Finally this approach may be seen to not dispense entirely with problematic distinctions based on a 'true' self conception. This approach justifies self-binding by creating different categories of will and preference. Flynn and Arstein-Kerslake justify intervention against an individual's wishes to remove them from a harmful situation and establish their 'true' will and preference.[575] By drawing distinctions between categories of will and preference, this approach comes very close to drawing a divide line between different versions of self, which is argued in Chapter 2 as being incompatible with the CRPD. It therefore risks upholding some form of a true self-conception which, as discussed in Chapter 4, is problematic because of how 'true' self can create a divide which invalidates the decisions of self with mental health.

It could be argued that this approach does not validate a true self conception, but instead invalidates specific decisions. It therefore does not draw a divide on the basis of mental health difference but on the basis of the decisions a person is making. However the

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[575] E. Flynn and A. Arstein-Kerslake, 'Legislating Personhood: Realising The Right To Support In Exercising Legal Capacity' (2014) 10 International Journal of Law in Context, 93.

decisions a person would want to overrule using self-binding, would be made during a mental health experience. This likely correlation therefore muddies the distinction just drawn. We again start to look as though we are overruling will and preference based on the presence of mental health difference. Ultimately it has proven very difficult to justify any form of self-binding - something which is clearly desired by some participants - without doing so based on the presence of mental health. Further work on this is therefore needed.

While this approach has been successful in creating new thinking and framing participant responses on an alternative to mental capacity assessments/ a functional approach, it creates many additional questions and problems of its own. These questions contribute to a growing literature on the future of self-binding directives under the CRPD.

The next chapter summarises the arguments made in this thesis and reflects on the future of CRPD-compatible advance planning.

Chapter 7: Conclusion

By now you will have realised quite how complicated the story told at the beginning of this thesis - of Ulysses and the Sirens - really is. The question of to bind or not to bind involves consideration of self and personhood, asks which self's wishes we are upholding, why, and whether this can this be justified under the CRPD. It asks how we at an individual and societal level factors harm into a situation, how much harm we are willing to allow an individual to assume and questions the role and responsibility owed to Ulysses by his crew- his support person(s). The questions are many and any one could be a thesis in its own right.

This thesis has focused on identifying and exploring some of the biggest barriers to CRPD compatibility for advance plans and creating new thinking on how to overcome them. Specifically, it has focused on the more contested potential role of advance planning – to self-bind some decisions during a mental health crisis to safeguard self and others from harm. The barriers discussed have included problematic conceptions of self with mental health in mental capacity law (Chapter 4); whether *all* will and preference ought to be adhered to and how harm impacts that decision (Chapter 5); and what a CRPD compatible trigger for self-binding provisions might look like, decoupled from mental capacity assessments and a functional approach (Chapter 6).

Chapter 1 outlined that advance planning provisions as they are currently formulated under the Mental Capacity Act 2005, are not compatible in many regards with the CRPD. It explained how advance planning provisions are formulated under the Mental Capacity Act, their validity requirements, their legal influence/weight, how they interact with the Mental Health Act and practical and conceptual problems with their use. The paradigm shift brought about by the UN Convention on the Rights of Persons with Disabilities was outlined in relation to Article 12- the right to equal recognition before the law. Because of the emphasis the CRPD and the CRPD Committee place on respecting individual will and preference, and because of their prohibition of substitute decision making, it is argued that advance plans will likely play a much more significant role in delivering support under the CRPD, compared with their role currently. This is regarding the frequency with which they are used, the scope of decisions they contain which create legal obligation, and the detail in which these decisions are documented. Article 12 however poses a range of initial compatibility problems for advance plans. These include the fact advance plans are currently triggered by mental capacity assessments which are prohibited by the CRPD Committee; and that it appears will and preference must be adhered to at all times under the CRPD, whereas advance plans under the Mental Capacity Act could allow incapacitous will and preference to be overridden. This is usually justified in relation to protecting the individual and others from harm and as acting in that individuals' best interests.

Chapter 2 introduced another conceptual barrier to CRPD compatibility. It criticizes the concept of 'self' in many dominant social and philosophical theories from a mental health perspective. It argues that these theories create a conceptual divide between a 'healthy' and 'ill' self. This dividing line between the two versions of self is based on disability, where the ill self is juxtaposed with the healthy self and framed in reference to what the healthy self lacks. It argues that the social theory 'healthy' self and the legal autonomous self share many common elements, and that mental capacity assessments perpetuate this divide line on the basis of a 'disturbance in the functioning of the mind or brain.' They do this by relying on heavily cognitive criteria characteristic of the autonomous self, to divide the autonomous from non-autonomous self. Advance plans are triggered by these assessments and conceptually seek to uphold and extend the wishes of the autonomous healthy self for as long as possible. It argues the CRPD would not maintain this divide in selves, and instead challenges concepts of legal personhood via legal capacity, enriching 'self' in the rights discourse. Concepts of self with mental health in social and legal theory therefore need to be reconceptualised to remove this divide line, if CRPD compatibility is to be achieved.

After identifying all main barriers to compatibility, Chapter 3 outlined methodology. Empirical research involving persons with a variety of mental health experiences was conducted. This was to confirm whether those with experience of mental health difference view the barriers identified as in need of reform, and to provide discussion and practical suggestions on how to achieve CRPD compatible advance planning which also caters to the needs of those most likely to be using advance plans as a method of support. Participant experiences, chosen methodology and the research design was outlined amongst other things, including the three main data gathering activities. These include an elements of self interactive activity, situational case study vignettes and semi-structured questions.

Chapter 4 builds on Chapter 2 and used the interactive elements of self activity to ask participants how they conceive of self and how their self changes with mental health difference. This was to see whether their self-perception maintained the kind of dividing line between healthy and ill self, outlined in Chapter 2. Findings reveal how self with mental health is highly individual and therefore a one-size-fits all concept may not be helpful. It also showed how many participants communicate self and mental health as indivisible. Therefore self and mental health are intertwined and mental health is a part of their self, meaning no new ‘ill’ self was created. A divide line between selves was therefore not representative of the majority of participant experiences. Instead changes in self were grouped and discussed thematically. They include: the magnification versus shrinking of self; dissociation and compartmentalisation of selves; ability to work and a change in social role; isolation fear and loneliness; change in cycles; the impact of medication; awareness; and change as positive- mental health as a process for self understanding, reconstruction and recovery. These findings were discussed in reference to a ‘true’ self conception which is used to justify advance plans with self-binding provisions. The conclusion was reached that a true self conception is not an accurate reflection of self for many participants. Self was therefore conceived as being more continuous as opposed to periodic. This meant that while time, experience and mental health changes self, there was a definite sense of continuity between self pre-mental health experience and self during, according to participants. Indeed self with mental health for some participants, may in fact have been a ‘truer’ version of self than a version of self without. Therefore the justification for self-binding provisions which allow incapacitous will and preference to be overruled on the basis that they are a changed ‘ill’ self in conflict with the ‘true’ self, was brought into question.

Chapter 5 outlined that the justification in many domestic mental health laws for overruling will and preference is to protect the individual and others from harm. It outlined the lack of clarity on whether the CRPD would permit legitimate restrictions to legal capacity on the basis of harm and examine UN Treaty Body and academic interpretations. Academic interpretations include Bhailis and Flynn's 'imminent harm,' Bach and Kerzner's 'serious adverse effect' and the retention to a functional approach to justify disability-neutral restrictions to legal capacity. Ultimately however, the answer is unclear. The Chapter uses participant responses to case study vignettes to offer some guidance on how harm may influence adherence to incapacitous will and preference. Participants were asked whether they would want all will and preference during a mental health experience to be adhered to, and whether and why they would either overrule a contrary wish made during a mental health experience, in favour of an advance plan, or uphold that contrary wish. The case study vignettes of John, Mary and Ken were used to introduce a number of potential factors to see how they influenced participant decision making. Ultimately in response to the first question, a group of participants who experienced drastic changes in self did want some will and preferences made during a mental health experience to be overruled, based on past experience. They were therefore in favour of some form of self-binding. The majority of participants also established a cut-off-point in regard to adhering to harmful will and preference, believing that suicide permits state intervention against the individuals wishes. This is in line with the common ground established in academic theories which justify some form of compulsory intervention to prevent suicide given its serious and irreversible nature. A minority of participants did express the importance of allowing individuals to make harmful decisions which fall short of this cut off point. This is to retain individual control and prevent people from being denied a coping mechanism to fend off more significant harm. When discussing the role of support persons therefore when faced with harmful will and preference, participants emphasised the importance of negotiation, understanding and obtaining full informed consent in their care and treatment.

Since it had been established that some form of self-binding is desired, new thinking was required on how to determine when one version of self had ended and another had begun, in order to know when to privilege the wishes of one self over another. This could not rely on a mental capacity assessment nor a functional approach which are both incompatible with the CRPD and maintain inaccurate and problematic concepts of self with mental health, as outlined in Chapters 2 and 4. Chapter 6 shares participants experiences of mental capacity assessments and outlines suggested improvements- namely to make assessments less time specific and to ensure the assessor has some prior relationship with the assessee. Chapter 6 also presents a user-led statement on change in self as an alternative to mental capacity assessments, for the purposes of triggering self-binding statements. The purpose of this approach was to frame participant responses and provide an overall direction on a way forward. It argues this approach makes a number of improvements on current mental capacity assessments and addresses some of the current criticisms of advance planning provisions. While this approach is not without its flaws, it generates new thinking on self-binding under the CRPD and raises further questions which contribute to a growing literature. It argues that self-binding provisions can be an extension as opposed to a restriction of legal capacity. Therefore self-binding has the potential to be CRPD compatible. This is provided that whatever triggers favouring one version of self over another, avoids enforcing blanket problematic conceptions of self with mental health and avoids some of the biggest existing problems with advance planning provisions.

While this thesis has focused on advance planning provisions, many of these arguments and findings could be applied to other areas of CRPD compatibility more widely.

The originality of this thesis lies in its unparalleled deep dive into overcoming barriers to CRPD compatibility for advance planning provisions. This includes offering new thinking on a CRPD compatible trigger for self-binding provisions, which departs from a functional and mental capacity-based assessment. Ultimately however the originality of this thesis lies in participant responses. Participant feedback has allowed barriers to CRPD compatibility and new thinking on how to overcome these barriers, to be discussed in reference to their own experiences. Participants have also suggested additional improvements not previously considered, in relation to the role of support in harmful decision making- as one of informed negotiation, in relation to mental capacity assessments, and how the type of mental health difference and the way it changes self may impact how self-binding provisions work and are triggered.

To return to the earlier question then, of whether to untie Ulysses from the mast to hear the Siren's song, the answer - as is the case with many complicated questions - is, it depends. In order to retain CRPD compatibility, the answer to this question depends on how an individual conceives of self in relation to mental health difference- specifically whether they retain a true self conception for the purposes of validating some form of self binding. It depends on whether the CRPD acknowledges different classes of will and preference and allows some wishes to be overruled for the sake of protected higher or 'truer' wishes. It also depends on the scope of legal agency and which decisions can be protected under Article 12 and how this impacts self-binding. It depends on how much harm we are willing to allow an individual to subsume and how we factor in different types of harm. It depends on the role of elected support persons and how to allocate individual versus professional power. Finally it depends on how to justify privileging one version of self over another and how to know when one version ends and another begins without reference to a mental capacity/functional approach.

Based on findings from this research, I would advocate for Ulysses to remain bound and that this decision can be justified as CRPD compatible. Not only would Ulysses likely come to serious harm resulting in death were he to be untied, which was a clear cut-off point in adhering to will and preference according to participants; but he has elected to self-bind and instructed his support persons- his crew- to overrule his wishes to the contrary. The effect of the Sirens song is temporary and soon Ulysses will return to a version of himself similar to the one who made that initial request- all the wiser for his experience of the Sirens song. Upholding his wish to remain tied to the mast protected a higher class of will and preference which was more important to Ulysses than hearing the Siren's song. Therefore it could be argued that overruling his wishes to be unbound were in fact a continuation as opposed to a restriction of his legal capacity under Article 12 of the CRPD.

Practical Considerations: Moving Forward

This thesis makes a number of suggestions on how CRPD compatibility could be improved for advance planning provisions.

Initial observations in Chapter 1 outline that the inherent revocability of advance plans needs to be reconsidered in order to respect will and preference, retain the utility of advance plans and to encourage a rebalance of power towards the individual and away from medical professionals. Indeed many participants were of the opinion that advance plans were not worth the paper they were written on unless they were legally binding or created some form of legal obligation.

It also suggests that the scope of decisions in advance planning provisions needs to be reconsidered. This is because of the increased importance the CRPD places on individual will and preference and their desire to eradicate substitute decision making. Going off the Committee's definition, this includes the prohibition of substitute decision making which allows a decision maker to be appointed by someone other than the individual themselves and is based on objective best interests as opposed to a best interpretation of will and preference. Advance plans will be key for both appointing a support decision maker(s), and documenting will and preference for the purposes of a best interpretation. It may be beneficial therefore to consider documenting a wider scope of decisions, or to encourage individuals to document decisions in more detail.

Chapters 2 and 4 argue that reconceptualising self with mental health in social and legal theory, to move away from a divide line drawn on the basis of disability and cognition, is needed in order to achieve CRPD compatibility. This applies to advance planning but also more widely to mental capacity law in general. Suggestions on how self with mental health could be reconceptualised are offered in Chapter 4 via the themes of how self changes with mental health difference, and the discussion around whether a true self conception is accurate. I would encourage theories on personhood and self to consider and promote the inclusivity of persons with mental health difference. It may also be helpful for theories of self to consider the individual nature of self, the fact that a divide between a 'healthy' autonomous self and an 'ill' non-autonomous self is not representative for the majority, and that self with mental health may in fact be a 'truer' version of self.

The thesis also discusses the importance of further clarification on which decisions count as an exercise of legal agency. If not all will and preference are an exercise of legal agency, clarification is needed on what the legal difference is in terms of enforceability for will and preference which fall short of constituting an exercise of legal agency. This has important implications for advance planning under the CRPD. For example if legal consequence is required for a decision to be protected under Article 12, as Flynn and Arstein-Kerslake believe, this narrows the scope of decisions in advance plans which can be awarded legal capacity and be legally enforced.[576] This would likely result in a version of advance planning very similar to what we currently have under the Mental Capacity Act. Refusal of treatment, financial and welfare decisions which involve obvious legal consequence would be protected under Article 12, whereas more subjective wishes would not be, unless the individual could create legal consequence. Participants have outlined that decisions outside this scope can carry great subjective importance to them and would be just as important if not more so, compared with financial and welfare decisions. If it is decided that will and preference which fall short of legal agency accrue no legal enforceability and are instead advisory, they mirror advance care plans and recovery plans. It may be possible therefore that these decisions could be overruled without it constituting a restriction to legal capacity. If however the scope of legal agency was more expansive, it is possible a wider array of decisions could be included and enforced at law. This relates to an earlier point- about it making sense to expand the scope and/or detail of will and preference included in an advance plan. Overall more clarification is needed on the scope of legal agency and how this relates to advance planning.

Some form of 'substitute' decision making is also desired by participants, particularly a provision similar to current lasting powers of attorney. The term 'substitute' is used

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[576] A. Arstein-Kerslake and E. Flynn, 'The Right To Legal Agency: Domination, Disability And The Protections Of Article 12 Of The Convention On The Rights Of Persons With Disabilities' (2017) 13 International Journal of Law in Context.

loosely here, provided that if a support person were to be elected by the individual to take over for certain decisions detailed in an advance plan, and these decisions seek to uphold that persons ‘true’ will and preference, this would likely not be interpreted as substitute decision making.[577] In order to achieve CRPD compatibility however, this kind of provision must be detached from a capacity/incapacity framework. A user-led statement on change in self succeeded in creating new thinking on an alternate trigger for self-binding provisions but had problems of its own. More work is needed therefore on a CRPD compatible trigger for self-binding provisions.

A particular difficulty for this thesis, was finding a CRPD compatible trigger which caters equally well for those with broadly different types of mental health difference. Currently advance planning provisions under the Mental Capacity Act work the same for everyone. The CRPD Committee also believe people with disabilities have a right to engage in advance planning on an equal basis with others.[578] However, a recurring theme in participant discussions of self, mental health and decision-making, is a perceived difference between those whose mental health is characterised by defined episodes and those whose mental health progresses over time. This is in terms of a comparative difference in experience of mental health, including what an individual may want during that experience and the decisions they may be inclined toward. This is also in terms of the comparative ability to ‘regain’ a version of self similar to the one who made the advance plan. A prolonged period of drastic change could mean that a person, for all-intent-and-purposes, could be a very different self to the one who created the plan or statement.

This is reminiscent of arguments put forward by Parfit[579] and applied by Dresser in the case of advance directives to justify a prohibition on self-binding.[580] This has also been recognized by Berghman who acknowledge that based on this concept of self, advance plans for those with dementia should be less relevant as time goes by and as more changes in self occur.[581] While mental health difference and the way it impacts self contains no bright lines and cannot be categorised so neatly, these differences no doubt had some impact on participants opinions on how advance plans should work and the scope of decisions they should contain. Participants were more content to allow a person

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[577] C. Bhailis and E. Flynn, 'Recognising Legal Capacity: Commentary And Analysis Of Article 12 CRPD' (2017) 13 International Journal of Law in Context, 13.

[578] United Nations Committee on the Rights of Persons with Disabilities, 'Article 12: Equal Recognition Before The Law General Comment No 1'(2014) para 17.

[579] D. Parfit, Reasons And Persons (Clarendon Press 1984).

[580] R. Dresser, 'Life, Death And Incompetent Patients: Conceptual Infirmities And Hidden Values In The Law' (1986) 28 Ariz. L. Rev.

[581] R. L. P. Berghmans, 'Advance Directives For Non-Therapeutic Dementia Research: Some Ethical And Policy Considerations.' (1998) 24 Journal of Medical Ethics, 34.

with experience of well-defined episodes to self-bind a wider variety of decisions for example, compared with someone who is in the early stages of dementia. This difference is also likely to impact considerations of how any self-binding provisions would trigger. Indeed, in the previous chapter it was outlined that a user-led change in self does not adequately cater for those with progressive mental health difference. It may therefore be helpful for future research on CRPD compatible advance planning to think about self-binding provisions differently according to the different ways mental health impacts self. This is in regard to both the content and scope of self-binding provisions available to an individual and regarding a CRPD compatible trigger. This is to ensure any advance planning provisions tailor support according to how mental health impacts self, and to ensure they retain utility for persons with mental health difference, who are the group most likely to use advance planning provisions.

Before concluding it is worth reflecting on the future of advance planning in England and Wales. The government published a white paper in January of 2021 titled 'Reforming the Mental Health Act' which introduces 'advance choice documents.'[582] While still in draft form, these advance choice documents provide insight into the future of advance planning in a mental health context in England and Wales. This allows us to make some initial observations based on this research, on the extent to which progress is being made to achieve CRPD compatibility and how this research bears on reforms.

An initial thing to note is the lack of any mention of the CRPD in the proposal, despite having ratified the CRPD in 2008. Despite the opportunity for drastic reform and clear blue thinking therefore, the CRPD is written off as offering insufficient safeguards for disabled people and no real attempts are made to achieve compatibility reform nor engage in meaningful conversation on CRPD compatibility.[583]

Greater emphasis is placed on the individuals will and preference which seems to be the greatest impact the CRPD has had on these reforms. It's also worth noting that advance choice documents trigger when an individual is assessed as lacking mental capacity, in line with the Mental Capacity Act. These reforms therefore maintain a capacity/incapacity divide despite the CRPDs clear prohibition. There is no attempt therefore at clear blue thinking on how to trigger an advance plan at a point earlier than

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[582] Department of Health and Social Care, 'Reforming the Mental Health Act' (Cm 355, 2021).

[583] S. Wessley, 'Modernising The Mental Health Act Increasing Choice, Reducing Compulsion Final Report Of The Independent Review Of The Mental Health Act 1983' (2018) <https://www.gov.uk/government/groups/independent-review-of-the-mental-health-act#governance> accessed 14 January 2021, 12-13.

an inability to communicate will and preference, aside from a mental capacity assessment.

Everyone is entitled to make an advance choice document. However the reforms intend on privileging those with prior experience of receiving treatment under the Mental Health Act.[584] Experience was a major factor for participants when discussing the availability of self-binding provisions and the content of those provisions. It is therefore encouraging to see reforms also privilege past experience in advance planning provisions.

In addition, individuals are able to include in their advance choice document "behaviours to be aware of which may indicate early signs of relapse [and] circumstances which may indicate that the person has lost the relevant capacity to make relevant decisions."[585] This is reminiscent of 'early warning signs' in crisis planning and draws on individual insight of their past experiences to assist in seeking additional support. This addition helps recognise the individual nature of how self changes with mental health and allows the individual an input to guide assessors in determinations of capacity and when to offer support despite verbally refusing support. This could therefore help tailor capacity assessments to the individual. This was desired by the majority of participants in their discussion of current mental capacity assessments and how they could be improved.

Advance choice documents seem to be recovery plans, advance care plans and advance refusals all rolled into one. They include, but are not limited to, decisions on treatment refusal, care and treatment preferences and advance consent for informal admission.[586] They are the first provision to expressly recognise advance consent in English and Welsh law, despite what the reforms say.[587] This increased scope of decisions included in advance planning provisions is desired by participants and makes sense regarding the CRPDs emphasis on privileging individual will and preference. It also reflects the idea that some decisions which appear less important societally may be of equal of not more importance to an individual, as discussed in Chapter 5.

Under the proposed reforms, there is also a legal obligation for relevant clinicians to consider advance choice documents when developing care and treatment plans. This is an improvement on current advance planning provisions, as many of the decisions included in advance choice documents do not currently create any legal obligations. As discussed in Chapter 1 many provisions, except for advance refusals and lasting powers of attorney, are merely advisory. This proposal reflects participant insistence that

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[584] Ibid 36.
[585] Ibid 36-37.
[586] Ibid.
[587] Ibid 69-70.

advance plans must be awarded legal enforceability for them to have any practical utility in a mental healthcare setting.

There are more safeguards to protect the will and preference in an advance choice document therefore, compared with current advance planning provisions under the Mental Capacity Act depending on the category of treatment. However they can be overruled never-the-less. This would go against an absolutist interpretation of the CRPD, however in regard to harm this is not the interpretation that found favour with participants. The majority of participants believed that regardless of wishes contained in an advance plan, there exists a cut-off point for adherence to will and preference, being wishes would result in suicide or serious self-harm. This cut off point seems to be reflected with appropriate safeguards for category 2 (invasive) treatment and category 3 (all other medication) treatment regarding urgent treatment, meaning treatment is necessary to save the patient’s life or prevent a serious deterioration of their condition. However the reforms also propose upholding a relevant clinicians ability to overrule an advance choice document for category 3 (all other medication) for the first 14 days of detention (reduced from the current 3 months) before this decision is reviewed by a SOAD. This allows treatment refusals to be overruled for situations which fall well below the cut-off point participants identified. This therefore is not in line with participant responses. It places too little power with the individual and too much power with the relevant clinician.

It is my hope that this research on advance planning provisions under the CRPD will continue to create new ideas and new hope for CRPD compatible reform.

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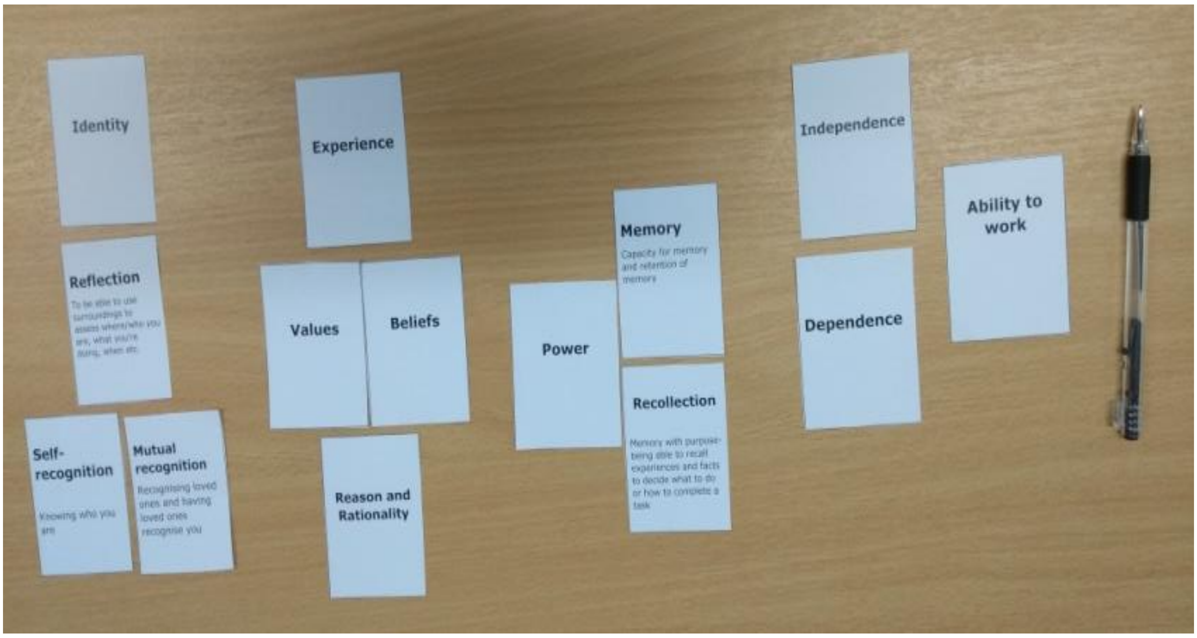
Appendix
Pictorial of the Elements of Self Interactive Activity and Group Composition

Focus Group 1 (IMH)
(1/10/19)

Participant 1: Olive- early-stage dementia, white, woman of retirement age

Olive arranged cards into 'little groups' because they are "mutual" or "make a little story up." Ability to work was outlined in both a professional working capacity and in terms of housework and cleaning. Olive said it "meant nothing to her!" and that volunteering was now her "joy."



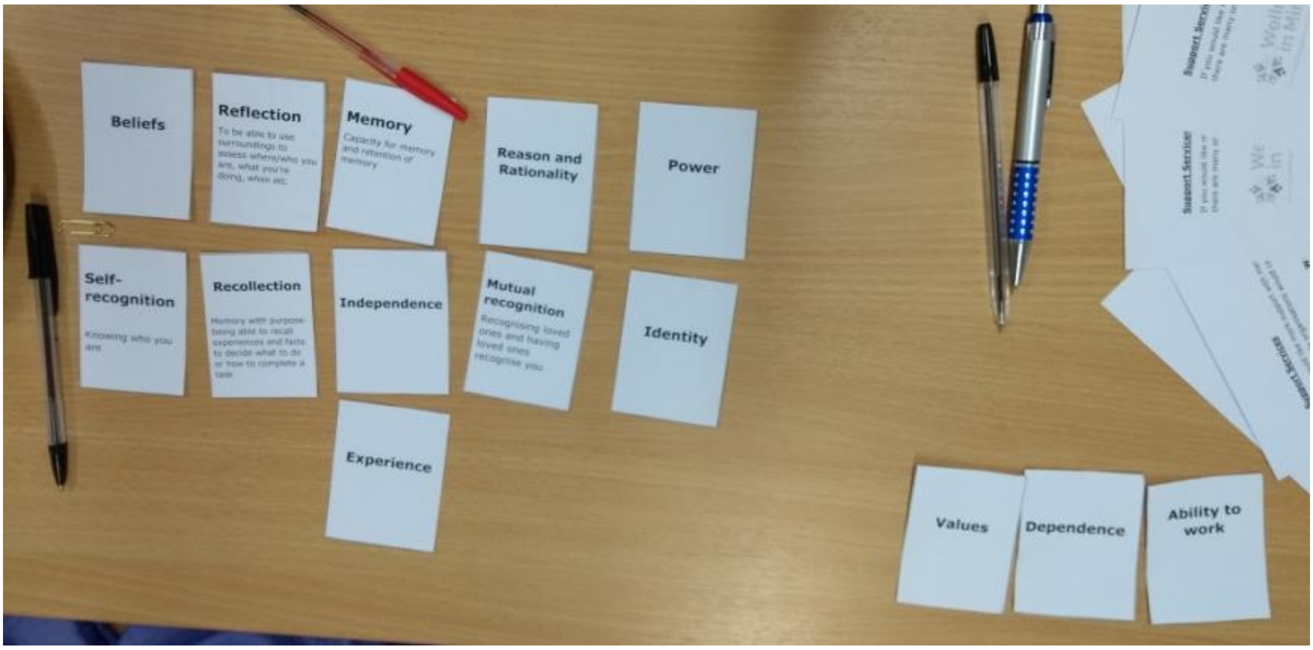
Participant 2: Sandra- memory loss following a stroke, white, woman of retirement age

Sandra felt she could not organize or categorize the elements as they all applied to her:

"I can't separate any of these…I can't put them in a box because they're all me…I can relate to all of them… they're all so important…to be a normal upright citizen, and…I am terrified of coming out of the box- that I'm gunna not remember myself… be able to do the sudoku in the paper…lose my independence, …I don't wanna lose my wonderful memories of holidays…"

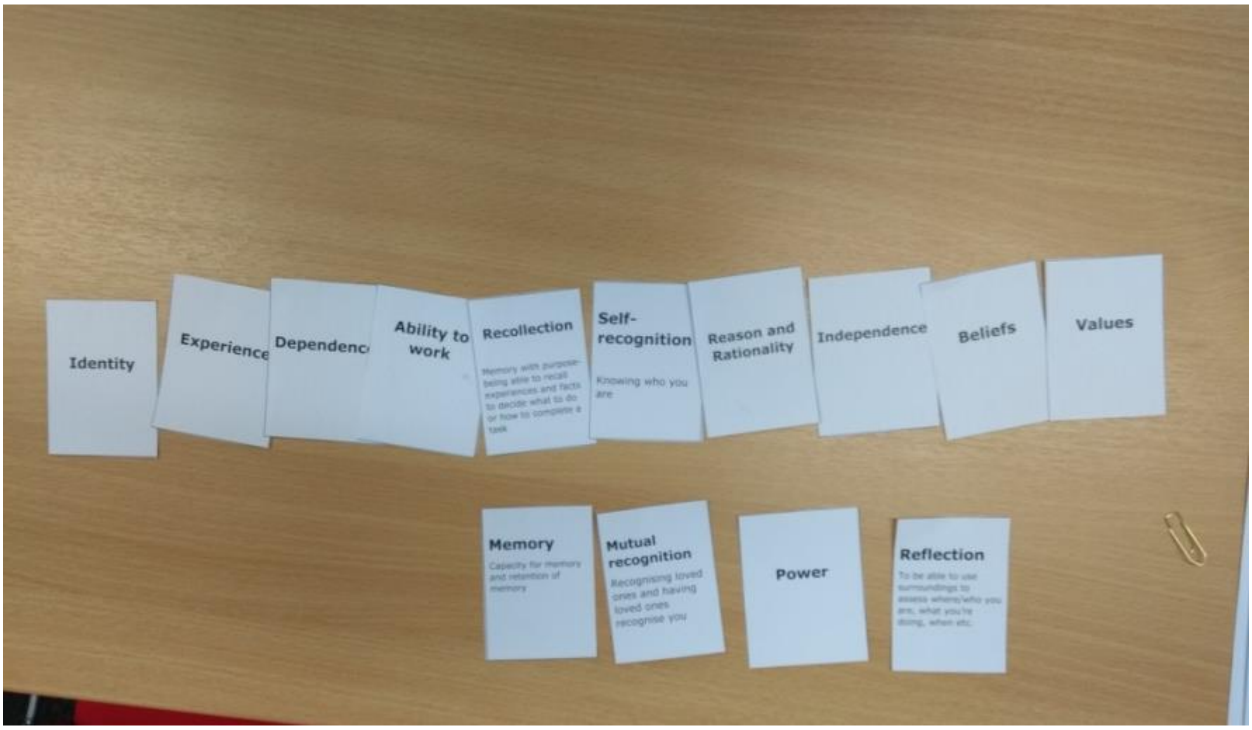
Participant 3: Betty- early-stage dementia and secondary experience of caring for her mother with late-stage dementia, white woman of retirement age

Betty sorted hierarchically from the top left being most important, going across and down in rows. Values, dependence and ability to work were excluded.



Participant 4: Robert- memory loss, has not sought a diagnosis, white male of retirement age

Robert sorted the elements hierarchically from top left to right most important, with the bottom row representing things he is beginning to lose/is scared to lose.

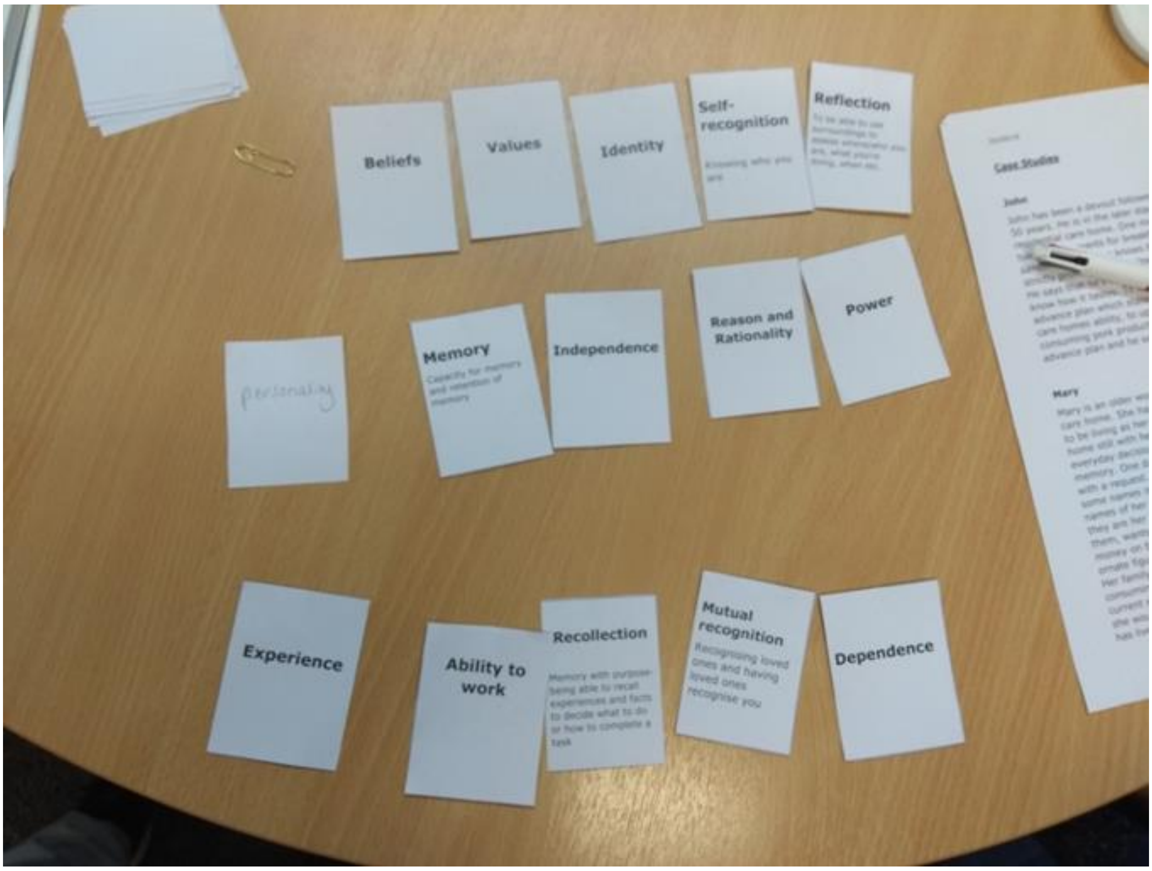


Individual Interview 1 (IMH)
(4/11/19)

Nicole- experience of psychosis, black, woman, middle-aged, of Kenyan origin

Bottom row includes things Nicole has had to deal with post mental health experience. The second row is described as day to day perceptions of self and the top row describes “the best things that have come out of this whole, issue…”

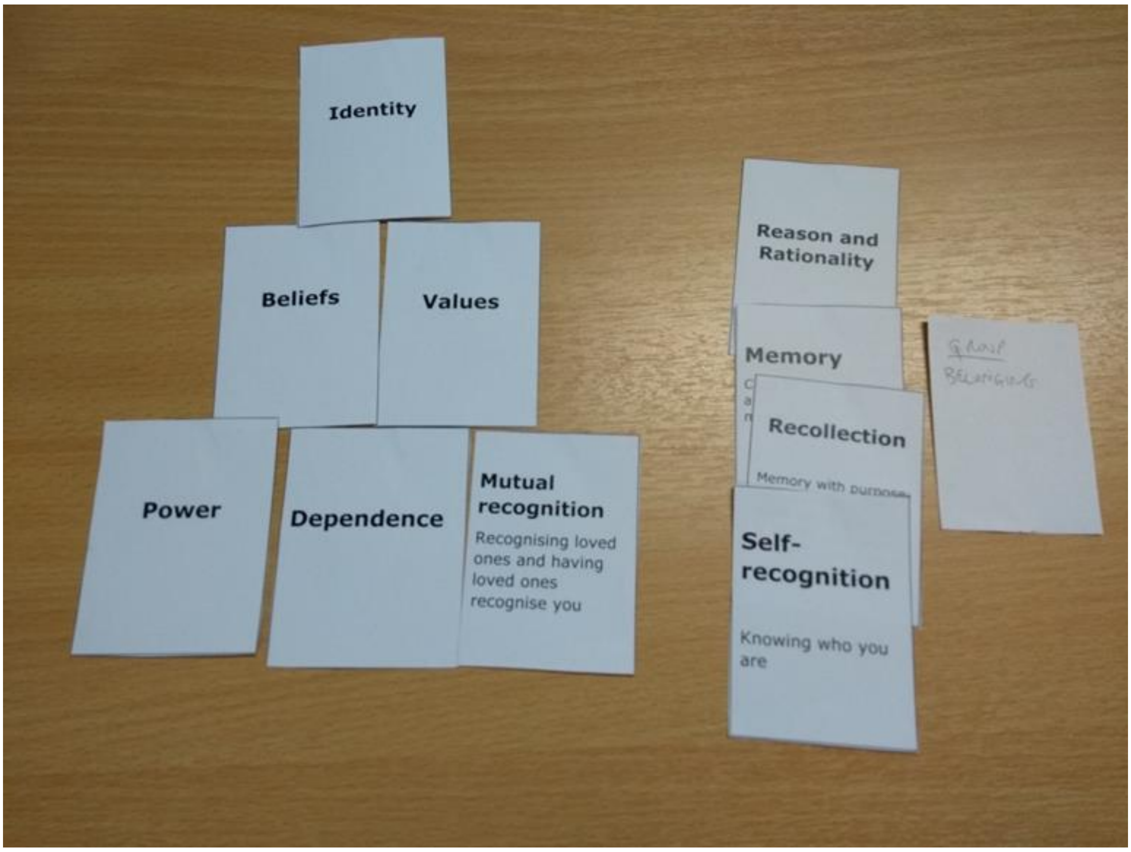
Added personality.


Beliefs
Values
Identity
Self-recognition
Knowing who you are
Reflection
To be able to use surroundings to assess where/who you are, what you're doing, when etc.
Case Studies
John
Mary
personality
Memory
Capacity for memory and retention of memory
Independence
Reason and Rationality
Power
Experience
Ability to work
Recollection
Memory with purpose- being able to recall experiences and facts to decide what to do or how to complete a task
Mutual recognition
Recognising loved ones and having loved ones recognise you
Dependence

Focus Group 2 (IMH)
(7/11/19)

Participant 1: Anthony- white, male, in his 30's with experience of schizophrenia. Anthony organized some elements hierarchically in a pyramid of 'core' self, and the other category is elements 'lost' during a mental health experience. Previous experience as a nurse, mental health researcher.

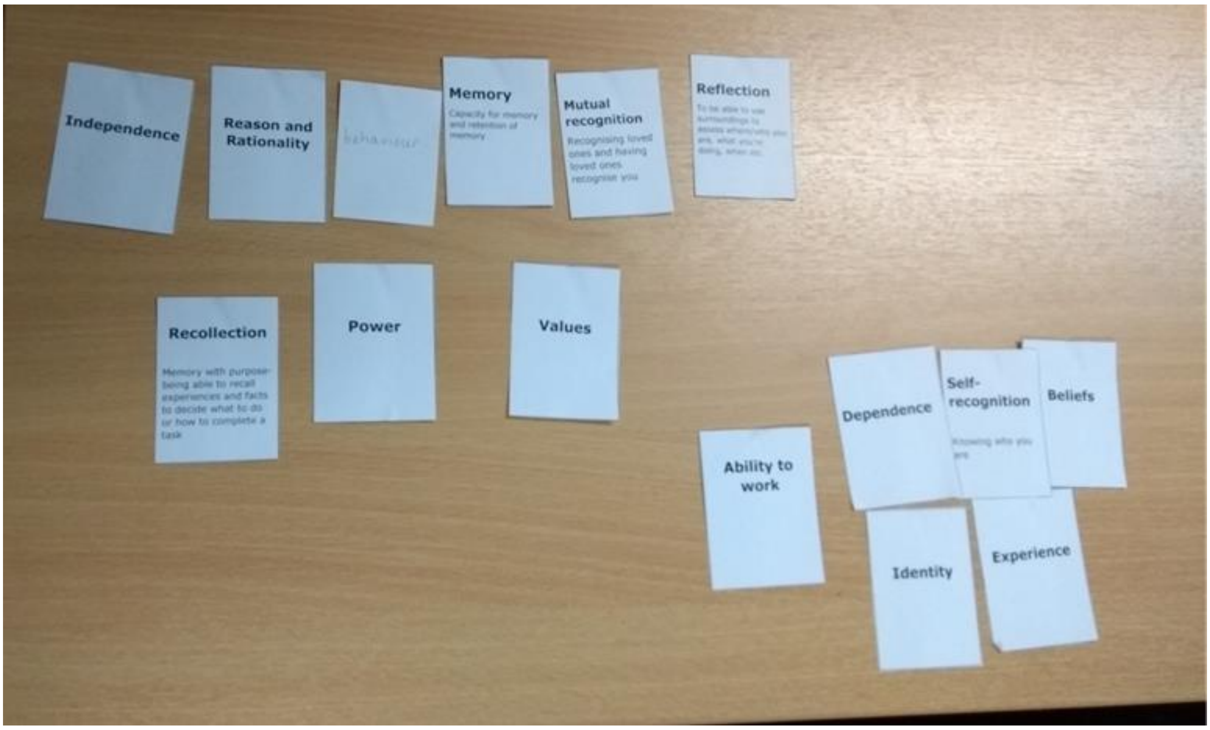
Group belonging was added.



Participant 2: Layla- borderline personality disorder, white woman, in her 40’s

Top row from left to right were described as the most important elements of self. The second row were described as elements Layla was ‘not sure what to do with,’ and the bottom right pile was excluded. Prior experience in some capacity working with the Care Quality Commission.

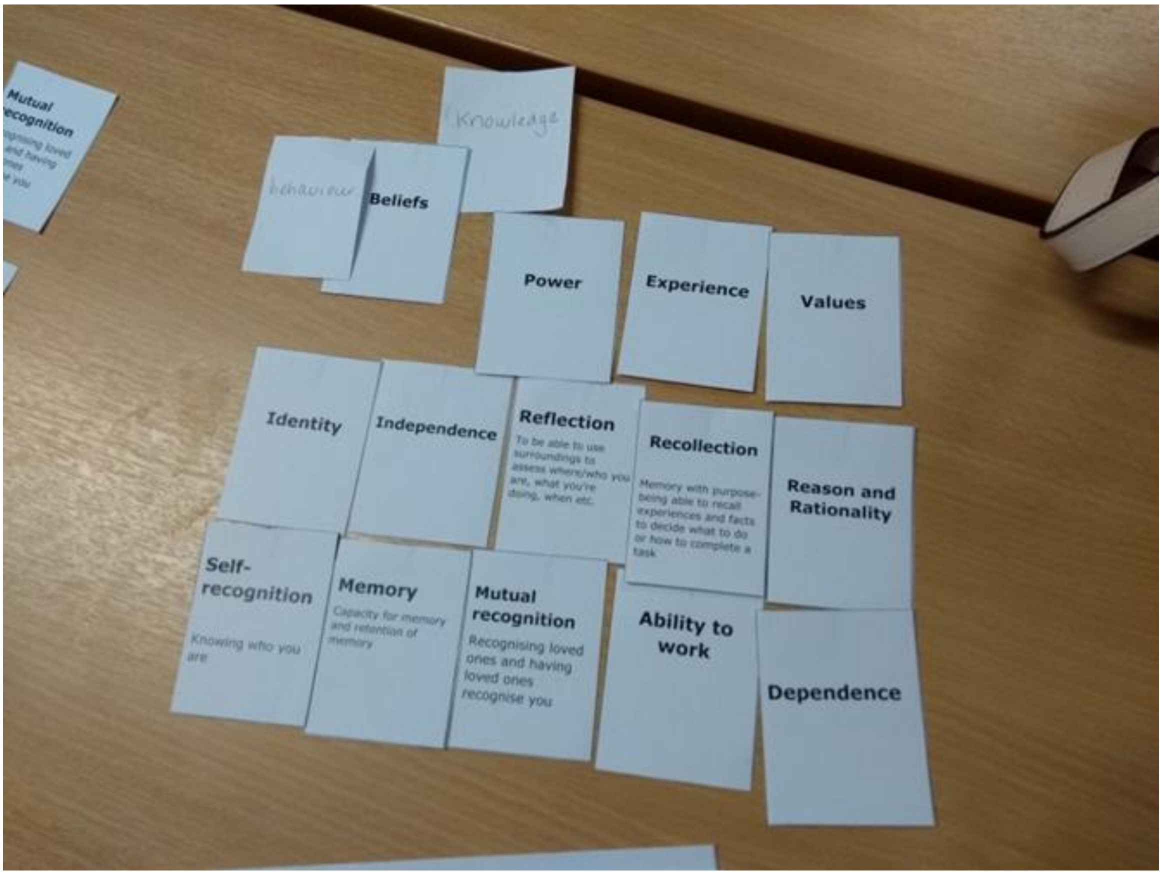
Behaviour was added.



Participant 3: Diego- clinical depression and anxiety, white male, aged 60+

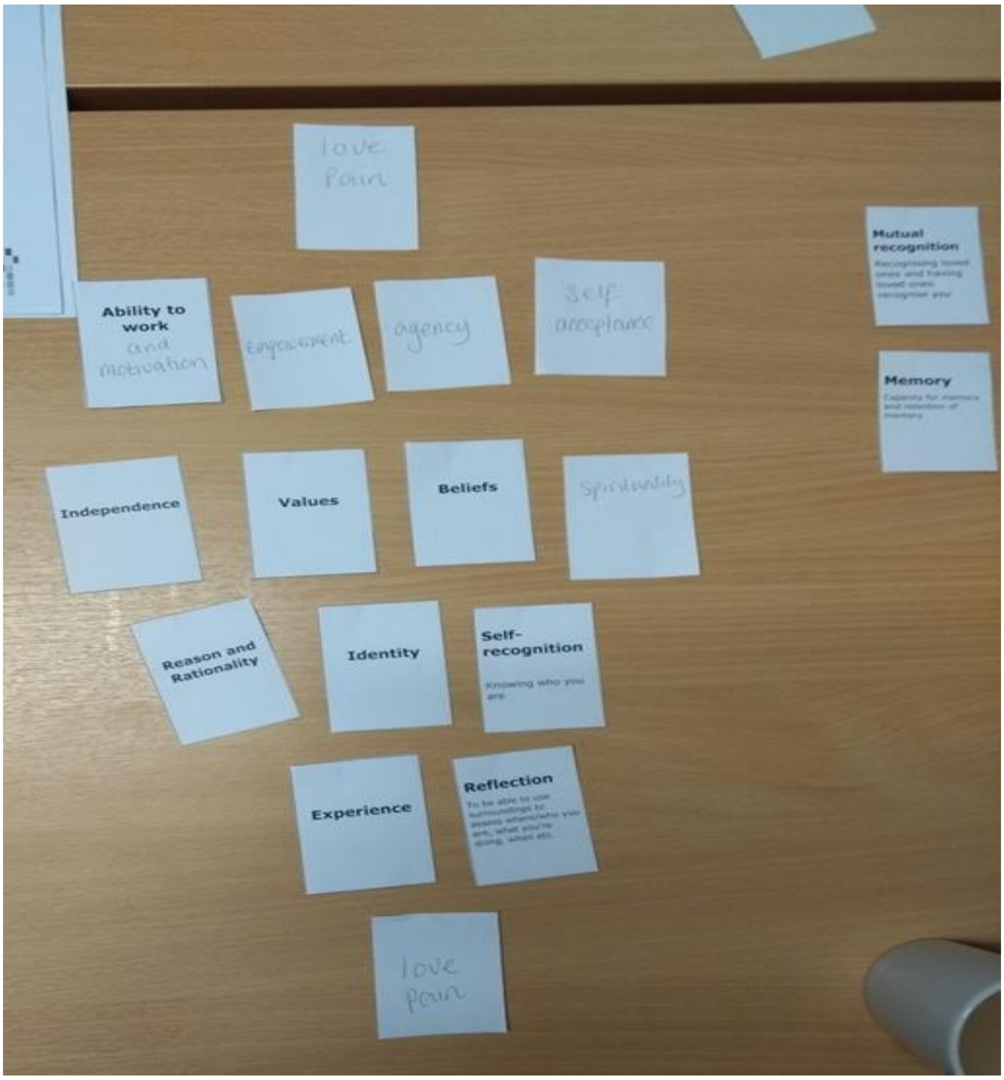
Diego described the top row as the most important elements, with knowledge as pinnacle of self influencing the top row. Rows left-right go down hierarchically with dependence last.

Knowledge and behaviour was added.



Participant 4: Jessie- white woman of retirement age who describes her mental health as "living with the impact of deep traumatic, mental and moral life wounds, broken and reborn, mad and not requiring to be fixed." Mental health advocate and researcher. Previous experience as an independent mental capacity advocate (IMCA). Jessie arranged the elements in a shape of self. She described love and pain as framing self, with all elements being interconnected. She explained it like growth from the bottom up.

Added love and pain, empowerment, agency, self-acceptance and spirituality.



Individual Interview 2 (IMH)
(12/11/19)

Samantha: Spousal carer for her husband with late-stage frontotemporal lobe dementia (FTD) white woman of retirement age

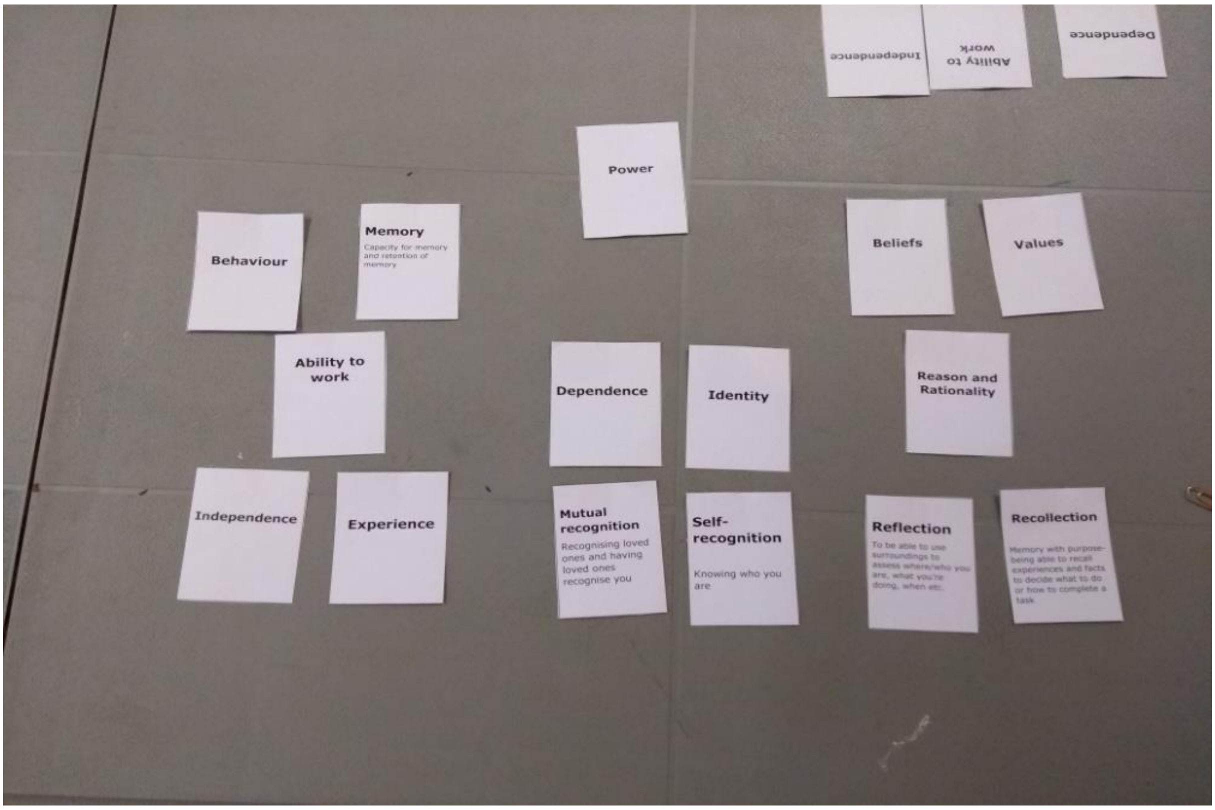
Samantha chose to go through each element and talk about it in reference to her spouse rather than organize them. Therefore there is no picture to accompany her communication of her spouses self.

Focus Group 3 (START)
(14/11/19)

Participant 1: Ella- bipolar and fibromyalgia- previous employment as a carer, white woman in her 40's, in a relationship with Humphrey

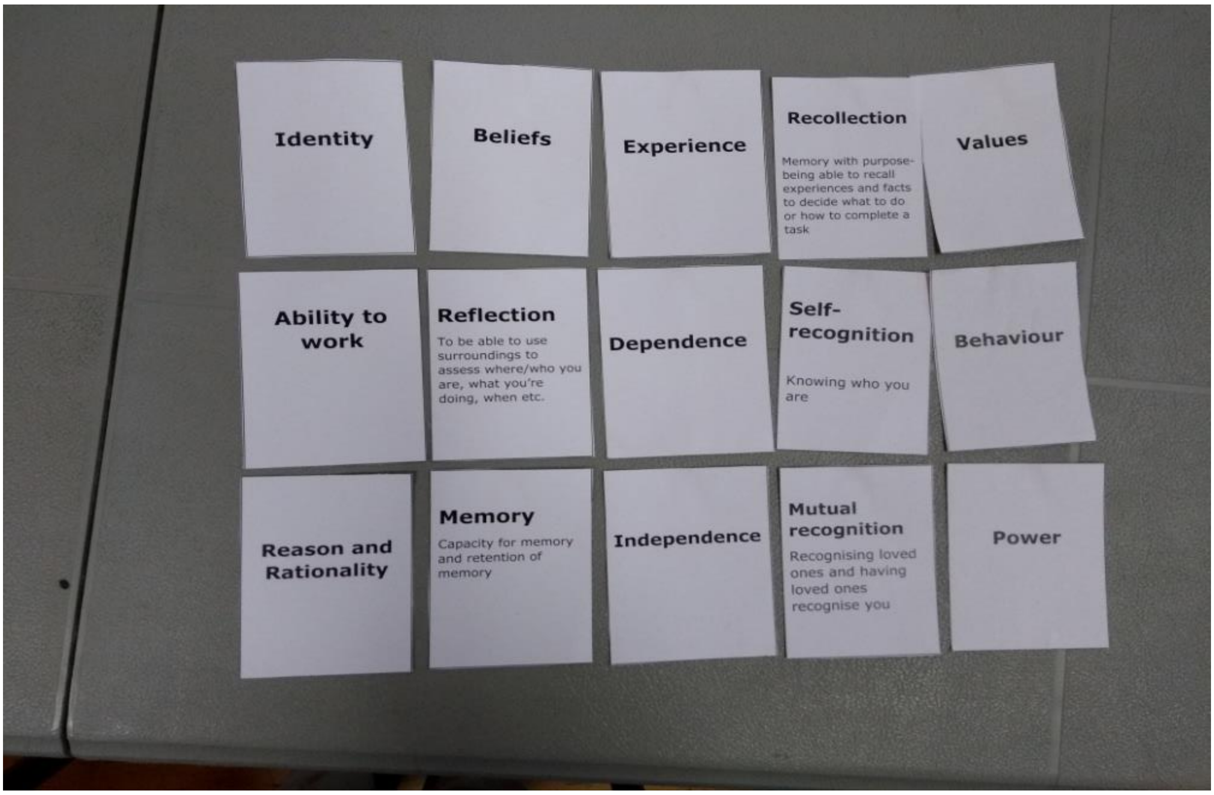
Arranged the elements in groups according to what Ella felt 'go together.' She felt power could be at the top or the bottom.

Power was a stand-alone transcendental element which could be either at the top or bottom of self. It can be at the top because they know they have power over and can exercise control over all other elements, and vice versa it can fall to the bottom because of a lack of power caused by mental health experience, physical health and disempowering relationships where people hold power over them or are in a power struggle.



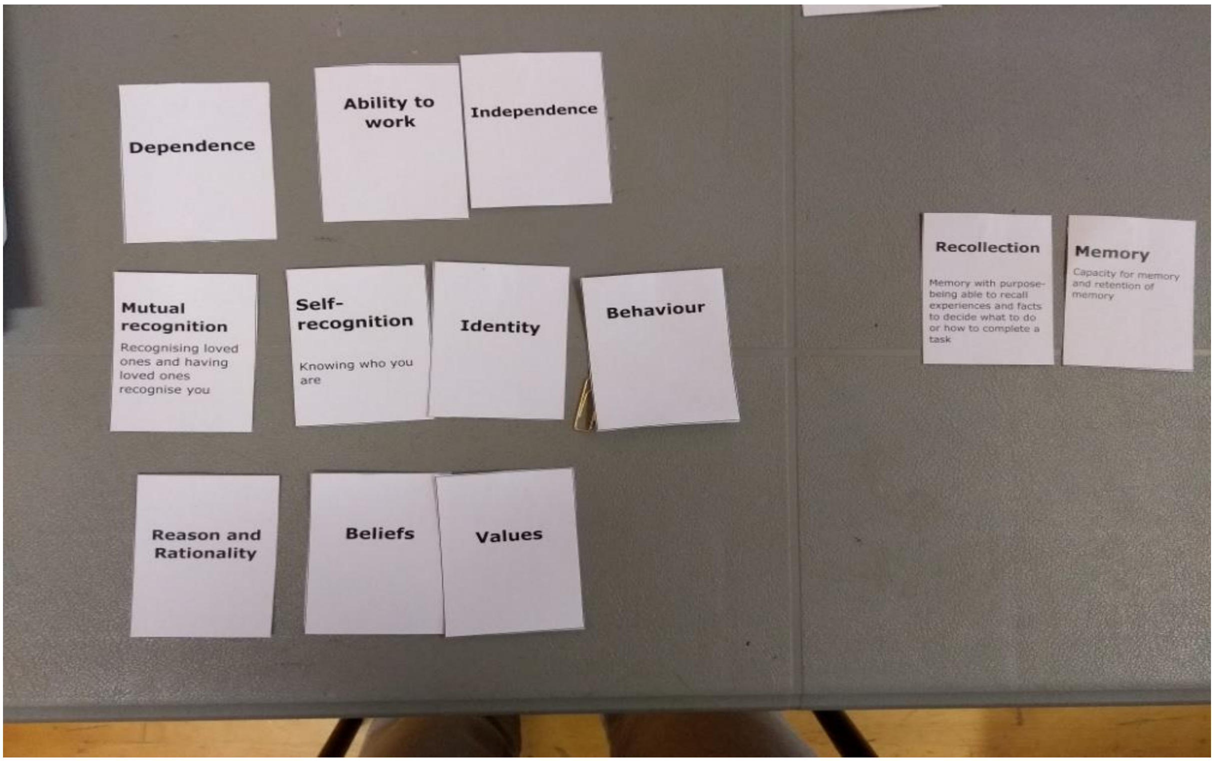
Participant 2: Humphrey- depression, anxiety and has seizures which resulted in deficits to cognitive functioning, has prior experience as a support worker, white male in his 40’s, in a relation with Ella

Humphrey organized the elements hierarchically from top left to bottom right in horizontal rows.



Participant 3: Daria- manic bipolar, fibromyalgia and autism, cares for her partner with physical disabilities, white woman in her 30's

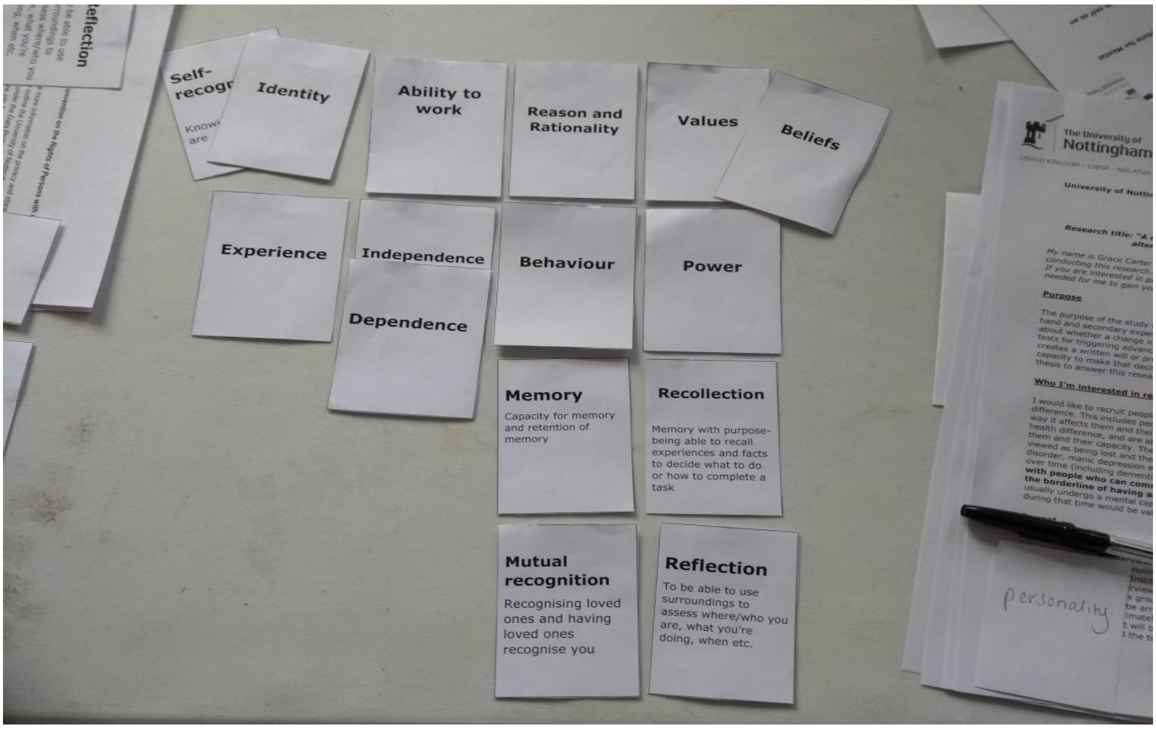
Daria organized the elements into four categories. The top row is things they would like to be able to do, the row below is linked with their self-discovery after learning of an autism diagnosis, the bottom row is why they behave the way they do; the category to the right is things they struggle with post mental health experience.



Focus Group 4 (START)
(15/11/19)

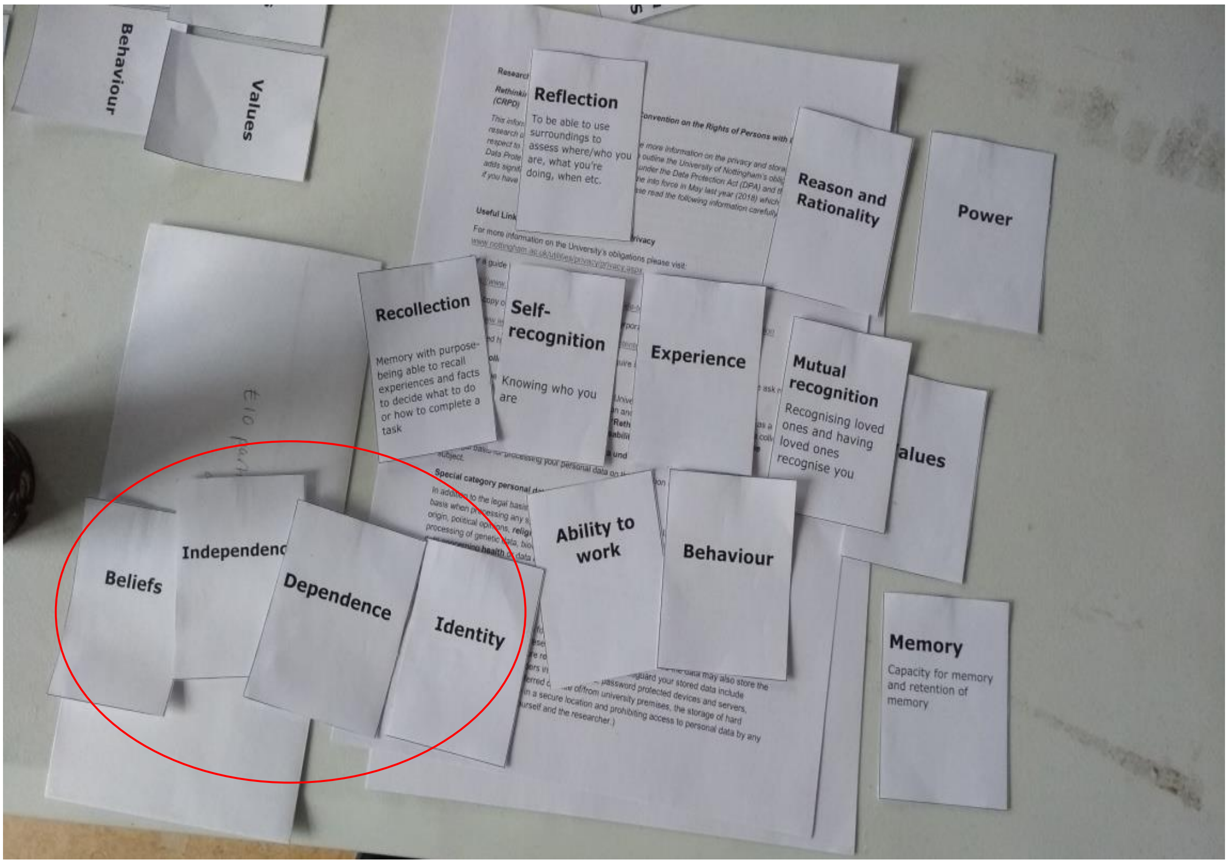
Participant 1: Rebecca- experience of obsessive-compulsive disorder, white woman in her 20’s

Rebecca was shuffling and re-organizing the elements whilst others were talking, right up until it was their ‘turn’ to discuss. They feel some things ‘go together’ but the elements were not particularly ordered. They felt identity and self recognition ‘went together’ and were impacted by mental health. They feel ability to work and reason and rationality are impacted by mental health. Independence and dependence were paired together. They also talk about their OCD impacting their behaviours and how they worry they come off as apathetic towards their parents and their shared home, when in fact they ‘care too much.’ Power is framed negatively as “feel[ing] like you don’t have the power to, sort yourself out” and memory is referenced in terms of its loss as a side effect of medication.



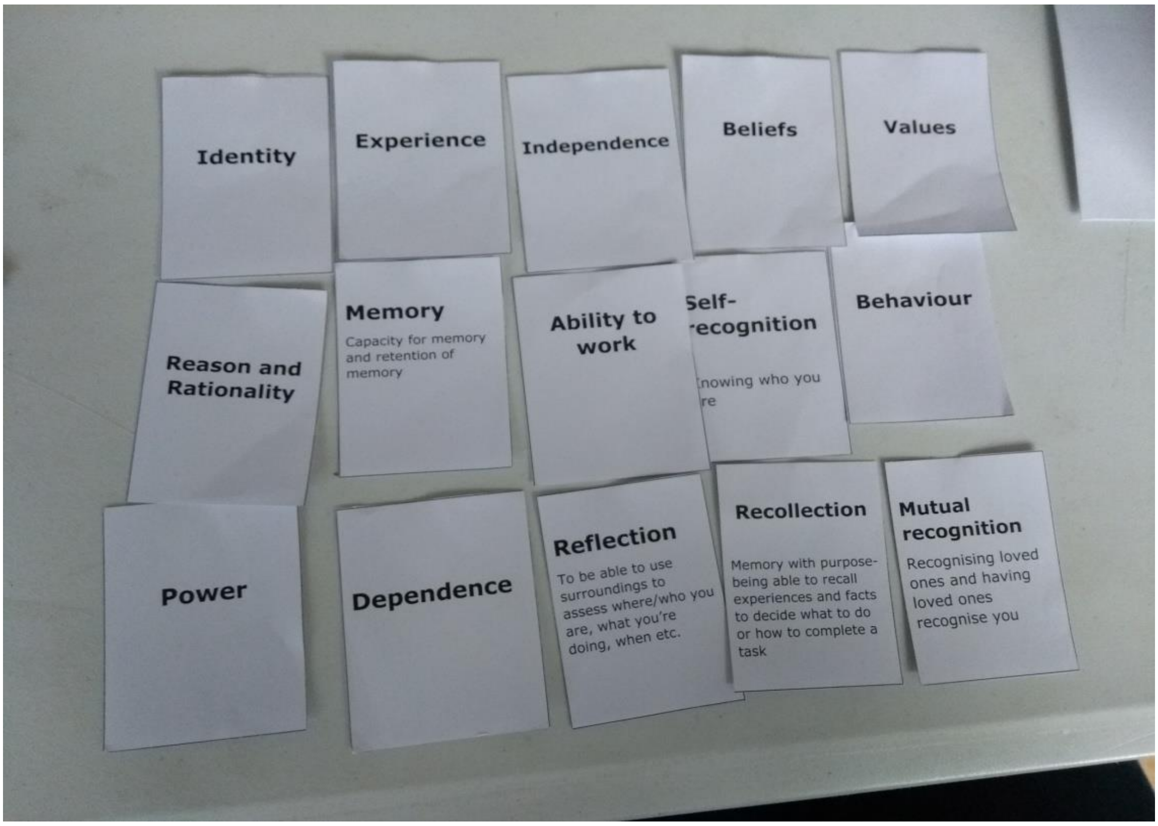
Participant 2: Lulu- depression and secondary experience of long-term psychosis via their brother whom she helps care for, experience of autism and self-harming tendencies via her daughter, white woman in her 60’s

Lulu picked out four elements which spoke to her and put them in a 'little pile.' When asked how they had ordered the rest they said- "randomly, that is my life as it is! [laughs]…it's just a mash a mess of everything cause my head I feel is like that." The four elements selected include beliefs, independence, dependence and identity. Beliefs were discussed as believing in oneself and having less self doubt, independence was discussed in reference to Lulu being a carer and lacking time for herself. Identity was discussed as feeling part of an identity and wanting that identity to be liked and loved. Dependence was discussed in terms of lacking someone/something to be dependent on because of how many people were relying on her.



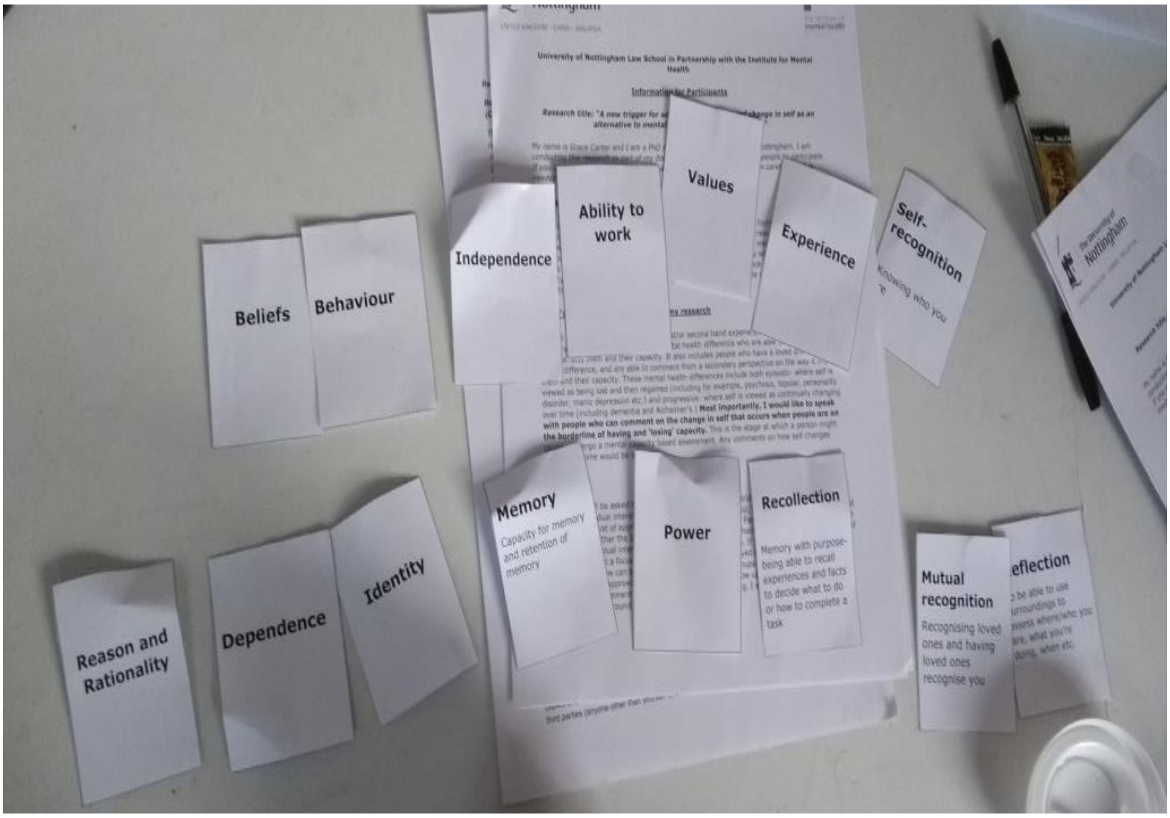
Participant 3: Peter- schizophrenia and secondary experience of dementia, white male in his 40’s

Peter organizes his elements hierarchically in rows. Their most important element is identity, which is described as a façade. This is followed by experience, independence, beliefs and values. Power (referenced negatively- as someone having power over you,) dependence, reflection, recollection and mutual recognition were placed in the bottom row.



Participant 4: Jill- undisclosed episodic mental health difference, secondary experience of dementia through running a dementia and carers group at START, white woman of retirement age

Jill organized the elements in two rows- one expressing knowing 'how [they] are now' and one relating to which elements changed with mental health. The other row is discussed much less (only memory and reflection are discussed) and seems not to play a dominant role in self. The top row includes behaviour which was the first element they discussed- saying "…well behaviour…that was when, my behaviour was shocking at one time…[it's improved] I put that down to my medication you know like helping me…" This row also includes beliefs, independence (phrased as 'I can get out of the house,') ability to work (phrased as volunteering to help people,) values (family) experiences ("effects the person a lot… with the experience, you know how you are now,") and self-recognition ('recognizing my illness…my loved ones…what I put them through and them recognizing who I am now.') The elements in this top row do not seem to be ordered hierarchically.



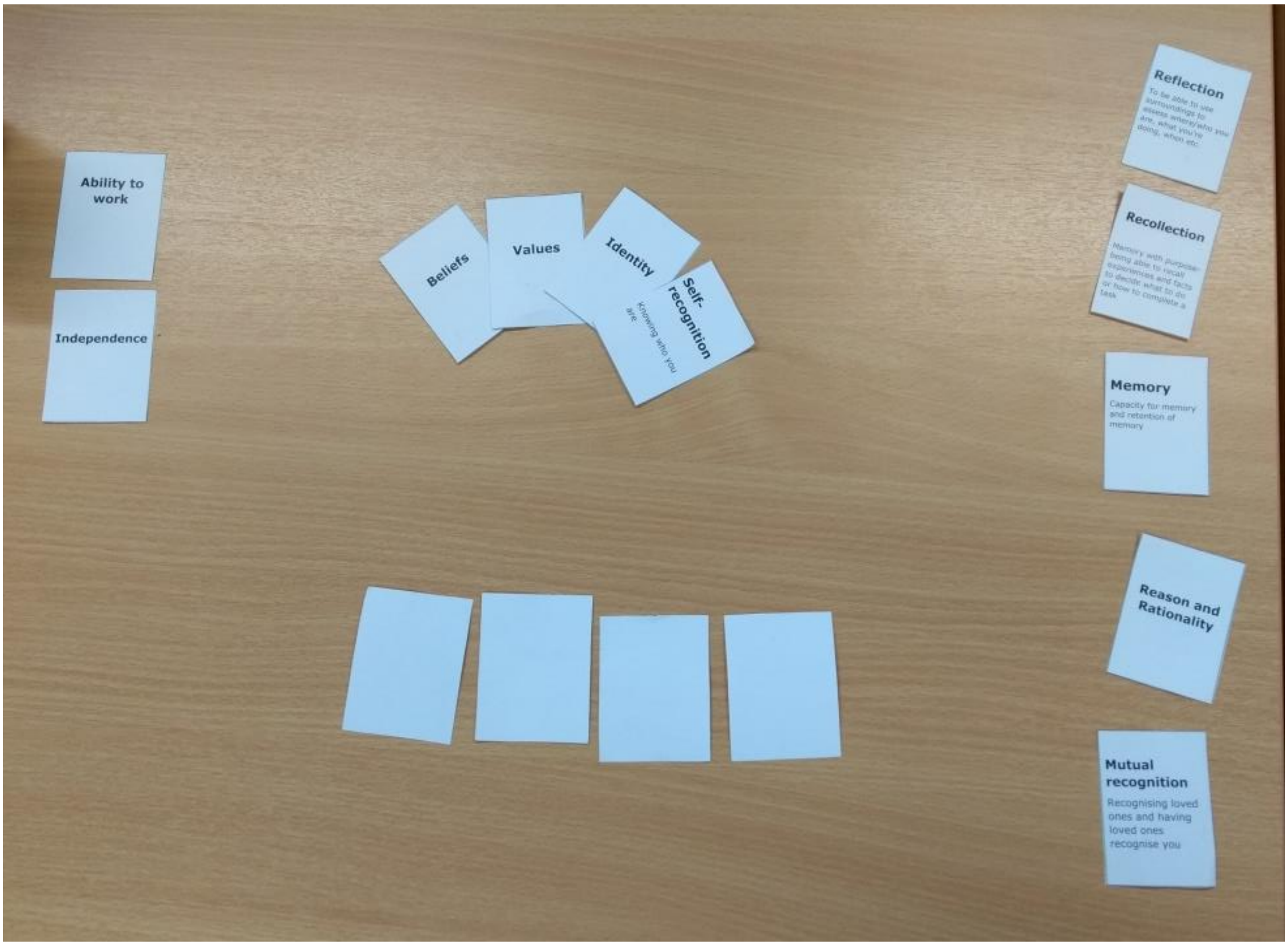
Individual Interview 3 (START)
(15/11/19)

Steph: depression, anxiety and post-traumatic stress disorder and secondary experience of late-stage dementia via their mum and both parents-in-law, white woman in her 50's

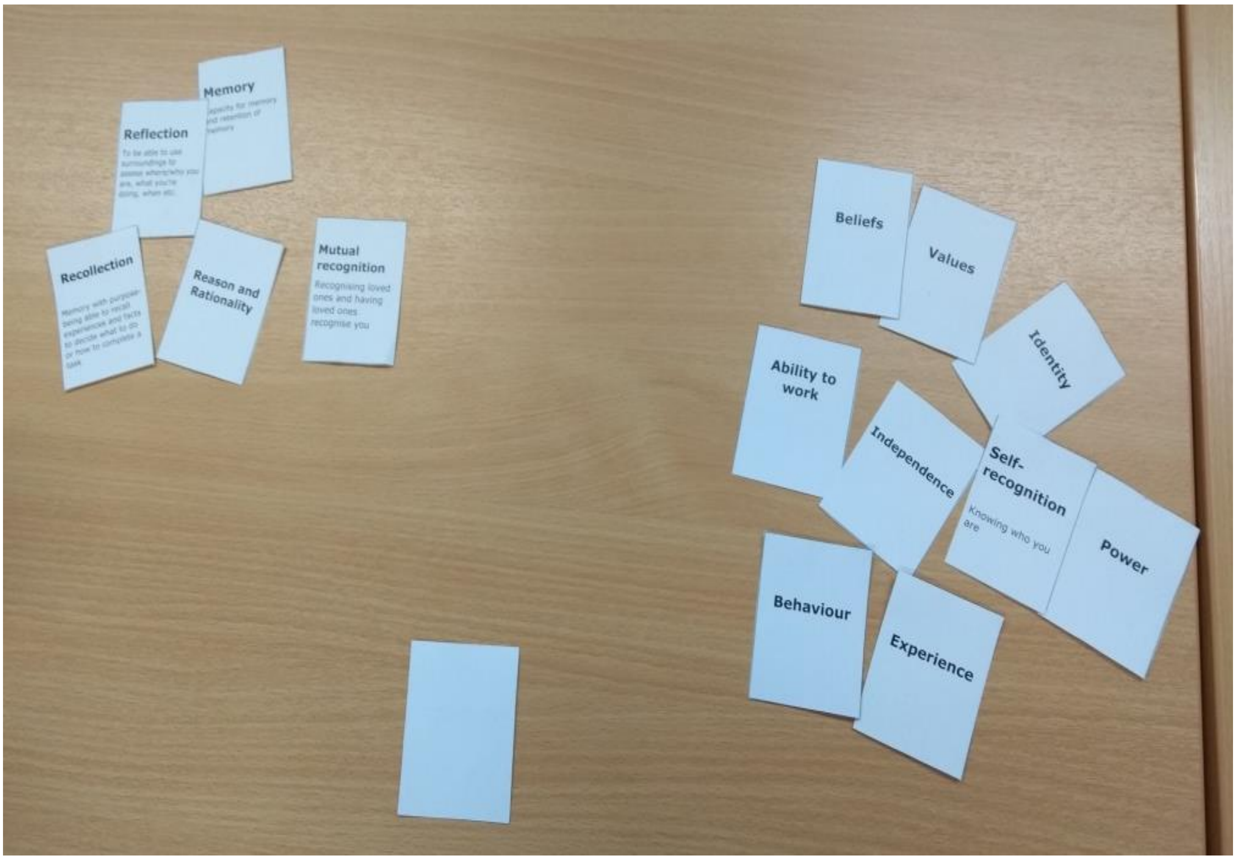
Steph organized their elements into two piles quite quickly and left some out entirely. One pile pertained to how they saw their self and the other pile was elements they felt did not apply. There is no picture of this organization as all elements were gone over in discussion. The elements they felt pertain to their self included values, beliefs, reason and rationality, the capacity for reflection, and the ability to work. The elements which were excluded include power and identity, mutual recognition, dependence and memory. Steph became emotional when she read ‘memory’ and did not discuss it.

Focus Group 5 (IMH)
(18/11/20)

Participant 1: Michelle- manic bipolar with psychotic and depressive episodes, white woman in her 20’s, daughter of Joseph. Michelle arranged the elements into a well self and a poorly self. The well self contains four piles. The far rights pile includes “things I definitely know are me, or are things I can do,” the middle semi-circle of elements were described as ones Michelle used to have; the cards turned upside down were ones they ‘didn’t really get’ and the far left pile are elements she feels she no longer has post mental health experience.

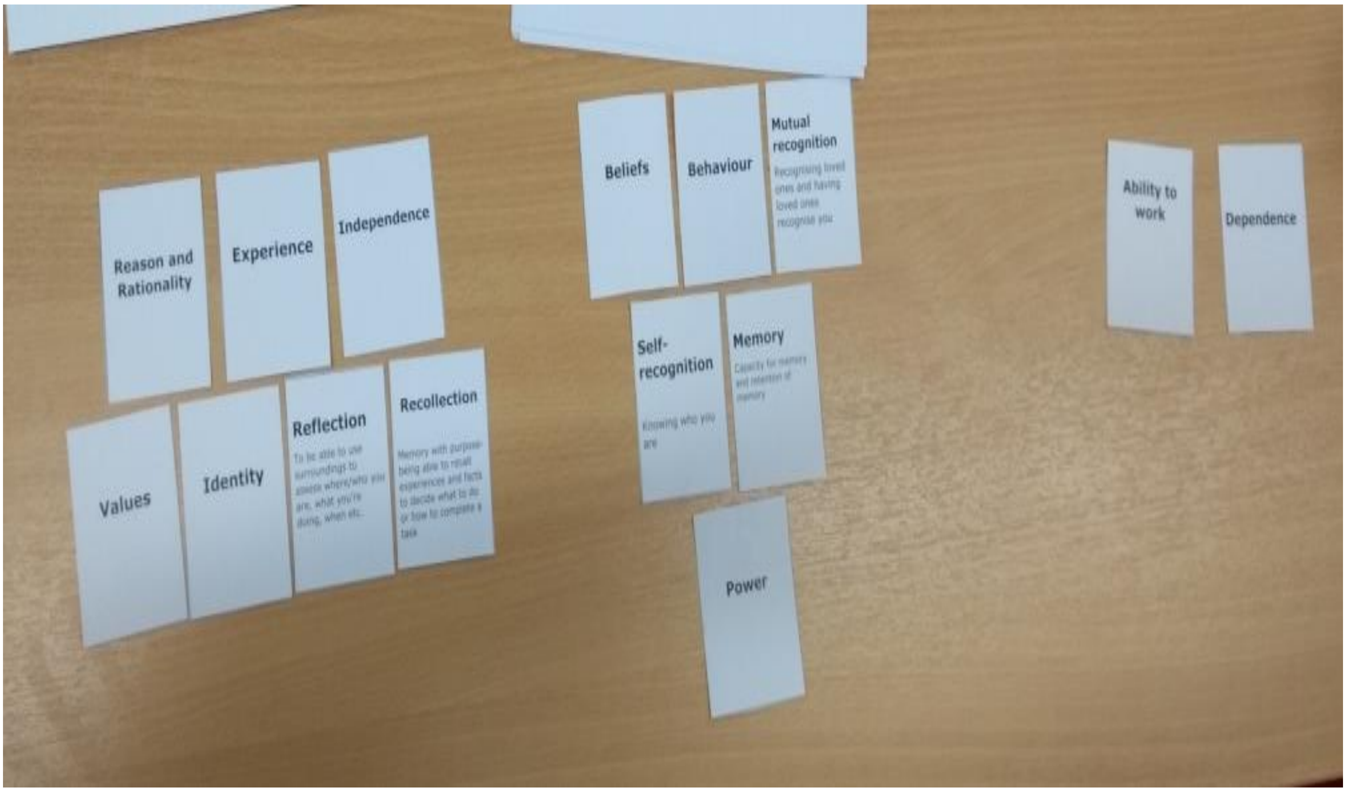


Shortly afterwards she rearranged the cards to represent her ‘poorly self.’ In the left pile everything Michelle previously felt were ‘definitely things I know are me or I can do’ were lost, and the right pile represents all elements they struggle with, feel they cannot do or has lost when well, are regained and ‘magnified.’



Participant 2: Joseph- Michelle's father, who therefore has close secondary experience of her mental health, white male of retirement age.

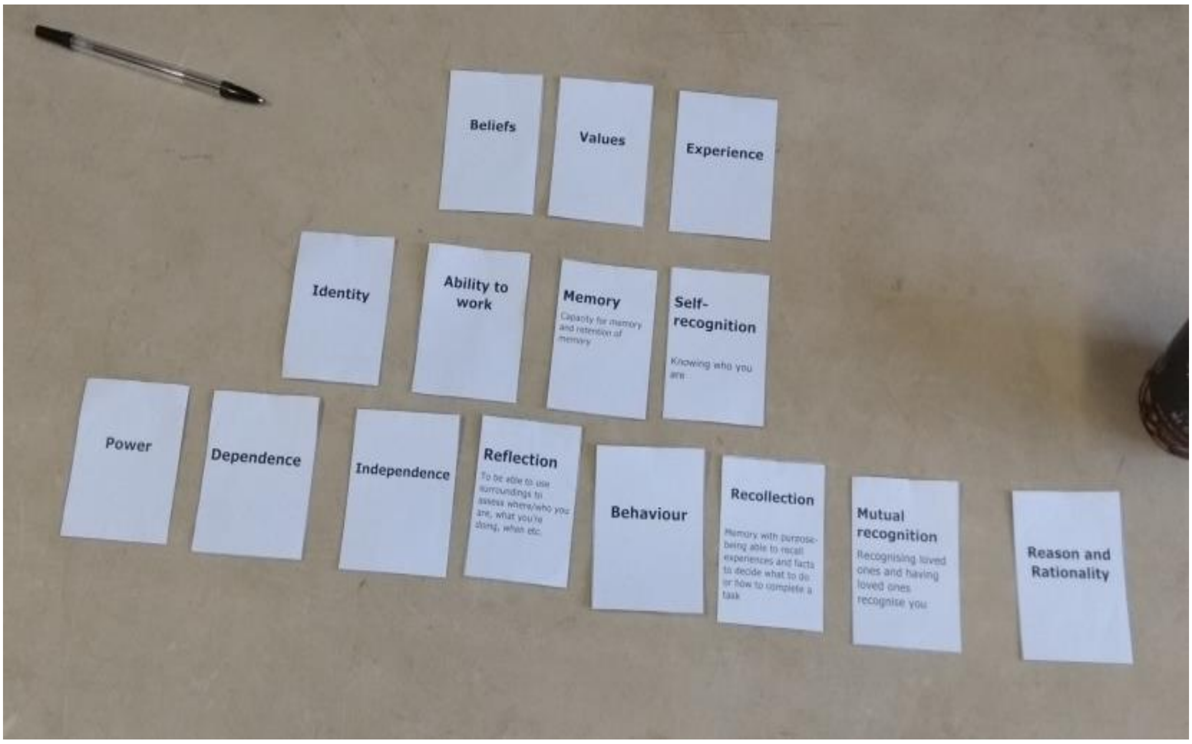
Joseph categorized the elements hierarchically, with the first pile being most important to their self, the second pile being less so as they change i.e. with age, but all of which stem from power- viewed positively as self empowerment to act, and the last pile being elements which no longer apply to their self.



Focus Group 6 (START)
(21/11/19)

Participant 1: Debbie- personality disorder, depression and previous experience as a nurse, white woman in her 50’s

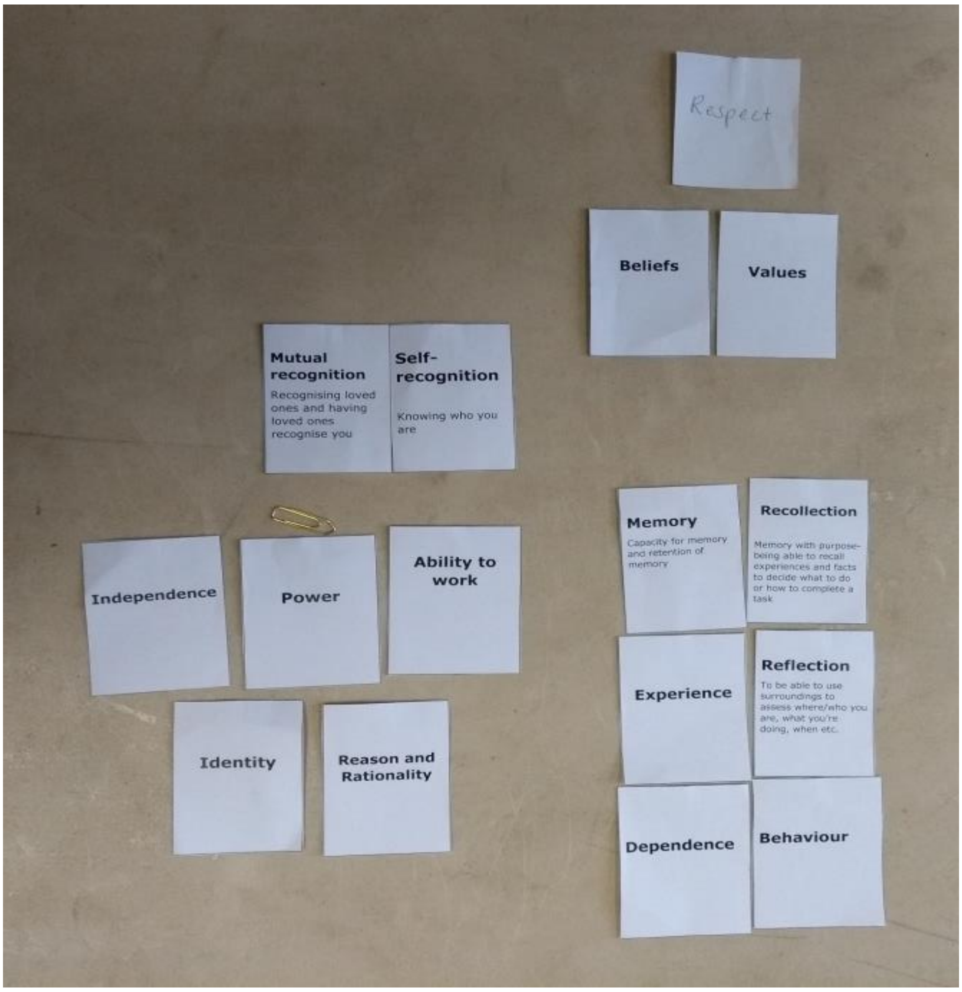
Debbie organized her elements into three rows. The top row are elements she feels are strong within her and which have saved her life, the second row are elements she feels most challenged by post mental health and which she struggles with frequently, and the bottom row comprises of elements which have changed because of mental health but which she maybe feels less strongly about.



Participant 2: Jane- depression and experience as a secure mental health facility nurse for eight years, white woman in her 50’s

Jane organized elements into three categories, the first being those which are of most importance to them/which they have retained. This includes values and beliefs and respect. The second category are things they feel they have lost and includes independence, power, ability to work, identity and reason and rationality- with the most prominent losses being in self recognition and mutual recognition. Jane was less clear on what the third bottom right category represents. They do not believe dependence applies to them.

Added respect



Individual Interview 4 (START)

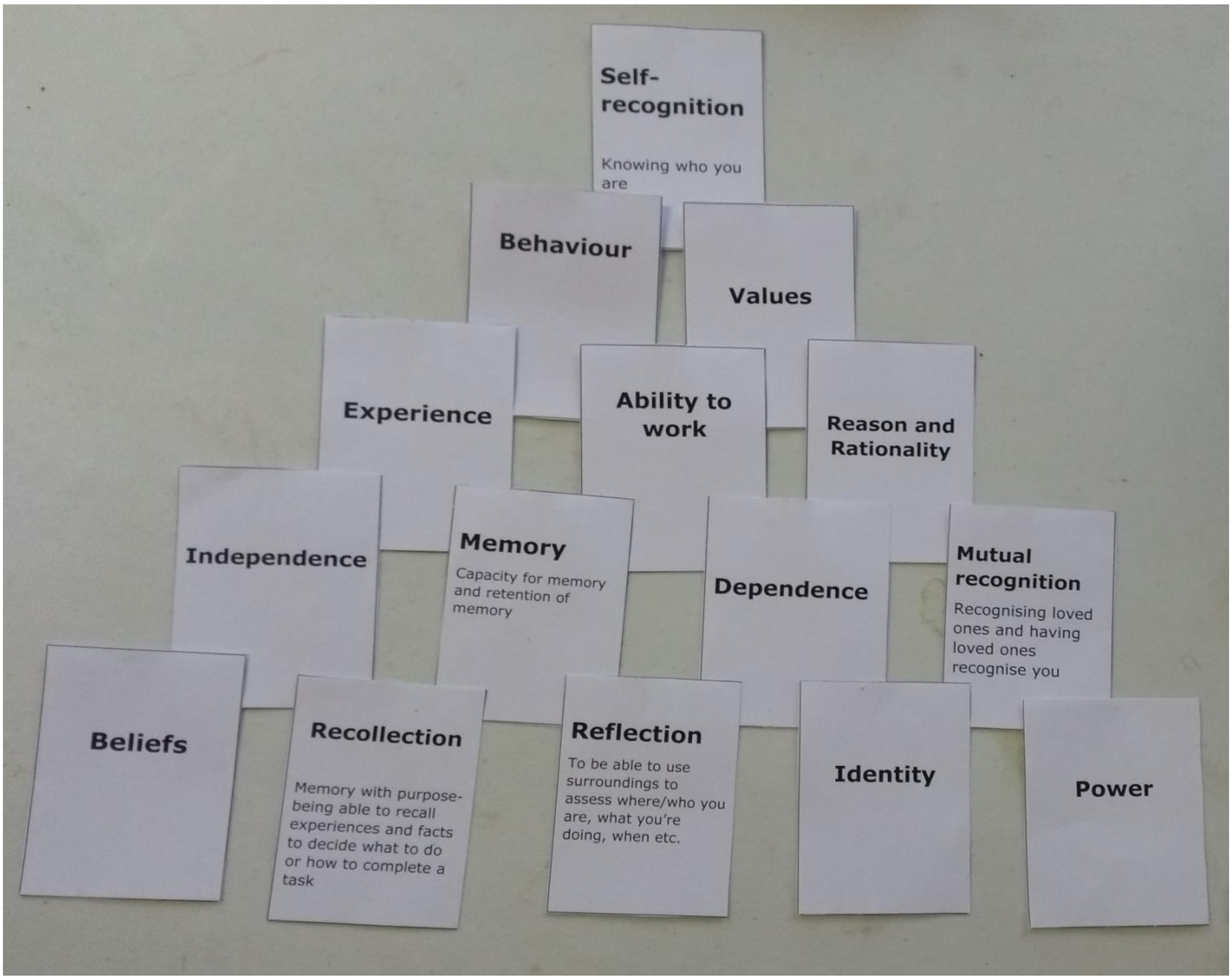
(22/11/19)

Klein: depression and secondary experience of late-stage dementia via his dad, white male in his 60’s

Klein organized elements hierarchically into a pyramid, in order of importance. It also appears they have grouped some elements together within the pyramid, including memory, reflection and recollection. In order of importance their elements of self are first, self recognition- as the pinnacle of wanting to know self and make a positive life change moving forward: “…knowing who I am what I wanna be, the real person, not the person that has been coasting along for 40yrs, I’m tryna discover the new me…” This was followed by behaviour and values- discussed with heavy reference to family and of values as a way of passing on moral standards generationally within a family, and as a foundational influence in making life decisions.

Klein discussed ‘self’ as very much what was important to his self right now, in the moment, and discussed most elements with reference to a career change.

This is different from other participants who draw on more long term or long held conceptions of self for this activity, and may be representative of the fact that this participant felt they could only attempt to communicate their self as it was in that moment.

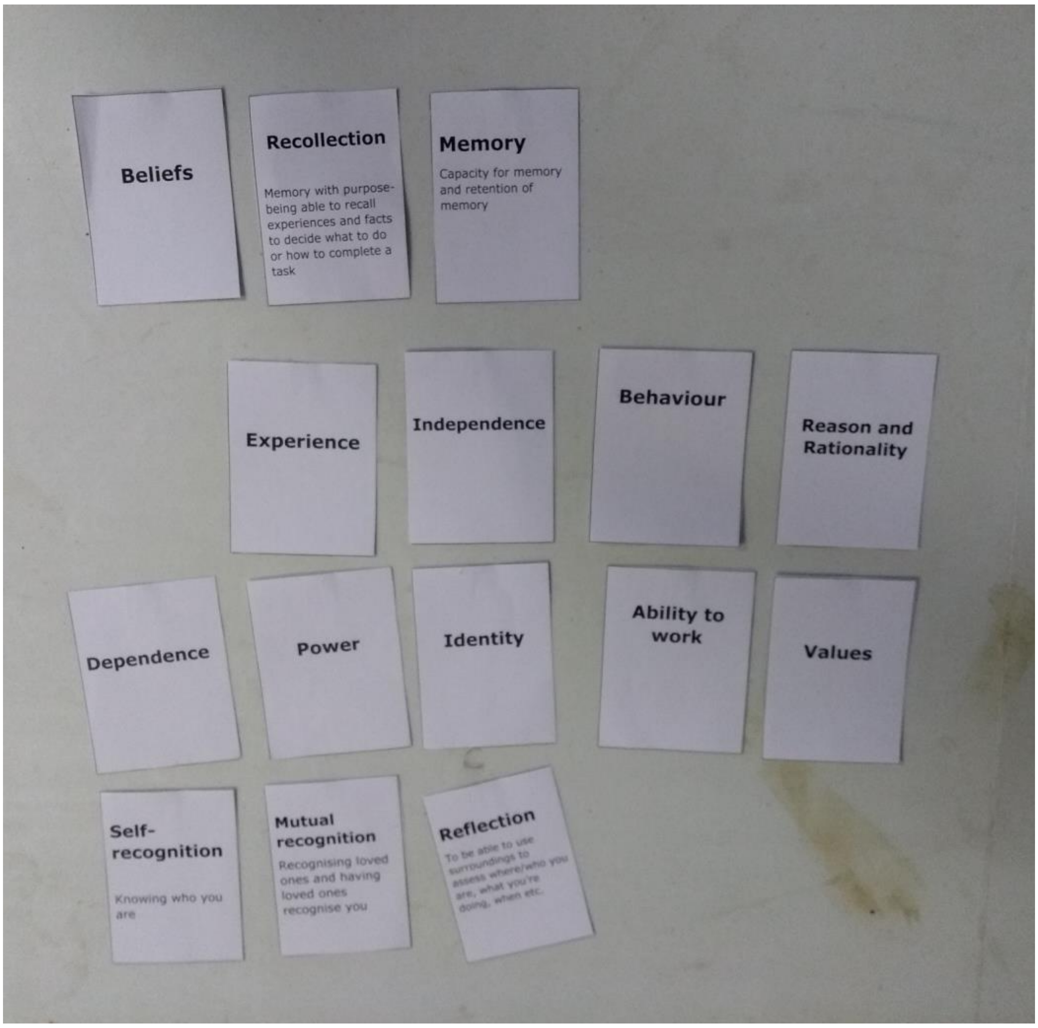


Individual Interview 5 (START)

(22/11/19)

Steven: ongoing psychosis, white male in his 40's

Steven seemed to organize their elements in groupings which informed one another. For example the first grouping is beliefs, memory and recollection because "my beliefs are…based on recollection and memory." Steven talks about doubting their own memory- "I don't know if it's a true memory or a false memory," and talk about having a sense of self from a young age. Another dominant topic was beliefs- mainly in how they constituted the participants place in life, and including beliefs which could be described as conspiracy theories and about having a higher purpose in life. Admittedly in this interview the grouping and explanation of elements was not discussed at length as the interview was shorter than usual. This was because of time constraints and ethical considerations which have now been resolved.



Individual Interview 6 (START)
(3/12/19)

Molly: carer for her husband with late-stage dementia, experienced a stroke, white woman of retirement age

Molly chose to categorize the elements of self hierarchically from most important- top left- to less important- bottom right. Memory played a dominant role as did behaviour because of the participant’s secondary experience of witnessing loved ones change because of mental health difference, which has in turn influenced which elements they perceive as important in self. Memory, recollection and mutual recognition were grouped together.