International Journal of Mental Health and Capacity Law

Articles

On Detaining 300,000 People: the Liberty Protection Safeguards

Empowering Young People: Multi-Disciplinary Expressive Interventions Utilising Diamond9 Evaluative Methods to Encourage Agency in Youth Justice

The State's Obligation to Protect Life and Health of Vulnerable Adults: the Order of 26 July 2016 of the German Federal Constitutional Court in the Light of the CRPD and ECHR

Opinion

Engagement and Participation as a Part of the Mental Welfare Commission for Scotland

Personal Independence Payments, Mental Distress and Uniform Policy in Determining Mobility Claims



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Contents

Editorial

Jill Stavert	rt	

Articles

On Detaining 300,000 People: the Liberty Protection Safeguards	
Lucy Series	

Opinions

Engagement and Participation as a Part of the Mental Welfare Commission for
Scotland
Graham Morgan167
Personal Independence Payments, Mental Distress and Uniform Policy in Determining Mobility Claims <i>Zia Akhtar</i>

Articles and pieces in this issue have been edited by: Professor Jill Stavert (lead editor), Simon Burrows, Dr Piers Gooding and Dr Giles Newton-Howes.

Editorial assistance has been provided by: Hal (Zhan) Brinton Page

EDITORIAL

As with previous issues this issue reflects the diverse and rich range of topics and concerns that fall under the umbrella of, or are aligned with, mental health and capacity law. This time we offer three peer-reviewed articles and an Opinion piece, and a non-peer reviewed case comment. What has, however, struck me is that each of the contributions - from England, Wales, Scotland and Germany - essentially highlights issues of equality and non-discrimination in relating to rights enjoyment for persons with lived experience of psychosocial, intellectual and cognitive disabilities. Moreover, when we started work on this issue, we did not expect to be experiencing a global pandemic and one which has brought equality and non-discrimination into even sharper relief.

In the first article, *On Detaining 300,000 People*, Dr Lucy Series outlines the background to the Mental Capacity (Amendment) Act 2019 which introduces the new Liberty Protection Safeguards in England and Wales. These are due to come into force later this year (although may be delayed as a result of the coronavirus) and replace the much criticised Mental Capacity Act 2005 Deprivation of Liberty Safeguards designed to address Article 5 European Convention on Human Rights (ECHR) concerns over persons who are considered to lack capacity to consent to a deprivation of liberty. She argues, however, that the new scheme still fails to deliver adequate detention safeguards and answer the fundamental question of what are these safeguards are actually for. Finally, Dr Series also highlights the very important and worrying issue that Coronavirus 'lockdown' measures may be unlawfully depriving many people in care homes and other care settings of their liberty.

The second article, *Empowering Young People*, authored by Professor Raymond Arthur and Drs Rachel Dunn and Nicola Wake present data collected using the Diamond9 mixed method approach and semi-structured interviews to evaluate sports and artsbased interventions within Secure Children's Homes in England and Wales. The results provide an original insight into this under-researched area of the criminal justice system and highlight the importance of adopting a child-centred approach to intervention models in order to engage young people, break down barriers relating to perceptions of authority and lack of individual autonomy.

Elisabeth Rathemacher's article *The State's Obligation to Protect Life and Health of Vulnerable Adults* covers a common issue for many jurisdictions of how to address the apparent differences in approaches to individual autonomy and protection in national constitutions, the ECHR and the Convention on the Rights of Persons with Disabilities (CRPD). These differences are particularly pertinent when it comes to considering justifications for forced medical treatment and hospitalisation to protect life and health of adults with serious mental illnesses who are refusing medical treatment. The matter is discussed in the context of the 2016 German Federal Constitutional Court *BVerfG* ruling. Interestingly, the article concludes that although the ruling apears to fly in the face of current understandings of the CRPD approach, it may in fact actually be CRPD compatible.

The active and meaningful involvement of persons with lived experience in the development, review and monitoring of mental health and capacity law and related rights is essential. In the Opinion piece *Engagement and Participation as a Part of The Mental Welfare Commission for Scotland,* Graham Morgan MBE, Engagement and Participation Officer (Lived Experience) at the Mental Welfare Commission for Scotland, provides an interesting account of the work of the Commission's Engagement and Participation Officers with lived experience as users and carers. The history of user and carer involvement in the Commission, as well as the reason for the employment of the existing workers and the creation of its department of engagement and participation, are discussed. Graham Morgan is also an Executive Team member of the current Scottish Mental Health Law Review chaired by John Scott QC.

Finally, in the case comment *Personal Independence Payments, Mental Distress and Uniform Policy in Determining Mobility Claims*, Zia Akhtar discusses the English High Court 2017 ruling of *RF v Secretary of State* which found that the 2016 Personal Independent Payment regulations discriminated against persons suffering from mental ill-health. The article also considers the anomalies and inequalities surrounding implementation and evaluation of eligibility for this social security benefit.

I thank fellow members of this issue's editorial team – Simon Burrows, Piers Gooding and Giles Newton-Howes – and Editor-in-Chief, Kris Gledhill - for their considerable support whilst we have worked on its production, as well as Hal Brinton for his copyediting assistance.

We hope that you find this issue interesting and informative.

Jill Stavert

ON DETAINING 300,000 PEOPLE: THE LIBERTY PROTECTION SAFEGUARDS

$\mathsf{DR} \ \mathsf{LUCY} \ \mathsf{SERIES}^*$

ABSTRACT

The Mental Capacity (Amendment) Act 2019 will introduce a new framework—the Liberty Protection Safeguards (LPS)—for authorising arrangements giving rise to a deprivation of liberty to enable the care and treatment of people who lack capacity to consent to them in England and Wales. The LPS will replace the heavily criticised Mental Capacity Act 2005 deprivation of liberty safeguards (MCA DoLS). The new scheme must provide detention safeguards on an unprecedented scale and across a much more diverse range of settings than traditional detention frameworks linked to mental disability. Accordingly, the LPS are highly flexible, and grant detaining authorities considerable discretion in how they perform this safeguarding function. This review outlines the background to the 2019 amendments to the MCA, and contrasts the LPS with the DoLS. It argues that although the DoLS were in need of reform, the new scheme also fails to deliver adequate detention safeguards, and fails to engage with the pivotal question: what are these safeguards *for*?

Keywords: Mental Capacity (Amendment) Act 2019; Mental Capacity Act 2005; deprivation of liberty safeguards; liberty protection safeguards; article 5 European Convention on Human Rights; *P v Cheshire West and Chester Council and another; P and Q v Surrey County Council* [2014] UKSC 19; [2014] A.C. 896; [2014] H.R.L.R. 13

I. INTRODUCTION

The Mental Capacity (Amendment) Act 2019 was supposed to be a 'really small, uncontroversial' Bill,¹ one the whips could safely steer through a febrile parliamentary session engulfed by Brexit-related chaos. Its object and purpose was to replace the current administrative framework for authorising deprivation of liberty in care homes and hospitals – the Mental Capacity Act 2005 deprivation of liberty safeguards (DoLS) – which were universally agreed to be broken and in need of reform. As it happened, the whips were wrong; the Bill was widely criticised and the government was defeated three times in the Lords. However, the Bill received Royal Assent in May 2019 and is planned to commence in October 2020.²

The 2019 amendments to the Mental Capacity Act 2005 (MCA) replaced the DoLS with a successor scheme: the Liberty Protection Safeguards (LPS).³ The LPS are intended to deliver safeguards compliant with article 5 of the European Convention on Human Rights

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¹ Hansard, HL Series 5, Vol. 797 col. 622, (24 April 2019) – The Baroness Thornton.

² Department of Health & Social Care, 'Will-write letter' from Minister of State for Care (10 June 2019) at <u>data.parliament.uk/DepositedPapers/Files/DEP2019-</u>

<u>0635/letter from Caroline Dinenage Liberty Protection Safeguards.pdf</u> (unless otherwise stated, all URLs were last accessed on 19 July 2019).

³ The DoLS are contained in MCA schedules A1 and 1A. The LPS are contained in the new MCA schedule AA1.

(ECHR),⁴ the right to liberty and security of the person, for people who are deprived of their liberty in connection with arrangements to enable their care and treatment.

It is envisaged that the LPS will authorise an estimated 304,132 detentions annually in England and Wales.⁵ To put this into perspective: in 2018-19 there were just under 50,000 new detentions to provide inpatient treatment for mental disorder under the MCA's sister statute (the Mental Health Act 1983 MHA),⁶ the prison population in England and Wales stood at just over 82,000,⁷ and over 26,000 people passed through immigration detention.⁸ The new LPS will represent a high-water mark in the history of detention in the UK (Figure 1, below).

These are not 'paradigmatic' cases of deprivation of liberty.⁹ The affected population is predominantly older adults with dementia and people with intellectual disabilities, autism or brain injuries.¹⁰ A minority, less than 2%, will be receiving inpatient treatment for mental disorder in psychiatric hospitals.¹¹ Some will be treated for physical conditions in general or acute hospitals. The largest affected group will be in residential care or nursing homes.¹² More perplexingly, the LPS will also apply to tens of thousands of adults living in private homes, including 'supported living' accommodation and, in what is likely to be a source of growing social and political anxiety, some adults living with their families.¹³

Internationally, there is growing concern about the 're-institutionalisation' of disabled adults in community settings,¹⁴ with some states and international bodies beginning to

⁹ S.W. Stark, 'Deprivations of liberty: beyond the paradigm' (2019) (April) Public law [380-401].

 ⁴ Convention for the Protection of Human Rights and Fundamental Freedoms (Council of Europe) 213 UNTS 222, ETS No 5, UN Reg No I-2889; [Opened for Signature] 4th Nov 1950, [Entered into Force] 3rd Sep 1953].
 ⁵ Department of Health and Social Care, 'Impact Assessment: Mental Capacity (Amendment) Bill (Revised IA, dated 31/01/2019): at <u>https://publications.parliament.uk/pa/bills/cbill/2017-2019/0323/MCAB%20Impact%20Assessment%20FINAL.rtf%20SIGNED.pdf</u>

⁶ NHS Digital, 'Mental Health Act Statistics' Annual Figures 2018-19: at <u>https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-act-statistics-annual-figures/2018-19-annual-figures</u>

⁷ Ministry of Justice, HM Prison Service and Her Majesty's Prison and Probation Service, 'Official Statistics, Prison population figures 2018' (2019): at <u>https://www.gov.uk/government/statistics/prison-population-figures-2018</u>

⁸ Home Office, 'Immigration statistics, year ending March 2018' : at https://www.gov.uk/government/statistics/immigration-statistics-year-ending-march-2018

¹⁰ NHS Digital, Supplementary information: DoLS activity by disability group during reporting period 2017-18' (2019): at <u>https://digital.nhs.uk/data-and-information/find-data-and-publications/supplementary-information/2019-supplementary-information-files/dols-activity-by-disability-group-during-reporting-period-2017-18.</u>

¹¹ In 2017-18, 5,260 DoLS applications in England were from 'mental health establishments' out of a total of 240,455 (2%). However, the LPS will apply to a larger population because it incorporates new settings and age groups. NHS Digital, 'Mental Capacity Act 2005, Deprivation of Liberty Safeguards England, 2018-19' (2019) at: https://digital.nhs.uk/data-and-information/publications/statistical/mental-capacity-act-2005-deprivation-of-liberty-safeguards-assessments/england-2018-19. Equivalent data are not given for Wales: Care Inspectorate Wales and Healthcare Inspectorate Wales, 'Deprivation of Liberty Safeguards Annual Monitoring Report for Health and Social Care 2017-18' (2019), at: https://careinspectorate.wales/deprivation-liberty-safeguards-annual-monitoring-report-health-and-social-care-2017-18.

¹² Ibid.

¹³ Response to request for information from the Law Commission under the Freedom of Information Act 2000, 10 May 2019, available upon request from author.

¹⁴ N. Crowther, 'The right to live independently and to be included in the community in European States: ANED synthesis report' (*European Network of Academic Experts in the Field of Disability (ANED)*, 2019) at: https://www.disability-europe.net/theme/independent-living.

view this through the lens of detention.¹⁵ The LPS will be of interest to states contemplating regulatory responses to non-paradigmatic detentions. Whether they will improve upon the DoLS—which were regarded internationally as a cautionary tale¹⁶— remains to be seen.

The application of the detention paradigm to settings that have until very recently represented freedom in the community raises searching questions about how, and why, we have come to invoke this right in these contexts. These pressing questions are beyond the scope of this review; which considers the operational challenges of securing article 5 compliant safeguards on this scale. I outline the background to the DoLS and the LPS, before examining their provisions in greater detail and charting the key issues and debates that arose during the law reform process.

II. BACKGROUND

The MCA 2005 is an unlikely vehicle for the detention of over 300,000 people. Unlike the MHA it is not generally viewed as a 'compulsory power', ¹⁷ and is often described domestically as 'empowering'.¹⁸ It provides a framework for making substitute decisions in the 'best interests' of a person considered to lack the 'mental capacity' to make a particular decision. Whereas the MHA includes a 'public protection' remit, the focus of the MCA is on the protection of the individual.

The MCA potentially applies to almost all decisions in a person's life; from what they eat for breakfast, to where they live, their relationships with others, and decisions about medical treatments. It is central to almost all aspects of the care and treatment of populations whose capacity may be in doubt.

A key characteristic of the MCA is its 'informality'. Even very serious medical and personal welfare decisions can potentially be made without the involvement of courts or formally appointed decision makers. Instead, caregivers can rely upon a 'general defence' against

¹⁵ W. Boente, 'Some Continental European Perspectives on Safeguards in the Case of Deprivation of Liberty in Health and Social Care Settings' (2017) (23) International Journal of Mental Health and Capacity Law [69-83]; Fritze, Chesterman, Grano, 'Designing a deprivation of liberty authorisation and regulation framework: Discussion paper' (Office of the Public Advocate, Victoria 2017); Victorian Law Reform Commission, 'Guardianship final report background paper: Legislative schemes regulating deprivation of liberty in residential care settings' (2012); Royal Commission into Aged Care Quality and Safety, 'Restrictive Practices Australia' (Background Residential Aged Care in Paper 4, 2019) in at: https://agedcare.royalcommission.gov.au/; UNHRC 'Report by Special Rapporteur on the Rights of Persons with Disabilities C Devandas Aguilar' UN Doc A/HRC/40/54, (11 January 2019) ; See also recent complaints brought to the CRPD Committee - DR v Australia (communication 14/2003) CRPD/C/17/D/14/2013), (19 May 2017); and also jurisprudence of the European Court of Human Rights, e.g. Stanev v Bulgaria (2012) 55 E.H.R.R. 22; [2012] M.H.L.R. 23. DD v Lithuania [2012] M.H.L.R. 209.

¹⁶ (Ibid) Victorian Law Reform Commission; (Ibid) Victoria Office of the Public Advocate, Fritze, Chesterman and Grano; Scottish Law Commission, Report on Adults with Incapacity (Scot Law Com No 240, 2014); C McKay and J Stavert, 'Scotland's Mental Health and Capacity Law: The Case for Reform' *Edinburgh Napier University* (2017) at: http://www.napier.ac.uk/about-us/news/mentalwelfarecommission; Department of Health (Ireland - An Roinn Sláinte), 'Deprivation of Liberty: Safeguard Proposals: Consultation Paper' (2017) at: https://health.gov.ie/consultations/

¹⁷ E.g. Wessely et al, 'Modernising the Mental Health Act' (Final report of the Independent Review of the Mental Health Act 1983) December 2018 [123].

¹⁸ E.g. Department for Constitutional Affairs, Mental Capacity Act Code of Practice (2007) [foreword by The Rt Hon. the Lord Falconer of Thoroton].

liability¹⁹, which codified the common law position that acts of care or treatment in the best interests of those lacking the capacity to consent can rely upon the doctrine of necessity.²⁰ This was viewed by the Law Commission in the 1990s as avoiding the stigma and 'bureaucracy' associated with mental health law, 'normalising' the care and treatment of people deemed to lack capacity.²¹ However, the defence has been described as operating in practice as a broad *de facto* power²² whilst providing few of the procedural safeguards commonly associated with compulsory powers.

The MCA contains a scheme of Independent Mental Capacity Advocacy (IMCAs)²³ and potential recourse to the Court of Protection, a superior court of record, in cases of doubt or dispute.²⁴ However, legal challenges to decisions made under the MCA are rare.²⁵

A. The Bournewood Case

The government did not initially associate the MCA with detention when developing the Bill.²⁶ This changed in October 2004, at the Bill's second reading, when the European Court of Human Rights (ECtHR) ruled in $HL \ v \ UK^{27}$ that an autistic man who was 'informally' admitted to Bournewood Hospital, apparently in his best interests and on grounds of necessity, had been unlawfully deprived of his liberty.

HL had been living in the community with his carers but had been taken to Bournewood Hospital following agitated behaviour at his day centre. For historical reasons, the MHA is primarily used to formally detain patients who are regarded as 'objecting' to admission or treatment; it is rarely used for those who are regarded as compliant with admission and treatment.²⁸ HL was sedated, and although his behaviour indicated that he was very distressed²⁹ he was not regarded by clinicians as 'objecting' or attempting to leave. Without the provisions of the MHA, there was no obvious mechanism for his carers or relatives to seek to discharge him or challenge his informal admission. A claim was brought on HL's behalf seeking judicial review of the decision to 'detain' HL and a writ of *habeas corpus* to secure his discharge. The domestic courts approached the question of whether HL had been detained through the lens of the tort of false imprisonment, with the House of Lords concluding that he was not falsely imprisoned because he had not actually

¹⁹ MCA ss 5, 6.

²⁰ *Re F (Mental Patient: Sterilisation)* [1990] 2 A.C. 1; [1989] 2 WLR 1025.

²¹ Law Commission, Mentally Incapacitated Adults and Decision-Making: An Overview (Law Com No 119, 1991).

²² A. Ruck Keene, 'Powers, defences and the 'need' for judicial sanction' (2016) (Autumn) *Elder Law Journal* [244-52].

²³ MCA s35-41.

²⁴ MCA ss 15, 16.

²⁵ L. Series, P. Fennell and J. Doughty, 'Welfare cases in the Court of Protection: A statistical overview' *Cardiff University, Report for the Nuffield Foundation* (2017), at: <u>http://orca.cf.ac.uk/id/eprint/118054</u>.

²⁶ Lord Chancellor's Office, Who decides? Making decisions on behalf of mentally incapacitated adults, Cm 2803 (1997); Lord Chancellor's Office, "Making Decisions" The Government's proposals for making decisions on behalf of mentally incapacitated adults, Cm 4465 (1999); Department for Constitutional Affairs, Draft Mental Incapacity Bill, Cm 5859 (2003).

²⁷ [2005] 40 E.H.R.R. 32; [2004] M.H.L.R 236 277.

²⁸ Recommendations of Lord Percy, Report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency. 1954-1957, Cmnd 169 (1957).

²⁹ *HL v UK* n 27, at [39]; Health Service Ombudsman, 'Annual Report for 2001-2: Case No. E. 2280/98-99' (2001).

attempted to leave. Even if he had been so detained, they held that the hospital had a defence against liability under the common law doctrine of necessity.³⁰

HL's family and carers successfully pursued the case to the ECtHR, which rejected the distinction relied upon by the House of Lords between 'actual restraint' and 'restraint which was conditional upon his seeking to leave'.³¹ HL 'was under continuous supervision and control and was not free to leave', and was thus deprived of his liberty.³² Noting the dearth of regulation and safeguards for informal admissions, the Strasbourg Court found a violation of the article 5(1) ECHR requirement for a 'procedure required by law' and no effective means to challenge the detention before an appropriately constituted authority (namely a court/tribunal etc) as is required by article 5(4). HL's detention, and that of thousands like him, was therefore unlawful under the Convention.

B. The Deprivation of Liberty Safeguards

The government consulted on what to do about the estimated 100,000 adults in care homes and hospitals who fell within the so called 'Bournewood gap' following the ruling in $HL \ v \ UK.^{33}$ The majority of respondents opposed the use of the MHA for the affected population, which was primarily older adults with dementia and people with intellectual disabilities or autism, mainly on grounds of its perceived stigma. Thus, a parallel framework for authorising detention in care homes and hospitals—the DoLS—was inserted into the MCA in 2007.³⁴

The DoLS will be compared with the LPS in more detail below. In outline, 'managing authorities' of hospitals and care homes must recognise that patients or residents are deprived of their liberty and must apply to 'supervisory bodies' for authorisation. These are mainly local authorities; although in Wales, Local Health Boards (LHBs) function as supervisory bodies for hospital detentions. Supervisory bodies must send out a Best Interests Assessor (BIA) and a Mental Health Assessor (MHAr) to assess whether six 'qualifying requirements' for detention under the DoLS are met. If all are met, the supervisory body must authorise the detention. Additional safeguards available to the 'relevant person' include the appointment of a 'Relevant Person's Representative' (RPR), usually from amongst their family and friends, potentially an IMCA (as well as or instead of an RPR), reviews by the supervisory body and the right to seek a judicial review of the authorisation from the Court of Protection under s21A MCA.

³⁰ *R. v Bournewood Community and Mental Health NHS Trust Ex p. L* [1999] 1 A.C. 458; [1998] 3 W.L.R. 107.

³¹ *HL v UK* n27, at [90].

³² *HL v UK* n27, at [91].

³³ Department of Health, 'Bournewood' Consultation' (2005); Department of Health, 'Protecting the Vulnerable: the "Bournewood" Consultation: Summary of Responses' (2006).

³⁴ MCA Scheds A1 and 1A, inserted via the Mental Health Act 2007.

The DoLS are regarded as 'very much the poor relation of the MHA':³⁵ notorious for their complexity,³⁶ with administrative costs double that of the impact assessment³⁷ and eye-wateringly expensive litigation.³⁸ Yet they did not provide an effective means to challenge detention when the detained person, or those close to them, objected.

The widely reported case of Steven Neary illustrates the difficulties.³⁹ Neary is an autistic man with intellectual disabilities who had been living with his father, with support funded by the London Borough of Hillingdon. Following a temporary stay in respite care, Hillingdon moved Neary into a 'positive behaviour unit' (a registered care home) against his wishes and those of this father. A litany of failures followed, including: an initial failure to even seek a DoLS authorisation, a long delay in appointing an IMCA to support Steven and his father (who was RPR), and a failure to seriously consider Steven's own wishes and feelings in assessments. It was almost a year before the case reached the Court of Protection, in part because the council misled the family that it was planning to return Steven home, and in part because Steven's father was scared that if he 'rocked the boat' the council might review Steven's entitlements to support if he returned home.⁴⁰ The Court of Protection discharged the authorisation, meaning Steven could return home, and found violations of both article 5 and rights to respect for home, family and private life under article 8 ECHR.

Neary established the principle that disagreements over 'significant welfare issues' that cannot be resolved by other means should be urgently placed before the Court of Protection.⁴¹ There is a positive obligation on the state to ensure that a person is '*not only entitled but enabled* to have the lawfulness of his detention reviewed speedily by a court' (emphasis added).⁴² Following *Neary*, other local authorities have been criticised for using the DoLS to remove people from their homes and families, sometimes restricting contact with loved ones, without ensuring these disputes are speedily brought to court.⁴³ Overall, the rate of appeal under the DoLS is around one per cent,⁴⁴ whereas the number of people

³⁵ R. Jones, '*Deprivations of Liberty: Mental Health Act or Mental Capacity Act?*' (2007) (16) Journal of Mental Health Law 170-74, [170]. See also: P. Bowen, Blackstone's Guide to The Mental Health Act 2007 (Oxford: OUP 2007); R. Hargreaves, '*The Deprivation of Liberty Safeguards - essential protection or bureaucratic monster?*' (2009) (19) Journal of Mental Health Law 117-27; M. Gunn, '*Hospital treatment for incapacitated adults*', (2009) (17) (2) Medical Law Review, 274-81.

³⁶ *C v Blackburn and Darwen Borough Council* [2011] EWHC 3321 (Fam), at [24]; [2012] M.H.L.R. 202. House of Lords Select Committee on the Mental Capacity Act 2005, Report of Session 2013–14 (Mental Capacity Act 2005: post-legislative scrutiny) (HL 139), at [271].

³⁷ A. Shah and others, '*Deprivation of Liberty Safeguards in England: implementation costs*', (2011) (199) (3) British Journal of Psychiatry, [232-38].

³⁸ L Series, P Fennell and J Doughty, n25.

³⁹ *London Borough of Hillingdon v Neary* [2011] EWHC 1377 (COP) [2011] 4 All E.R. 584; [2011] M.H.L.R. 404

⁴⁰ Ibid, at [146].

⁴¹ Ibid, at [33].

⁴² Ibid, at [202].

⁴³ Somerset v MK (Deprivation of Liberty: Best Interests Decisions: Conduct of a Local Authority) [2014] EWCOP B25; Essex County Council v RF (Deprivation of Liberty and damage) [2015] EWCOP 1; Milton Keynes Council v RR [2014] EWCOP B19; SR v A Local Authority [2018] EWCOP 36; Local Government Ombudsman, 'The Right to Decide: Towards a greater understanding of mental capacity and deprivation of liberty' (2017) [1], at: <u>http://collateral2.vuelio.co.uk/RemoteStorage/LGO/Releases/1176/DOLS%20AND%20MCA%20-%20EMB.pdf</u>.

⁴⁴ This is the rate of appeals per standard authorisation; the rate of appeals against emergency authorisations would be far lower.

who are said to be objecting to their confinement is estimated to be around 30 per cent.⁴⁵ There is a strong likelihood that when the person, or those close to them, objects to detention under the DoLS, they are not reliably able to exercise Article 5(4) ECHR rights of challenge.

In 2013-14 the House of Lords Select Committee on the MCA conducted post-legislative scrutiny of the 2005 Act.⁴⁶ Whilst finding that the MCA continues to be held in 'high regard', the Committee concluded the DoLS were 'poorly drafted, overly complex' and 'far from being used to protect individuals and their rights, they are sometimes used to oppress individuals'.⁴⁷ It called upon the government to 'start again'.⁴⁸

C. Cheshire West

The DoLS authorise 'deprivation of liberty'⁴⁹, defining this by direct reference to article 5 ECHR.⁵⁰ When the DoLS were inserted into the MCA, the Joint Committee on Human Rights (JCHR) and others had called for a statutory definition, but the government had refused on the basis that it was 'not possible' to supply one.⁵¹ Managing authorities and supervisory bodies adopted their own working definitions of 'deprivation of liberty', resulting in low and highly variable application rates. By 2014, it was believed that thousands of adults were unlawfully detained.⁵²

It is not necessary to define deprivation of liberty in order to authorise it (the MHA does not). An alternative approach would be to define a list of triggering circumstances when the safeguards must apply. This was at one point suggested by the Law Commission in their proposals to reform the DoLS (below).⁵³ This approach requires engagement with the elusive question posed by Peter Bartlett: what are the DoLS actually *for*?, beyond the circular answer of providing deprivation of liberty safeguards.⁵⁴ The meaning of article 5 is a technical lawyers' question, ultimately determined by the courts. Asking where safeguards would be necessary, beneficial or potentially counterproductive is a fundamentally more democratic question, requiring stakeholder consultation and parliamentary debate.⁵⁵

safeguards/written/80869.pdf.

 ⁴⁵ Department of Health and Social Care, Mental Capacity (Amendment) Bill: Impact Assessment (2018) 1.
 ⁴⁶ Mental Capacity Act 2005: post-legislative scrutiny, n36.

⁴⁷ Ibid, 7[.]

⁴⁸ Ibid.

⁴⁹ MCA Sched A1, s 1-3.

⁵⁰ MCA s64(5), as amended.

⁵¹ JCHR Fourth Report of Session 2006-07 (Legislative Scrutiny: Mental Health Bill) (HC 288, HL 40) at [84] and Appendix 3 [52] for government's response.

⁵² HL 139 (2014) n36, [7]; Care Quality Commission, 'Monitoring the use of the Mental Capacity Act Deprivation of Liberty Safeguards in 2012/13' (2014) at http://www.cqc.org.uk/public/news/protecting-people%E2%80%99s-human-rights-when-they-cannot-consent-treatment.

⁵³ Law Commission, Mental capacity and deprivation of liberty: A consultation paper (Consultation Paper 222, 2015) Provisional proposals 7-2 – 7-4.

⁵⁴ P. Bartlett, '*Reforming the deprivation of liberty safeguards (DoLS): What is it that we want?*' (2014) 20
(3) Web Journal of Current Legal Issues, <u>http://webjcli.org/article/view/355</u>.

⁵⁵ A. Ruck Keene, written evidence to the JCHR's 2018 inquiry into The Right Freedom and Safety, at: http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/human-rights-committee/the-right-to-freedom-and-safety-reform-of-the-deprivation-of-liberty-

The result of leaving the scope of the DoLS to the courts was, inevitably, near-continuous litigation on this issue. By 2014 a series of confusing, sometimes contradictory and controversial rulings had defined deprivation of liberty so narrowly that even a man who had broken down the door of a care home attempting to escape,⁵⁶ and a woman wanting to leave a care home to return to her own home,⁵⁷ were found not to be deprived of their liberty. Thus, the Supreme Court ruling in *P v Cheshire West and Chester Council and another; P and Q v Surrey County Council*⁵⁸ on the meaning of 'deprivation of liberty' in connection with care arrangements for people considered unable to consent to their care arrangements was keenly awaited.

The *Cheshire West* case concerned three people with intellectual disabilities living, variously, in a 'small NHS facility', a shared apartment with support, and with a foster parent. Being neither hospitals nor registered adult care homes, these were outside the limited scope of the DoLS, meaning authorisation would require costly annual court applications.⁵⁹ Delivering the leading judgment, Lady Hale relied upon what she took to be the ratio in *HL v UK* and later cases before the ECtHR,⁶⁰ holding that the 'acid test' of deprivation of liberty is whether a person is subject to continuous supervision and control and not free to leave.⁶¹ That they are not objecting, that the arrangements are the least restrictive possible and in their best interests, or 'normal' for a person with a similar condition, is irrelevant to the question of whether they are deprived of their liberty (but relevant to whether it is justified).

Whether *Cheshire West is* a landmark human rights victory or a perverse interpretation of article 5 ECHR is hotly debated.⁶² It's practical consequences, however, are undeniably challenging. Within a year of the 2014 judgment, the volume of DoLS applications increased by more than a factor of ten and continued to rise, as depicted in Figure 1. In 2018-19 supervisory bodies in England received 240,455 DoLS applications and they had acquired a backlog of over 131,350 unprocessed applications.⁶³ The Association of

⁵⁶ *C v Blackburn and Darwen Borough Council*, n36.

⁵⁷ *CC v KK and STCC* [2012] EWHC 2136 (COP) at [99] [2012] C.O.P.L.R. 627.

⁵⁸ [2014] UKSC 19; [2014] A.C. 896.

 ⁵⁹ Salford City Council v BJ (Incapacitated Adult) [2009] EWHC 3310 (Fam); [2010] M.H.L.R. 283.
 ⁶⁰ Stanev v Bulgaria; D.D. v Lithuania, n15; Kedzior v Poland [2013] M.H.L.R. 115; BAILII 2012 ECHR 1809;

Mihailovs v Latvia [2014] M.H.L.R. 87; BAILII 2013 ECHR 65.

⁶¹ Cheshire West, n 58, at [48]-[49].

⁶² E.g. I. Burgess, '*We should welcome this Supreme Court ruling- it enshrines social work values in law'* Community Care (London, 12 September 2014); Care Quality Commission, Monitoring the use of the Mental Capacity Act Deprivation of Liberty Safeguards in 2013-14 (2015); D. Whitaker, '*Social justice for safeguarded adults deprived of their liberty in the United Kingdom?*'(2014) (29) (9) Disability & Society 1491-95; N Allen, '*The (not so) great confinement*' (2015) (March) Elder Law Journal , 45-52; J. Holbrook, '*A distorted view*' (2014) 164 (7605) New Law Journal[7-9] ; Hewson B, '*How UK judges forgot the meaning of 'liberty''* (*Spiked* 2014) <u>http://www.spiked-online.com/newsite/article/how-uk-judges-forgot-the-meaning-of-liberty/14840#.UzlH4vldU41</u>.

⁶³ NHS Digital (2019); Care Inspectorate Wales and Healthcare Inspectorate Wales (2018), n 11.

Directors of Adult Social Services produced a 'priority tool'⁶⁴ to help supervisory bodies work out—in the words of the JCHR—'how best to break the law'.⁶⁵

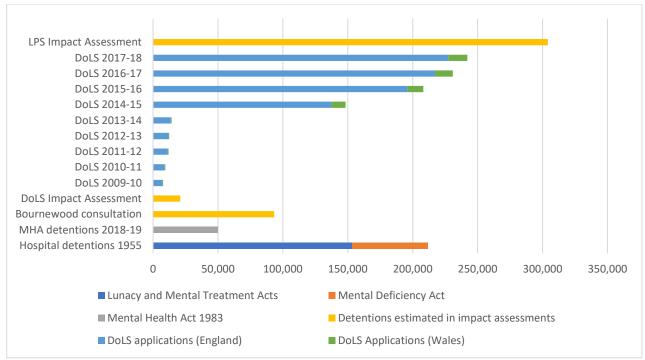


Figure 1 Estimated and actual annual detentions under the MHA, the DoLS and the LPS⁶⁶

Following *Cheshire West* an estimated 53,000 people outside the scope of the DoLS scheme will require safeguards.⁶⁷ This acid test encompasses people in supported living schemes, as well as people in private homes, receiving publicly or privately arranged care, or even care delivered by families themselves, known as 'domestic DoLS'.⁶⁸ The judgment also means that thousands of 16 and 17 year olds and other children in the care of the State would require detention safeguards.⁶⁹ The Law Commission estimated that if these

⁶⁷ 'Impact Assessment: Mental Capacity (Amendment) Bill' (2019) n 5.

⁶⁴ Association of Directors of Adult Social Services, 'A Screening tool to prioritise the allocation of requests to authorise a deprivation of liberty' (2016) https://www.adass.org.uk/adass-priority-tool-for-deprivation-of-liberty-requests/.

⁶⁵ JCHR, Seventh Report of Session 2017–19 (The Right to Freedom and Safety: Reform of the Deprivation of Liberty Safeguards) (HC 890, HL 161) (2018) [3]. See also: Local Government Ombudsman, 'Investigation into a complaint against Staffordshire County Council (reference number: 18 004 809)' (2019).

⁶⁶ It is not possible to give the actual detention rate for DoLS because so many applications remain unprocessed, hence the application rate is given here. Data sources: DoLS statistics from annual reports available on NHS Digital, at: https://digital.nhs.uk; statistics on the Lunacy and Mental Treatment and Mental Deficiency Acts from appendices of Report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency, n 28; data from impact assessments for the Bournewood consultations (n 33) and the Mental Capacity Amendment Bill (n 5); MHA detentions data from NHS Digital (n 6).

⁶⁸ Rochdale MBC v KW [2014] EWCOP 45; [2015] 2 F.C.R. 244 [2015] Med. L.R. 19. The London Borough of Tower Hamlets v TB & Anor [2014] EWCOP 53; [2015] C.O.P.L.R. 87. Rochdale Metropolitan Borough Council v KW & Ors [2015] EWCOP 13; [2015] 2 F.C.R. 255. KW & Ors v Rochdale MBC [2015] EWCA Civ 1054; [2016] 1 W.L.R. 198. Staffordshire CC v SRK & Ors [2016] EWCOP 27; [2016] 3 W.L.R. 867; [2016] Fam. 419. SSJ v Staffordshire CC & Ors [2016] EWCA Civ 1317; [2017] 2 W.L.R. 1131 [2017] C.O.P.L.R. 120. Haringey LBC v R [2016] EWCOP 33; [2016] C.O.P.L.R. 476 W City Council v L [2015] EWCOP 20; [2015] C.O.P.L.R. 337. SCC v MSA & Anor [2017] EWCOP 18.

⁶⁹ *Re Daniel X* BAILII 2016 EWFC B31; *A Local Authority v D* [2015] EWHC 3125 (Fam); *Northumberland County Council v MD, FD and RD* BAILII 2018 EWFC 47; *Trust A v X and A Local Authority* [2015] EWHC 922

populations were given safeguards compliant with article 5 ECHR (which they were not),⁷⁰ the overall cost of the existing scheme would exceed £2bn a year.⁷¹ The father of Steven Neary subsequently told the JCHR that the Council that had unlawfully detained him now sought authorisation for alleged deprivation of liberty in his own home.⁷²

An analysis of *Cheshire West* is beyond the scope of this article,⁷³ but it was the key precipitating factor for the extraordinary increase in detentions under the MCA and the operational challenges facing both DoLS and the LPS. Its underpinning policy rationale, spelled out by Lady Hale, was that if the appellants were not found to be 'deprived of their their best interests.⁷⁴ The 'extreme vulnerability' of the affected population means we should 'err on the side of caution' when deciding what constitutes a deprivation of liberty.⁷⁵

It might plausibly be argued that *Cheshire West* was a legal response to the minimal procedural safeguards available under the MCA and wider concerns about the provision of adult social care.

D. The Law Commission

The government asked the Law Commission to review the DoLS. They concluded the DoLS were indeed broken and in need of reform: too complex, too inflexible, their scope too limited, with a lack of oversight and effective safeguards.⁷⁶ The DoLS were too narrowly focussed on article 5—'a technical legal solution to a technical legal problem'77—when the key substantive issues were better captured by article 8 ECHR-rights to enjoyment of home, family and private life.

The Commission's initial proposals for two tiers of safeguards, promoting a wider range of rights, were scaled back to a framework for authorising deprivation of liberty-the LPSand modest amendments to the MCA.⁷⁸ To align the MCA more closely to the UN Convention on the Rights of Persons with Disabilities (CRPD),⁷⁹ the Commission proposed

⁽Fam); A Local Authority v D [2015] EWHC 3125 (Fam); Re D (A Child) [2017] EWCA Civ 1695; Re D (A Child) [2019] UKSC 42.

⁷⁰ A McNicoll, 'Councils' failure to make court applications leaving 'widespread unlawful deprivations of liberty' vear after Cheshire West ruling' Community Care (London, 17 June 2015) а at https://www.communitycare.co.uk/2015/06/17/councils-failure-make-court-applications-leavingwidespread-unlawful-deprivations-liberty-year-cheshire-west-ruling/.

⁷¹ Law Commission, Mental Capacity and Deprivation of Liberty (Law Com No 372, 2017).

⁷² JCHR, The Right to Freedom and Safety: Reform of the Deprivation of Liberty Safeguards, n 65.

⁷³ I discuss the judgment in L Series, 'Making sense of Cheshire West' in Claire Spivakovsky, Linda Steele and Penelope Weller (Eds) The Legacies of Institutionalisation: Disability, Law and Policy in the 'Deinstitutionalised' Community (Hart forthcoming 09-07-2020).

⁷⁴ Cheshire West, n 58, at [1], see also [32].

⁷⁵ Ibid, at [57].

⁷⁶ Law Commission (2015) n 53.

⁷⁷ Ibid, at [2.15], citing P. Bartlett n 54.

⁷⁸ Law Com (2017), n 71.

⁷⁹ Analysis of article 12 CRPD is beyond the scope of this paper, but see: P. Bartlett, '*The United Nations* Convention on the Rights of Persons with Disabilities and Mental Health Law' (2012) 75 (5) Modern Law Review, 752-78; R. Harding, 'The Rise of Statutory Wills and the Limits of Best Interests Decision-Making in Inheritance' (2015) 78 (6) Modern Law Review, 945-70; E. Jackson, 'From 'Doctor Knows Best' to Dignity: Placing Adults Who Lack Capacity at the Centre of Decisions About Their Medical Treatment', (2018) 81 (2)

placing 'particular weight' on the wishes and feelings of the person in best interests decisions, ⁸⁰ and a statutory framework for supported decision making. ⁸¹ As an intermediate safeguard, they recommended that the general defence should only be available for very serious decisions if certain information were recorded.⁸² They also proposed a new tort of unlawful deprivation of liberty, ⁸³ and provisions for 'advance consent' to a potential deprivation of liberty.⁸⁴ Subsequently the JCHR largely endorsed the Law Commission's approach.⁸⁵

E. The Mental Capacity (Amendment) Bill

In July 2018 the Mental Capacity (Amendment) Bill⁸⁶ was tabled in the House of Lords. There had been no further public consultation, yet the Bill differed from the Law Commission's proposals in important respects.⁸⁷ The government estimated the 'adjusted' LPS scheme in the Bill would save over £200m per year,⁸⁸ whilst improving and extending existing safeguards and fixing an overwhelmed system. Even the Minister responsible—Lord O'Shaughnessy—commented that this sounded almost 'too good to be true'.⁸⁹

To the dismay of organisations representing disabled people, the scope of the Bill was narrowly focused on article 5 ECHR, without the amendments to bring the MCA closer to the CRPD.⁹⁰ Gone too was the tort of unlawful deprivation of liberty, provisions for advance consent and requirements for a written record for serious decisions. The government's Bill was considerably shorter than the Law Commission's, with many clauses and provisions omitted.⁹¹ The government insisted that key operational details could be included in the

⁸⁷ Compare and contrast: HM Government, 'Final Government Response to the Law Commission's review of Deprivation of Liberty Safeguards and Mental Capacity' (Department of Health and Social Care written statement, 14th March 2018) at <u>http://qna.files.parliament.uk/ws-attachments/861932/original/180314%20Response%20to%20Law%20Commission%20on%20DoLS%20-</u>

Modern Law Review, 247-81; 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 , 1101-15.

⁸⁰ Law Com No 372, n 71, recommendation 40.

⁸¹ Ibid, recommendation 42.

⁸² Ibid, recommendation 41.

⁸³ Ibid, recommendation 45.

⁸⁴ Ibid, recommendation 43.

⁸⁵ JCHR, The Right to Freedom and Safety, n 65.

⁸⁶ Information about the Bill's progress, including different versions of the Bill, amendments, links to debates in Hansard, Ministerial 'will write' letters and other supporting documentation can be found on its parliamentary website: https://services.parliament.uk/Bills/2017-19/mentalcapacityamendment.html.

<u>%20final.pdf</u>; Department of Health and Social Care, 'Annex A: Law Commission recommendations and Government Responses' (Attached to 'will write' letter from Lord O'Shaughnessy to peers dated 24/07/18) at http://data.parliament.uk/DepositedPapers/files/DEP2018-

^{0796/}Annex A Law Commission Recommendation and govt. action.pdf .

⁸⁸ Mental Capacity (Amendment) Bill (Revised IA, dated 31/01/2019, 2019) n 5.

⁸⁹ Hansard, HL Series 5, (2nd Reading) Vol 792 col 1106 (16 July 2018).

⁹⁰ See written evidence of People First and Inclusion London to the Public Bill Committee (MCAB46) (n 86), and G. Loomes, 'The Mental Capacity Legislation and Our Human Rights' Report commissioned by Inclusion London, 2019) at: https://www.inclusionlondon.org.uk/uncategorised/inclusion-londons-report-mental-capacity-and-our-human-rights/.

⁹¹ The Law Commission's draft Bill was 33 pages long (Appendix A, Law Commission No 372, n 71). The Bill as introduced in July 2018 (HL Bill 117, n 86) was only 25 pages long.

Code of Practice, despite recent confirmation that the MCA's codes cannot *create* legal obligations that are not already established via other sources of law.⁹²

The Bill was heavily criticised by stakeholders, including: professional bodies,⁹³ local government,⁹⁴ care providers,⁹⁵ civil rights organisations,⁹⁶ and organisations representing older and disabled people.⁹⁷ Almost 200,000 people signed a petition calling for better protection of the rights of disabled people.⁹⁸ Peers declared the Bill 'one of the worst pieces of legislation ever brought before this House'.⁹⁹

⁹⁴ Local Government Association, 'Briefing: The Mental Capacity (Amendment) Bill Committee stage, House of Lords' (5 September 2018), at:

https://www.local.gov.uk/sites/default/files/documents/LGA%20briefing%20-

%20The%20Mental%20Capacity%20%28Amendment%29%20Bill%20-%20CMTTEE%20HL%20-%2005092018%20FINAL.pdf.

briefings/health--wellbeing/age-uk-briefing---mental-capacity-amendment-bill-hl-committee--stage---

august-18.pdf; Inclusion London, 'Inclusion London's Briefing on the Mental Capacity Amendment Bill' (September 2018), at: https://www.inclusionlondon.org.uk/wp-content/uploads/2018/09/Briefing-on-the-Mental-Capacity-Amendment-Bill-for-DDPOs.pdf; 'Mental Capacity Act (Amendment) Bill Briefing from Third sector Second Reading [Commons]', signed by Mencap, National Autistic Society, Mind, Rethink Mental Illness, Alzheimer's Society, VoiceAbility, Disability Rights UK, POhWER, Parkinson's UK, BIHR, Sense, Liberty, Learning Disability England, the Disabled Children's Partnership and the Challenging Behaviour Foundation, at: http://www.edgetraining.org.uk/wp-content/uploads/2018/12/Mental-Capacity-Bill-Third-sector-briefing-2R-debate-18.12.2018-1.pdf. See also the evidence submitted by the Relatives and Residents Association, Inclusion London and People First, Independent Age, Rethink Mental Illness, Mencap, Learning Disability England and others to the Public Bill Committee (n 86); Mind, 'A guick look at the draft Liberty Protection Safequards', https://www.mind.org.uk/news-campaigns/legal-news/legal-newsletter-septemberat: 2018/mental-capacity-act-amendment-bill/ (visited 11 April 2019); Disability Rights UK, 'Social care sector Capacity (Amendment) unites in condemnina Mental Bill' (8 Februarv 2019), at: https://www.disabilityrightsuk.org/news/2019/february/mentalcapacitybillopenletter.

⁹⁸ 'To: Caroline Dinenage, Minister of State for Care and the UK government: Protect the human rights of people receiving care and support' (38 Degrees petition, created by the Reclaiming Our Futures Alliance), at: https://you.38degrees.org.uk/petitions/promoted/protect-the-human-rights-of-people-receiving-care-and-support.

⁹⁹ Hansard, HL Series 5, Vol 794 col 1247 (12 November 2019) (The Baroness Barker).

⁹² An NHS Trust & Ors v Y & Anor [2018] UKSC 46; [2019] A.C. 978, at [97].

⁹³ British Association of Social Workers, 'BASW England response to the Mental Capacity (Amendment) Bill' (October 2018) at https://www.basw.co.uk/media/news/2018/oct/basw-england-response-mental-capacityamendment-bill; Association of Directors of Adult Social Services, 'The Mental Capacity (Amendment) Bill – ADASS Statement – 4th September 2018', at: https://www.adass.org.uk/adass-responds-to-mental-capacityamendment-bill; Law Society, 'Parliamentary briefing: Mental Capacity (Amendment) Bill – House of Lords committee stage' (2018) at https://www.lawsociety.org.uk/policy-campaigns/public-affairs/parliamentarybriefing/parliamentary-briefing-mental-capacity-amendment-bill-hol-committee-stage/. See evidence submitted to the Public Bill Committee (n 86) by the British Medical Association, Royal College of Psychiatrists, Royal College of Nursing, and the Royal College of Speech and Language Therapists.

⁹⁵ These were largely led by the Voluntary Organisations Disability Group and Care England, see for example: 'A cross-sector representation of issues and concerns relating to the Mental Capacity (Amendment) Bill HL' (October 2018), with 16 signatories, at: https://www.vodg.org.uk/news/leading-social-care-interest-groupswarn-government-that-its-mental-capacity-reforms-are-not-fit-for-purpose/; Care England, Conflict of Interest (2018) < http://www.careengland.org.uk/news/conflict-interest-0 ; Dimensions, 'Dimensions briefing on the Mental Capacity (Amendment) Bill (16 July 2018)' (2018) at https://www.dimensionsuk.org/press-release/mental-capacity-amendment-bill-briefing/; Care England, Conflict of Interest (2018) http://www.careengland.org.uk/news/conflict-interest-0.

⁹⁶ Liberty, '*To protect vulnerable people, the government must fix the Mental Capacity Amendment Bill'* (14 January 2019), at: https://www.libertyhumanrights.org.uk/news/blog/protect-vulnerable-people-government-must-fix-mental-capacity-amendment-bill.

⁹⁷ Age UK, 'Briefing: Mental Capacity (Amendment) Bill (HL) Committee Stage – October 2018', at: https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-

The Bill proceeded in haste. Parliamentarians complained of excessively short sitting times and insufficient time to consider government amendments.¹⁰⁰ It progressed in parallel to an independent review of the MHA,¹⁰¹ meaning many key matters about the relationship of detention under the MCA to mental health law were debated before the review had made its final recommendations.¹⁰² Accessible materials on the Bill for disabled people were produced too late in the Parliamentary process for any significant contributions to amendments or debate.¹⁰³ Key decisions—for example, over whether to include a statutory definition of deprivation of liberty—were made so late the Bill entered 'Ping Pong'¹⁰⁴. Considerable energy was expended fighting major problems, such as the 'care home arrangements', whilst issues that emerged later around advocacy, renewals, and 'domestic' deprivation of liberty received limited attention. The government maintained there was an urgent need for action following *Cheshire West.¹⁰⁵* But the frantic pace of the Bill could also be explained by fears that it would be overtaken by wider political events connected with Brexit.¹⁰⁶

III. THE (ADJUSTED) LIBERTY PROTECTION SAFEGUARDS

The main distinguishing characteristic of the LPS from the DoLS is their flexibility in where and how they operate. Greater flexibility is necessary to cope with the scale and diversity of deprivation of liberty following *Cheshire West*, yet this inevitably inserts complexity, discretion and the potential dilution of safeguards.

A. From 'Accommodation' to 'Arrangements'

The DoLS construct deprivation of liberty as a function of being 'accommodated' in a care home or hospital.¹⁰⁷ The LPS deal instead with 'arrangements' to 'enable' care or treatment that 'give rise to' a deprivation of liberty.¹⁰⁸ The authorisation of 'arrangements' is more fluid, applying to potentially any setting, multiple settings, and transfers between settings. The Commission hoped this would give responsible bodies greater control over 'the ways in which a person may justifiably be deprived of liberty', ¹⁰⁹ instead of approaching

¹⁰⁰ E.g. Hansard, HL 5 Series Vol 794 col 593 (27 November 2018); Hansard, HC 6 Series Vol 651 col 731 – and col 754 (18 December 2018); Hansard, HC Public Bill Committee (1st Sitting) col 10 (15 January 2019); Hansard, HC Public Bill Committee (6th Sitting) col 186 (22 January 2019); Hansard, HC Series 6 (Report Stage) Vol 654col 847 (12 February 2019).

¹⁰¹ 'Modernising the Mental Health Act', n17.

¹⁰² Ibid. The review was published on 6 December 2018, at which point the Bill was approaching its third reading in the House of Lords.

¹⁰³ Department of Health and Social Care, 'Mental Capacity (Amendment) Bill: easy read' (published 31 January 2019) at: https://www.gov.uk/government/publications/mental-capacity-amendment-bill-easy-read; Department of Health and Social Care, Equality Analysis: Liberty Protection Safeguards – Mental Capacity (Amendment) Bill (published 17 December 2018) https://www.gov.uk/government/publications/mental-capacity-amendment-bill-equality-analysis.

¹⁰⁴ This is a process in the UK Parliament where amendments are passed back and forth between the House of Commons and the House of Lords until agreement can be reached.

¹⁰⁵ Hansard, HC Series 6 (2nd Reading) Vol 651 cols 730 and 756 (18 December 2018).

¹⁰⁶ Such as the collapse of the Government, the proguing of Parliament or the urgent need for legislation to address matters connected with exiting the European Union.

¹⁰⁷ E.g. MCA Sched A1 s15; MCA Sched A1 s20(1).

¹⁰⁸ MCA Sched AA1 s2.

¹⁰⁹ Law Com 372 (n 71) at [1.29].

detention as a binary question.¹¹⁰ For example, authorising arrangements involving one set of restrictions, but not others.¹¹¹

The drafters of the LPS envisioned a 'bright line' distinction between the arrangements to enable care and treatment that give rise to a deprivation of liberty, and the underlying care and treatment decisions themselves. The LPS can only authorise the former, whilst care and treatment decisions would continue to be made informally under the general defence¹¹², or by attorneys or deputies. The MHA also distinguishes between authorisation of detention and treatment,¹¹³ but the need for assessment or treatment is still built into the admission and review criteria.¹¹⁴ It is unclear how far assessments, reviews and legal challenges under the LPS must take underlying care and treatment decisions as an indisputable starting point for the arrangements, with the only question left for the LPS to resolve whether the person should be deprived of their liberty to achieve these, or whether care and treatment decisions can themselves be scrutinised within the LPS processes. It may not always be conceptually or practically straightforward to distinguish care and treatment decisions from the arrangements to enable these. This issue will be revisited below.

B. The Authorisation Process

Article 5(1) requires deprivation of liberty to be in accordance with 'fair and proper procedures' executed 'by an appropriate authority'.¹¹⁵ The DoLS procedure required managing authorities of care homes and hospitals to apply to supervisory bodies for authorisation of a deprivation of liberty. This often led to a 'carousel',¹¹⁶ where public bodies commissioned care or treatment then required managing authorities to seek authorisation from them for it. The LPS seek to 'streamline' assessments into existing care and treatment planning processes. ¹¹⁷ Local authorities, NHS hospitals, clinical commission the care themselves.¹¹⁸ They may authorise the arrangements provided they are satisfied that the LPS apply,¹¹⁹ the authorisation conditions are met, and they comply with the procedural requirements described below.¹²⁰

Some administrative burdens will therefore be redistributed from local authorities to other NHS bodies. However, local authorities will still receive the highest proportion of applications; both because they commission the greatest number of care placements and

¹¹⁰ Ibid, [9.7].

¹¹¹ This may potentially operate in a similar way as the power of the supervisory body to set conditions on a DoLS authorisation: MCA Sch A1 s 53.

¹¹² Law Com 372 (n71) at [10.14]. See also: Department of Health and Social Care, 'Mental Capacity (Amendment) Act 2019: Explanatory Notes' (2019) at [35], http://www.legislation.gov.uk/ukpga/2019/18/notes/contents.

¹¹³ MHA 1983 Part IV.

¹¹⁴ E.g. s2(2)(a) MHA, s3(2)(a) s3(2)(d); s72(1)(a)(i), s72(1)(b)(i), s71(1)(b)(ii) MHA.

¹¹⁵ *Winterwerp v the Netherlands* (1979-80) 2 E.H.R.R. 387, at [45].

¹¹⁶ Law Com 372, n 71, at [1.27].

¹¹⁷ E.g. under the Care Act 2014; the Social Services and Well-being Act 2014; or the NHS Act 2006.

¹¹⁸ MCA Sch AA1, ss 6-12.

 $^{^{119}}$ The test of whether the LPS 'applies' concerns its interface with the MHA, provided for by Part 7 of Schedule AA1 and discussed below.

¹²⁰ MCA Sch AA1, s17-18.

because the hierarchical approach adopted¹²¹ leaves them with responsibilities for privately arranged care, care provided informally by friends or family, and—owing to concerns about financial conflicts of interest—independent hospitals.

C. Care Home Arrangements

The largest proportion of DoLS and LPS applications concern people living in residential care.¹²² The government's 'adjusted'¹²³ LPS model introduced a new and separate procedure for authorising arrangements in residential care settings: the 'care home arrangements'.¹²⁴ The care home arrangements flow from the desire to 'streamline' the LPS into existing care planning processes, and relieve pressure on local authorities.

The government's initial idea was that care home managers could take on some functions otherwise performed by the responsible body, albeit with local authorities as responsible bodies still holding overall responsibility for issuing the authorisation. Care home managers were to arrange all LPS assessments themselves and make certain critical decisions around representation and advocacy. The responsible body would conduct a pre-authorisation review based on a statement by the care home manager.¹²⁵ Yet, the government assured care providers it would be the responsible body who would be liable if things went wrong.¹²⁶

The care home arrangements were not consulted upon by the government. Professional bodies, local government bodies and care providers themselves expressed concerns about financial conflicts of interest, the competence and ability of care homes to conduct the relevant assessments, and the impact of these additional responsibilities on an already struggling sector.¹²⁷ No additional resources were allocated for this assessment and administration role.¹²⁸ There were concerns that care homes might pass these costs on to residents.¹²⁹

The government initially argued that LPS assessments by the responsible body would 'duplicate' those already being undertaken by care homes.¹³⁰ Yet more than half of all care home placements are at least partially funded and arranged by local authorities or the NHS ¹³¹, ergo reintroducing the 'carousel' the Commission had sought to remove. Furthermore, the assessments undertaken for the LPS are distinct from those undertaken by care homes for operational purposes. Simply put, the LPS are concerned with examining the proposed arrangements in comparison with potential alternative options; including

¹²¹ MCA Sch AA1 s6, s10.

 $^{^{122}}$ 71 per cent of all DoLS applications in 2017-18 were from care homes (residential or nursing). NHS Digital (n 11).

¹²³ The Government described the scheme contained in the 2018 Bill as the "*Adjusted Liberty Protection Safeguards*" – Department of Health and Social Care, Mental Capacity (Amendment) Bill: Impact Assessment (2018) 1.

¹²⁴ MCA Sch AA1 s17(i), defined s3.

¹²⁵ See initial version of the Bill, dated July 2018 (n86).

¹²⁶ 'Mental Capacity (Amendment) Bill: Impact Assessment' (2018), (n 123) at [8.9].

¹²⁷ See n 90, n 93, n 94, n 95.

¹²⁸ Mental Capacity (Amendment) Bill: Impact Assessment' (2018), (n 123) at [8.6], [12.16].

¹²⁹ Hansard, HC Public Bill Committee (1st Sitting) col 67 (15 January 2019) (Alex Cunningham MP); Hansard,

HC Series 6 (Report Stage) Vol 654 col 824 (12 February 2019) (Alex Cunningham MP).

¹³⁰ Mental Capacity (Amendment) Bill: Impact Assessment (2018) para 8.3, n 123.

¹³¹ W. Laing, *Adult specialist care: UK market report* (Second edition edn, Laing & Buisson 2016).

those in other settings than the care home. This is integral to the 'least restriction' principle contained in the MCA, DoLS and LPS, and is also a necessary ingredient of capacity assessments.¹³² Conversely, it is unlikely that the care home's own internal assessments—under the MCA—would explore alternative arrangements other than those that the care home could put in place. It is not the role of the care home manager to investigate other possible places where the person could receive care and support.

The care home arrangements were fiercely criticised in the Lords. The government responded by giving the responsible body discretion over whether they or the care home hold the reins in arranging the assessments.¹³³ Where the care home does, regulations will prohibit anybody with a 'prescribed connection' to the care home from conducting the key assessments. This is to protect against conflicts of interest.¹³⁴ Care homes will therefore be forbidden from relying upon their own internal assessments and will be required to source these from other professionals; yet it is unclear who will provide these assessments. This may be relatively straightforward when local authority and NHS professionals arrange care on behalf of these public bodies, however privately arranged care will not necessarily involve independent professional assessments under the MCA. This issue is revisited for the different assessments below.

D. Authorisation Conditions and Assessments

The DoLS have six qualifying requirements, assessed by the Best Interests Assessor (BIA) or the Mental Health Assessor (MHAr). The government boasted of reducing this to three assessments under the LPS:¹³⁵ medical, mental capacity and 'necessary and proportionate'. In reality, responsible bodies will still need to be assured of similar criteria and make similar determination as under the DoLS.¹³⁶ What has changed is who can determine whether these are met.

E. Age

Although the MCA applies from age 16 upwards,¹³⁷ the DoLS only applied to people aged over 18.¹³⁸ However, following *Cheshire West* ¹³⁹ potentially thousands of children and young people in the care of the state are considered to be deprived of their liberty.¹⁴⁰ At

¹³³ MCA Sched AA1 s17.

¹³² A pre-requisite of a capacity assessment, see: CC v KK and STCC [2012] EWHC 2136 (COP).

¹³⁴ MCA Sched AA s21(5) (for medical and mental capacity assessments) and s22(3) (for the necessary and proportionate determination).

¹³⁵ 'Equality Analysis: Liberty Protection Safeguards – Mental Capacity (Amendment) Bill' (n 103) [6].

¹³⁶ National DoLS Leads Group written evidence to the Public Bill Committee, at: https://publications.parliament.uk/pa/cm201719/cmpublic/MentalCapacity/memo/MCAB02.pdf.

¹³⁷ MCA s2(5).

¹³⁸ MCA Sched A1 s13.

¹³⁹ See *Cheshire West*, n 58, and n 69 for deprivation of liberty cases concerning people aged under 18.

¹⁴⁰ The Law Commission estimated this might affect 2,667 16- and 17-year olds who lacked capacity to consent to arrangements amounting to deprivation of liberty in special schools, residential care or hospitals. Response to request under the Freedom of Information Act 2000, 10 May 2019, n 13. See also: Children's Who they? Where they? Children Commissioner, are are locked up (2019)at: https://www.childrenscommissioner.gov.uk/publication/who-are-they-where-are-they/. In Re D (A Child) (n69) the Supreme Court confirmed that parents cannot consent to a deprivation of liberty on behalf of children.

present, these must be authorised by the courts. The Law Commission recommended that the LPS apply to 16- and 17-year olds. ¹⁴¹ The government accepted this recommendation, ¹⁴² and the LPS will apply from 16 upwards. ¹⁴³ The care home arrangements, however, only apply from 18 upwards. ¹⁴⁴

F. Mental Disorder

Article 5(1) ECHR permits detention only on certain limited grounds, including 'unsoundness of mind'.¹⁴⁵ This ground directly conflicts with article 14 CRPD,¹⁴⁶ which provides that 'the existence of a disability shall in no case justify a deprivation of liberty.'¹⁴⁷ The Law Commission concluded that the CRPD Committee's approach required 'a greater process of change over a much longer timescale',¹⁴⁸ prioritising (for now) compliance with the ECHR.

Article 5(1)(e) requires 'objective medical evidence' of a 'true mental disorder' of a 'kind or degree warranting compulsory confinement'.¹⁴⁹ The DoLS 'mental health' criterion employs the definition of 'mental disorder' established by the MHA—'any disorder or disability of the mind'¹⁵⁰—but with a qualification restricting the MHA's application to people with learning disabilities¹⁵¹ removed.

The Law Commissioners were concerned that this potentially excluded people with 'pure' brain disorders, such as a stroke.¹⁵² It is not obvious why this would not constitute a 'disorder or disability of the mind', but this may reflect a cultural reluctance within psychiatry to apply the MHA to these populations. To accommodate these cases, the Commission initially proposed use of the MCA's diagnostic threshold—'an impairment of, or a disturbance in the functioning of, the mind or brain'¹⁵³—but later concluded that this

¹⁴¹ Law Com 372 (n 71), Recommendation 5.

¹⁴² 'Final Government Response to the Law Commission's review of Deprivation of Liberty Safeguards and Mental Capacity', n 87, Recommendation 5.

¹⁴³ MCA Sched AA1 s2(2)(a).

¹⁴⁴ MCA Sched AA1 s3, s20(1)(a).

¹⁴⁵ Article 5(1)(e).

¹⁴⁶ P. Fennell and U. Khaliq, 'Conflicting or complementary obligations? The UN Disability Rights Convention, the European Convention on Human Rights and English law' (2011) (6) European Human Rights Law Review , 662-74; P. Bartlett, 'A mental disorder of a kind or degree warranting confinement: examining justifications for psychiatric detention' (2012) 16 (6) International Journal of Human Rights , 831-44. Although see also: E. Flynn, 'Disability, deprivation of liberty and human rights norms: Reconciling European and international approaches' (2016) 22 International Journal of Mental Health and Capacity Law, 75-101 http://journals.northumbria.ac.uk/index.php/IJMHMCL/article/view/503/997. Also considered in: Rooman v Belgium [2018] M.H.L.R. 250; BAILII 2019 ECHR 105 – and 'Modernising the Mental Health Act', n 17, Annex B.

¹⁴⁷ See also: Committee on the Rights of Persons with Disabilities, 'Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities' GAOR, 72nd session, Suppl no 55 Annex, 2017 (Adopted by the CRPD during its 14th session, 17 August-4 September 2015).

¹⁴⁸ Law Com CP 222, n 53, [3.22].

¹⁴⁹ *Winterwerp*, n 115, at [39].

¹⁵⁰ MHA s1(2).

¹⁵¹ MHA s(2Å), as amended by MHA 2007. The term 'learning disability', rather than intellectual disability, is used in UK legislation and policy. Where referring to specific UK legislation or policy, the phrase 'learning disability' will accordingly be used.

¹⁵² Law Com CP 222, n 53 [6.8]-[6.9].

¹⁵³ MCA s2(1).

was too broad. Applying Goldilocks logic, they eventually recommended a test of 'unsoundness of mind' for its fit with article 5(1)(e).¹⁵⁴ Predictably this caused widespread offence, and the government amended the Bill so that the LPS now employs the same 'mental disorder' test as the DoLS.¹⁵⁵

The DoLS require the 'mental health' assessment to be conducted by the MHAr, who must be a registered medical professional with specialist qualifications and experience.¹⁵⁶ However the LPS do not replicate this role; there is limited specification of who can undertake the 'medical assessment' of whether a person has a mental disorder. The Law Commission noted 'encouraging developments' in Strasbourg suggesting 'general practitioners, psychologists and psychotherapists' could provide the necessary medical evidence¹⁵⁷, and the government repeated this in parliamentary debates.¹⁵⁸ Medical professional bodies were concerned that the 2019 amendments did not require those undertaking the 'medical assessment' to have medical qualifications.¹⁵⁹ The ECtHR has more recently indicated that in some circumstances psychiatric expertise is necessary.¹⁶⁰ Statutory 'requirements' for those undertaking LPS medical assessments has been deferred to regulations.¹⁶¹ Initial impact assessments indicate the government expects GP's to perform LPS medical assessments for free.¹⁶² However, there is no mandatory obligation on them to do so and charging regulations do not prohibit them from charging patients for this.¹⁶³

G. Mental Capacity

The DoLS require assessment of whether the person has the mental capacity to decide 'whether or not he should be accommodated in the relevant hospital or care home for the purpose of being given the relevant care or treatment.'¹⁶⁴ This assessment may be conducted either by the BIA or the MHAr. Of the six DoLS qualifying requirements, 'mental capacity' is the one that is most frequently found not to be met by DoLS assessors.¹⁶⁵

Under the LPS, the assessment of mental capacity no longer concerns accommodation but 'consent to the arrangements'.¹⁶⁶ Here, the tricky distinction between care and treatment and detention itself, which also figures under the DoLS, comes into sharp relief. Do the LPS require capacity assessors, reviewers, and the Court of Protection to only consider

¹⁵⁴ Law Com CP 222, n 53, [9.19].

¹⁵⁵ MCA Sch AA1 s13(b).

¹⁵⁶ The Mental Capacity (Deprivation of Liberty: Standard Authorisations, Assessments and Ordinary Residence) Regulations 2008 SI 2008/1858, Regulation 4.

¹⁵⁷ Law Com 372 (n 71), [9.60].

¹⁵⁸ Hansard, HC Public Bill Committee (3rd Sitting)col 99 (17 January 2019) (Caroline Dinenage MP).
¹⁵⁹ Written evidence submitted to the Public Bill Committee by the Royal College of Psychiatrists (RCPsych) (MCAB44) and the British Medical Association, at: https://services.parliament.uk/Bills/2017-19/mentalcapacityamendment/committees/houseofcommonspublicbillcommitteeonthementalcapacityamend mentbillhl201719.html.

¹⁶⁰ *Ilnseher v Germany* [2019] M.H.L.R. 278; BAILII 2018 (Grand Chamber) ECHR 991, [130].

¹⁶¹ MCA Sched AA1 s21(3).

¹⁶² 'Impact Assessment: Mental Capacity (Amendment) Bill' (2019) (n 5) [8.6].

¹⁶³ D. Lock QC, 'Chapter 8: When can fees be charged to a patient by a GP Practice?' *GP Law*, at: <u>http://www.gplaw.co.uk/chapter-8-when-can-fees-be-charged-to-a-patient-by-a-gp-practice#Chapter808</u>. ¹⁶⁴ MCA Sched A1, s15.

¹⁶⁵ NHS Digital (2019), n 10, Annex A Table 6.

¹⁶⁶ MCA Sched AA1 s13(a).

whether a person can make decisions about the 'arrangements' to facilitate care and treatment, not the underlying care and treatment decision itself? For example, should LPS capacity assessors simply accept—without question— underlying assessments that a person lacks capacity to consent (or refuse) a specific treatment, or to restrict contact with loved ones, or even where to live? If a regime of supervision and control is imposed to prevent sexual activity on the basis that a person lacks the capacity to consent to sex,¹⁶⁷ must the LPS capacity assessment start from the premise that this assessment is correct and merely consider the arrangements to secure this protection? The Code may offer guidance here, but the issue forces a reckoning with the underlying question of what the LPS are safeguards against.

Regulations will 'make provision' for who can provide a capacity assessment under the LPS.¹⁶⁸ For care home arrangements, assessments cannot be undertaken by anyone with a 'prescribed connection' to the care home.¹⁶⁹ Care homes will therefore need to source capacity assessments from third parties. Where care is publicly funded or arranged, public bodies should in theory have undertaken capacity assessments for the care and treatment itself. For private self-funders, it is less likely that independent professionals will have assessed a person's capacity to consent to care arrangements, as local authority social workers or NHS professionals will be less likely to have arranged or commissioned the care. The government appears to believe that GPs will also conduct LPS capacity assessments for free,¹⁷⁰ yet they play little role in most decisions concerning residential care. This promises to be a major practical sticking point for the LPS unless resolved.

Although regulations specify who can conduct capacity and medical assessments, the responsible body or care home manager must 'determine' whether these authorisation conditions are met.¹⁷¹ The 'determination' may be based on a previous LPS assessment, or an assessment for another purpose, provided it appears 'that it is reasonable to rely on the assessment',¹⁷² having regard to: the length of time since it was carried out, its purpose, and whether there has been a change in the person's condition.¹⁷³

IV. FROM 'BEST INTERESTS' TO 'NECESSARY AND PROPORTIONATE'

Detention under article 5(1)(e) ECHR must be necessary and proportionate with regard to the risk of harm to the person or to others.¹⁷⁴ Additionally, and so far as is possible, protective measures should reflect 'the wishes of individuals capable of expressing their will'.¹⁷⁵ These elements of the lawfulness of deprivation of liberty are dealt with under the LPS's new 'necessary and proportionate' test, which replaces the DoLS 'best interests' assessment.

¹⁶⁷ *IM v LM* [2014] EWCA Civ 37, [1]).

¹⁶⁸ MCA Sched AA1 s21(4).

¹⁶⁹ MCA Sched AA1 s21(5).

¹⁷⁰ 'Impact Assessment: Mental Capacity (Amendment) Bill' (2019) (n 5) [8.6].

¹⁷¹ MCA Sched AA1 s21(2).

¹⁷² MCA Sched AA1 s21(8).

¹⁷³ MCA Sched AA1 s21(9).

¹⁷⁴ *Litwa v Poland* (2001) 33 E.H.R.R. 53 [78]; [2000] M.H.L.R. 226. *Stanev v Bulgaria*, n 15, [143]; *Saadi v UK* (2008) 47 E.H.R.R. 17 at [54].

¹⁷⁵ *Mihailovs v Latvia*, n 60, [145].

The DoLS' best interests assessment is regarded by many as the 'cornerstone' of the authorisation process.¹⁷⁶ It must be conducted by the BIA, typically a social worker, who must have specialist skills, training and experience¹⁷⁷, and be independent of the person's care and treatment.¹⁷⁸ The BIA must determine whether it is in the person's 'best interests' to be a 'detained resident', whether it is necessary for them to be detained 'in order to prevent harm to the relevant person' and whether this is a proportionate response to the likelihood and seriousness of that person suffering harm if they were not detained.¹⁷⁹ In practice, it is extremely rare for the 'best interests' requirement of the DoLS to be found not to be met.¹⁸⁰ However, it is possible that the process of assessment, and the potential for BIA's to recommend 'conditions' for authorisation, may still lead to reduced restrictions or substantive changes to care arrangements. No data are collected on this, however.

BIAs told the Law Commission that the test could be difficult to apply in practice. Unlike the MHA, risk of harm to others is not a potential ground for detention under the DoLS. However, at the fringes of the DoLS were cases like *P v A Local Authority* ¹⁸¹, where the real reason for the restrictions were less to prevent harm to the person than to others.¹⁸² This included cases (like P's) of young men with intellectual disabilities who were sexually attracted to children, as well as people who sometimes acted aggressively towards other residents or loved ones, or people who might otherwise be detained under the MHA. It was sometimes argued that it is in a person's best interests to prevent them from harming others, for example if they themselves would have wished to be prevented from hurting other people, or to prevent serious consequential risks such as a community backlash, imprisonment or detention in hospital under the MHA.¹⁸³ In P v A Local Authority, the authorisation was discharged by the Court of Protection as not being necessary and proportionate in relation to the risk to P himself. Reportedly, P subsequently offended and was imprisoned.¹⁸⁴ The Commission's suggestion of including a new ground of risk of harm to others within the best interests test¹⁸⁵ received a mixed response at consultation: some viewed this as avoiding intellectual dishonesty or more restrictive measures, others were nervous about the MCA straying into the traditional public protection terrain of the MHA. Some asked 'how far can this be taken before it goes beyond the remit of the Mental Capacity Act'?186

The Commission also heard that BIAs found it hard to describe some care arrangements as being in the 'best interests' of a person, when in reality they were the only available

¹⁷⁶ Law Com 372 (n71) 75.

¹⁷⁷ The Mental Capacity (Deprivation of Liberty: Standard Authorisations, Assessments and Ordinary Residence) Regulations 2008 SI 2008/1858, regulation 5.

¹⁷⁸ Ministry of Justice, Mental Capacity Act 2005: Deprivation of Liberty Safeguards Code of Practice (Lord Chancellor's Office, 2008), [4.13], see also [4.66].

¹⁷⁹ MCA Sched A1, s16.

¹⁸⁰ NHS Digital (2019), n 12, Annex A, Table 6.

¹⁸¹ *P v A Local Authority* [2015] EWCOP 89.

¹⁸² See also: *Birmingham City Council v SR* [2019] EWCOP 28; *Y County Council v ZZ* [2012] EWCOP B34; *Re (N) (Deprivation of Liberty)* [2016] EWCOP 47.

¹⁸³ Ibid, and Law Com CP 222, n 53, [7.42].

¹⁸⁴ Hansard, HL Series 5 (Committee Stage 1st Sitting) Vol 792 col 1851 (5 September 2018) (The Baroness Ilora Finlay).

¹⁸⁵ Law Com CP 222, n53, Provisional proposal 7-10.

¹⁸⁶ Law Commission, 'Mental Capacity and Deprivation of Liberty - Consultation Analysis' (2017) [6.69] – [6.80], at: http://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/.

option.¹⁸⁷ The best interests test, the Commission concluded, added 'nothing' to the assessment in the 'vast majority of cases',¹⁸⁸ but added 'complications'¹⁸⁹ in cases where the real concern was harm to others. They reached a radical conclusion: abolish the DoLS best interests requirement altogether, and replace it with a new test of whether the deprivation of liberty was necessary and proportionate with regard to either the risk of harm to the person *or to others*.¹⁹⁰ This test reflected the position under the ECHR¹⁹¹ and could accommodate cases like P's.¹⁹²

The Commission envisioned the MCA's best interests principle still playing a role in 'formulating the arrangements as a whole', strengthened by their wider proposed reforms to the MCA.¹⁹³ Yet they – and later the independent review of the MHA – acknowledged that the MCA's 'best interests' principle sits uneasily alongside public protection.¹⁹⁴ It was unclear whether the Commission intended that the LPS would empower responsible bodies to authorise arrangements that could potentially be said *not* to be in the person's best interests, extending powers of detention under the LPS beyond the traditional remit of the MCA, and bringing the MCA's detention framework into conflict with its main statutory principles.

The initial version of the government's Bill did not specify what detention must be 'necessary and proportionate' in relation to, as the MHA review was simultaneously considering the matter.¹⁹⁵ The government subsequently confirmed the LPS would include risk of harm to others,¹⁹⁶ but this would only be spelled out in the Code of Practice.¹⁹⁷ However there was no discussion of this issue in in any of the Bill's supporting materials, so it was unclear how the new test would sit alongside the wider provisions of the MCA, or how open ended it might be. The Minister appeared to believe (incorrectly) that this mirrored the existing position under the DoLS.¹⁹⁸

Significant potential dilemmas arise in extending this ground of detention to include risk of harm to others. It would introduce a new public protection ethos within the MCA that is alien to its foundational principles. It would create new powers to detain on public protection grounds with very weak safeguards, and no consideration has been given to whether this might be used for new and unintended populations. It would, paradoxically, give public bodies administrative powers of detention on public protection grounds that

¹⁹³ Law Commission No 372 (n 71), at [9.31].

¹⁸⁷ Law Com 372 (n 71) at [9.25].

¹⁸⁸ Ibid, at [9.27].

¹⁸⁹ Ibid, at [9.28], [9.29].

¹⁹⁰ Ibid, at [9.30].

¹⁹¹ Litwa v Poland, n 174, at [78]; Stanev v Bulgaria, n 15, at [143]; Saadi v UK, n 174, at [54].

¹⁹² The case of $P \lor A$ Local Authority was not discussed by the Commission, most likely because it was not reported publicly or placed on BAILII until 2019.

¹⁹⁴ Ibid, at [9.35]; 'Modernising the Mental Health Act', n 17, at [217].

¹⁹⁵ Annex A: Law Commission recommendations and Government Responses', n 87. Response to Recommendation 10⁻

¹⁹⁶ Hansard, HL Series 5 (Committee 2nd Sitting) Vol 793 col 384 (15 October 2018) (The Baroness Stedman Scott OBE – Government Spokesperson for the Lords, in response to a direct question from The Baroness Barker).

¹⁹⁷ Hansard, HL Series 5 (Report Stage 1st Sitting) Vol 794 col 285 (21 November 2018) (The Lord O'Shaughnessy).

¹⁹⁸ Hansard, HL Series 5 (Committee Stage 3rd Sitting) Vol 793 col 710 (22 October 2018) (The Lord O'Shaughnessy).

cannot be exercised by the Court of Protection itself. And there is a risk of highly complex interactions with the rest of the MCA when detention could be authorised under the LPS but cannot be justified on best interests grounds. The Lords voted to restrict the necessary and proportionate test to risk of harm to the person themselves,¹⁹⁹ and the government did not seek to reverse this. Consequently, 'risk of harm to others' is not grounds for detention under the LPS.²⁰⁰ Shortly afterwards the MHA review recommended including a ground of harm to others to enable the LPS to authorise inpatient detention in some circumstances where the MHA currently has to be used.²⁰¹ This issue may be revisited in a future mental health bill.

Those making necessary and proportionate 'determinations' must have regard 'to the cared-for person's wishes and feelings in relation to the arrangements'.²⁰² Although the DoLS' best interests test also required this²⁰³, wishes and feelings – and the need for strong justification to override these - assume greater visibility in the LPS. This is arguably one benefit of removing the 'best interests' test, and may be an incremental step towards the emphasis on the 'will and preferences' of the person required by the CRPD.²⁰⁴ However the presence of LPS criteria linked to disability will continue to remain an obstacle for CRPD compliance.

Once again, questions arise over how far consideration of underlying care and treatment decisions bleed into determinations of whether the arrangements are necessary and proportionate. For example, should those making the determination consider whether restrictions on contact with named persons, or finely balanced or contested medical treatments, are themselves necessary and proportionate? The ECtHR has recently clarified that article 5(1)(e) imposes an obligation to ensure 'appropriate and individualised therapy, based on the specific features of the compulsory confinement'. The court did not analyse the specific *content* of treatment, but sought to confirm that 'an individualised programme' was in place.²⁰⁵ LPS assessors will therefore need to make *some* enquiries into the 'therapeutic' purpose of detention. Notably, the government also intended the LPS to protect article 8 rights,²⁰⁶ implying some consideration of underlying care and treatment decisions.

Regulations will specify who may undertake the 'necessary and proportionate' determination. If the arrangements are 'care home arrangements' they may not have a 'prescribed connection' to the care home.²⁰⁷ There is no provision for use of prior or equivalent assessments for the necessary and proportionate determination, implying it must be carried out afresh for each authorisation. Unlike the capacity and medical assessments, which putatively impose no additional costs, the necessary and proportionate

¹⁹⁹ Hansard, HL Series 5 (n 197) col 286 (Division 1, called by The Baroness Barker).

²⁰⁰ MCA Sched AA1 s13(c).

²⁰¹ 'Modernising the Mental Health Act', n 17. 125.

²⁰² MCA Sched A1 s22(2).

²⁰³ MCA s4(6).

²⁰⁴ On which see: E. Jackson, n 79; L. Series, n 79; A. Ruck Keene and C. Auckland, 'More presumptions please? Wishes, feelings and best interests decision-making' (2015) 5 (3) Elder Law Journal 3, 293. ²⁰⁵ *Rooman v Belgium*, n146, at [205], [209].

²⁰⁶ 'Impact Assessment: Mental Capacity (Amendment) Bill' (2018) (n 123) 1, 9, [9.5], [16.8]; 'Impact Assessment: Mental Capacity (Amendment) Bill' (2019) (n 5) 1, [9.3], [16.8].

²⁰⁷ MCA Sched A1 s22(1) and 22(3).

assessment has been costed by the government (at £145.28).²⁰⁸ The expectation is that the responsible body will build this determination into care planning, with additional resources provided for responsible bodies to undertake the determination for those with privately arranged care.²⁰⁹

The DoLS required at least two assessors (BIA and MHAr), one of whom must be independent of the person's care (the BIA), to conduct the relevant assessments. The Law Commission had proposed two assessors for the three core LPS assessments.²¹⁰ The 2019 amendments do not stipulate this; it is to be hoped that the new LPS Code will impose more demanding guidelines.

A. Consultation

The government asserted, somewhat misleadingly, that the LPS established a 'new' and stronger duty to consult with the cared-for person and their family²¹¹, in order to ascertain the 'wishes or feelings' of the person.²¹² The main difference is that the LPS consultation duty is explicit and contained within Schedule AA1, whereas the DoLS consultation duty was implicit, resting on the MCA's best interests' duty to consult others involved in the person's care or interested in their welfare about the person's wishes and feelings. Unlike the LPS, the best interests consultation duty also encompassed the person's values and beliefs,²¹³ and a more demanding duty to 'permit and encourage' the person to participate in decision making as 'fully as possible'; these provisions are not replicated in the LPS.²¹⁴ The LPS duty initially (inadvertently) excluded the cared-for person themselves from the list of persons to be consulted,²¹⁵ but this was rectified during the passage of the Bill.²¹⁶

The LPS consultation duty is vital for identifying potential objections, which trigger other key safeguards discussed below. The duty falls on the responsible body or – under the care home arrangements – the care home manager.²¹⁷ No 'prescribed connection' regulations apply to consultation, meaning this pivotal role may be undertaken by a person with a potential financial conflict of interest. There are risks that people may not feel comfortable expressing objections to those directly responsible for their care, or that potential signs of objection may missed, dismissed or explained away. Meanwhile the person making the necessary and proportionate determination is under no statutory duty to consult the person directly,²¹⁸ and will therefore rely upon reports of their views by those carrying out the consultation. The capacity assessment offers a potential safeguard against

²⁰⁸ 'Impact Assessment: Mental Capacity (Amendment) Bill' (2019) (n 5) at [12.13].

²⁰⁹ Ibid, at [8.7], [12.13] and [12.32].

²¹⁰ Law Com 372 (n 71), Recommendation 13.

²¹¹ e.g. 'Mental Capacity (Amendment) Bill: Impact Assessment' (2018) (n 123) at [9.3]; 'Equality Analysis: Liberty Protection Safeguards – Mental Capacity (Amendment) Bill' (n 103) p 6; Hansard, HL Series col 1875 n 184 (The Lord O'Shaughnessy); Hansard, HC Series 6 (Ping Pong) Vol 657 col 972 (2 April 2019) (Jim Shannon MP).

²¹² MCA Sched AA1 s23(3).

²¹³ MCA s4(6)-(7).

²¹⁴ MCA s4(4).

²¹⁵ Law Com 372 (n71) Draft Sched AA1 s22(1).

²¹⁶ MCA Sch AA1 s23(2)(a).

²¹⁷ MCA Sch AA1 s23(1).

²¹⁸ However, the impact assessment does indirectly imply that they will 'visit' the person: 'Impact Assessment: Mental Capacity (Amendment) Bill' (2019), n 5, at [12.32].

distortion or misrepresentation of the person's views here, provided it properly documents any potential objections, since it *cannot* be undertaken by the care home.

B. 'No Refusals'?

The MCA enables a person with capacity to nominate their own preferred substitute decision maker in a Lasting Power of Attorney (LPA).²¹⁹ The Court of Protection may also appoint a deputy to make specified decisions on the person's behalf,²²⁰ and the person may themselves refuse specific medical treatments in advance.²²¹ The DoLS 'no refusals' requirement prohibited authorisations overriding a valid refusal of care and treatment by any attorney, deputy or the person themselves.²²² In effect, therefore, the DoLS do not empower supervisory bodies to 'trump' care and treatment decisions made by the person themselves, those they have selected to make decisions for them, or decision makers appointed by the court.

The Commission recommended a similar provision for the LPS,²²³ however it does not feature in the 2019 amendments. The government's rationale was that 'It is already the case that a best interest decision could not be taken which conflicted with a valid decision by an attorney/deputy.²²⁴ The Bill does not alter this.'²²⁵ Yet strictly speaking, there could be a valid objection to the *arrangements* authorised by the LPS but not the underlying care and treatment decisions.²²⁶ Had the LPS included a 'risk of harm to others' ground, this too could have circumvented objections insofar as it created scope for detention that is not justified on best interests grounds. Objections by attorneys or deputies and advance refusals may be considered under the necessary and proportionate determination, but the LPS offer no cast iron guarantee that they will be determinative.

The Law Society observed that the LPS could also be used to trump the objections of parents of 16 and 17 year olds without a court order.²²⁷ This seems to be confirmed by the Law Commission when they observe that parents would have a right to bring proceedings in the Court of Protection if they objected.²²⁸

There is therefore scope for highly complex litigation about the relative status of an LPS authorisation, the limits of parental authority, and other mechanisms for decision making under the MCA.

²¹⁹ MCA ss 9-14.

²²⁰ MCA s 16(2)(b).

²²¹ MCA s 24-26.

 $^{^{\}rm 222}$ Provided for by MCA ss22-25.

²²³ Law Com 372 (n 71) at [10.8]-[10.18]; Draft Schedule AA1, s15.

²²⁴ This is provided for by MCA s6(6), where a decision is made relying on the 'general defence'.

²²⁵ Annex A: Law Commission recommendations and Government Responses', n 87.

²²⁶ As noted by A. Ruck Keene, *Mental Capacity (Amendment) Bill – highlights from final day of Lords Committee stage'* (Mental Capacity Law and Policy) 23 October 2018, at: http://www.mentalcapacitylawandpolicy.org.uk/mental-capacity-amendment-bill-highlights-from-final-day-of-lords-committee-stage/#_ftnref1.

²²⁷ See Law Society, n 92.

²²⁸ Law Com 372 (n 71) at [7.37].

V. INTERFACE WITH THE MENTAL HEALTH ACT 1983

The interface between the DoLS and the MHA is notorious for its complexity.²²⁹ It is governed by a separate schedule²³⁰ and an 'eligibility assessment' undertaken by a BIA or MHAr with further specialist qualifications.²³¹ In summary:

1 DoLS can authorise detention outside of hospital provided this does not conflict with any requirements imposed under a community MHA regime, such as guardianship, supervised community treatment or conditional discharge by a tribunal.

2 DoLS may authorise inpatient treatment for a *physical* disorder.

3 If the detention is to secure inpatient treatment for mental disorder²³² and the patient is 'within scope' of the MHA (that is, an application for detention could be made under s2 or s3 MHA) then patient is *ineligible* for the DoLS if they are objecting.²³³

4 Patients within scope of the MHA who are not objecting may be detained under either the MHA or the DoLS. $^{\rm 234}$

5 Hospital inpatients may not fall 'within scope' of the MHA if they have recently been discharged by a tribunal²³⁵ or have learning disabilities²³⁶, in which case they may potentially be eligible for DoLS even if they are objecting.

The complexity of the two interlocking regimes can make it difficult for patients themselves to understand and exercise their rights, especially if subject to both simultaneously.²³⁷ The Law Commission heard reports of 'stand offs' between professionals arguing over which regime should be used.²³⁸

The issues at stake in this interface include the stigma and paternalistic culture associated with the MHA²³⁹ (although it is unclear whether same might also be said of DoLS and LPS) and the more rigorous procedural safeguards under the MHA. These include more initial assessments, powers of discharge for relatives, automatic referrals to the tribunal, safeguards governing treatment without consent and non-means tested aftercare. Their criteria for detention also differ: the MHA permits detention of those considered to have 'capacity' and also permits detention on grounds of risk to others, unlike the DoLS (and LPS).

²³² GJ v The Foundation Trust & Anor [2009] EWHC 2972 (Fam); [2010] M.H.L.R. 13.

²²⁹ E.g. Mental Capacity Act 2005: post-legislative scrutiny, n 36, at [271].

²³⁰ MCA Sched 1A.

²³¹ If undertaken by the MHAr, they must be an approved doctor under s12 MHA; if undertaken by the BIA, they must be qualified as an Approved Mental Health Professional.

²³³ MCA Schedule 1A s2 'Case E'.

²³⁴ *AM v South London & Maudsley NHS Foundation Trust and The Secretary of State for Health* [2013] UKUT 0365 (AAC); [2014] M.H.L.R. 181

²³⁵ R. Jones and E. Piffaretti, *Mental Capacity Act Manual* (8th edn, Sweet & Maxwell 2018) 354, citing *R. v East London and The City Mental Health Trust Ex P. Brandenburg* [2004] 2 A.C. 280; [2003] UKHL 58; [2004] M.H.L.R. 44.

²³⁶ By way of MHA s1(2A). *GJ v The Foundation Trust & Anor* n 232 at [29].

²³⁷ E.g. *C v Blackburn and Darwen Borough Council*, n 36; *KD v A Borough Council* [2015] UKUT 0251 (ACC); [2015] M.H.L.R. 358. *NM v Kent County Council* [2015] UKUT 125 (ACC); [2015] M.H.L.R. 343.

²³⁸ Law Com 372, n 71, at [13.11].

²³⁹ Ibid, at [13.16].

The Law Commission was troubled by the absence of a 'clear or meaningful test' for determining which scheme to use.²⁴⁰ One solution – favoured by the Commission and many consultees, but beyond its remit - was to 'fuse' the MCA and the MHA together, as Northern Ireland has.²⁴¹ Ultimately, the Commissioners were persuaded that retaining parallel legal regimes led to significant confusion and uncertainty in practice, and recommended that *only* the MHA should be available for detention on grounds of mental disorder (unless a patient had a learning disability).²⁴²

Following a 2017 election campaign pledge by Theresa May to address rising rates of detention under the MHA,²⁴³ an independent review of the Act had been established. Its recommendation was at odds with the Law Commission's: the DoLS/LPS should be retained for mental health detention, but discretion to use either regime should be eliminated by specifying that *only* the DoLS/LPS could be used in non-objecting cases.²⁴⁴ This would assist with the policy goal of reducing MHA detentions, but the same patients, subject to the same treatment and regimes, could instead be detained under the MCA, only with weaker procedural safeguards.

The interface rules between the DoLS and MHA are therefore more or less reproduced in the LPS at present,²⁴⁵ but may be revisited in the future. Responsible bodies (and care home managers) will therefore still be tasked with navigating this complex interface in ensuring the proposed arrangements are not excluded 'mental health arrangements' before they can be authorised.²⁴⁶ All that has changed is that this is no longer framed as a distinct 'assessment', and there are no statutory requirements for the qualifications or experience of those navigating this legal labyrinth.

A. Pre-Authorisation Review

The LPS aim to address the volume problem following *Cheshire West* by building the core assessments into existing care planning processes. It is hoped this 'streamlining' will lead to earlier and better consideration of the MCA and principles of necessity and proportionality during care and treatment decision making, *before* decisions are implemented.²⁴⁷ The cost of this streamlined approach, however, is reduced independent scrutiny by assessors who are not involved in care and treatment decisions. This independent safeguard against 'misjudgments and professional lapses' was a driving

²⁴⁰ Law Com CP 222, n 53, at [10.20].

²⁴¹ Mental Capacity Act (Northern Ireland) 2016 SI 2016/18.

²⁴² Law Com 372, n 71, recommendation 37.

²⁴³ M. Savage, '*Theresa May pledges mental health revolution will reduce detentions*' (The Guardian 7 May 2017) at: https://www.theguardian.com/politics/2017/may/07/theresa-may-pledges-mental-health-revolution-will-reduce-detentions.

²⁴⁴ 'Modernising the Mental Health Act', n 17, Recommendation 41.

²⁴⁵ MCA Sched AA1 Part 7, 'Excluded Arrangements: Mental Health'. Note that an LPS authorisation can now sit alongside a MHA detention, to cater for the simultaneous delivery of physical healthcare under mental health detention, a gap identified in *A NHS Trust v Dr. A* [2013] EWHC 2442 (COP); [2014] 2 W.L.R. 607. ²⁴⁶ MCA Sched AA1 s2(c) states that 'This Schedule' does not apply to arrangements excluded by Part 7 ('Excluded arrangements: Mental Health'). When authorising the arrangements the responsible body (s18(a)) or the care home manager (s19(b)(i)) must be satisfied that the schedule 'applies to the arrangements'. ²⁴⁷ Law Com No 372, n71, at [5.31].

motivation behind both *HL v UK*²⁴⁸ and *Cheshire West*.²⁴⁹ Where the same professionals are involved in planning care and treatment and in authorising detention, the ECHR requires 'guarantees of independence' and counterbalancing procedures.²⁵⁰

Under the LPS this independent element is provided through a pre-authorisation review by the responsible body.²⁵¹ This must be carried out by somebody who is not involved in the 'day-to-day care' of the person or providing any treatment to them, and without any 'prescribed connection' to the care home.²⁵² There is no statutory provision for regulations stipulating qualifications or experiences, but some guidance may be provided in the Code. The reviewer is *personally*²⁵³ responsible for determining 'whether it is reasonable for the responsible body to conclude that the authorisation conditions are met' based on 'the information on which the responsible body relies'.²⁵⁴ The Law Commission anticipated that reviewers would not make additional enquiries or commission fresh assessments,²⁵⁵ but there is no statutory bar to them doing so. It is debatable how effective a safeguard this desktop review will prove to be where the information itself is of dubious quality or inaccurate. Some reviewers may adopt a muscular approach, refusing to authorise on the basis of visibly poor-quality assessments. Much will depend on the skills and experience of the reviewer, and the culture and resources of the institution.

B. Approved Mental Capacity Professionals

The Law Commission recognised that the role of BIAs was particularly important under the DoLS. They proposed a revised role as Approved Mental Capacity Professionals (AMCPs), central to the authorisation of arrangements amounting to deprivation of liberty. Following *Cheshire West* there are simply not enough BIAs to undertake assessments for all DoLS applications (one cause of supervisory body backlogs),²⁵⁶ and the Commission felt it was not 'proportionate or affordable' for AMCPs to be involved in every case under the LPS.²⁵⁷ They identified cases where the arrangements were 'contrary to the person's wishes' as most in need of oversight.²⁵⁸ Accordingly, wherever 'there is reason to believe' the cared-for person does not wish to reside in a particular place, or to receive care or treatment there, the case must be referred by independent reviewers to AMCPs.²⁵⁹

The Commission also recognised that other situations could require oversight, giving as examples cases where the person's wishes were unclear, the restrictions were 'particularly intensive or intrusive' or where those close to the person were objecting.²⁶⁰ Initially the government did not include the Commission's proposed discretionary power to refer cases

²⁵³ Law Com No 372 (n 71) at [10.25].

²⁵⁷ Law Com No 372 (n71) at [10.32].

²⁵⁹ MCA Sched AA1 s24(2)(a)-(b).

²⁴⁸ *HL v UK*, n 27, at [121].

²⁴⁹ Cheshire West, n58, at [1], [9], [32] and [57].

²⁵⁰ *IN v Ukraine* (App 28472/08); [2019] M.H.L.R. 124; BAILII [2016] ECHR 565, at [81].

²⁵¹ MCA Sched AA1 s24.

²⁵² MCA Sched AA1 s21(1).

²⁵⁴ MCA Sched AA1 s26.

²⁵⁵ Law Com No 372 (n 71) at [10.25].

²⁵⁶ Local Government Ombudsman, 'Investigation into a complaint against Staffordshire County Council' (reference number: 18 004 809) (2019).

²⁵⁸ Ibid, at [10.35].

²⁶⁰ Law Com No 372 (n 71) [10.43], Draft Bill Sched AA1 s23(3)(a).

to an AMCP in such scenarios, but following objections by stakeholders²⁶¹ it was reinserted.²⁶² Because of concerns about conflicts of interest for independent hospitals, these cases must also be referred to an AMCP.²⁶³ The government estimates that 25 per cent of all LPS applications will require review by an AMCP.²⁶⁴

AMCPs must 'review the information on which the responsible body relies' and 'determine whether the authorisation conditions are met'.²⁶⁵ Before making this determination the AMCP must – if it appears to them to be 'appropriate and practicable to do so' – meet with the cared-for person and consult those listed under the consultation duty.²⁶⁶ The government's anticipates only a 'small number' of cases where it is not appropriate for the AMCP to meet with the cared-for person.²⁶⁷

AMCPs have more flexible powers than BIAs. They have an open-ended power to 'take any other action' that appears to the AMCP to be appropriate and practicable.²⁶⁸ This could potentially include undertaking assessments themselves, taking steps to resolve disputes, or exploring less restrictive alternatives. The 2019 amendments do not include the Law Commission's recommendation that if AMCPs refuse to authorise arrangements they should give written reasons explaining why and describing necessary steps to obtain approval,²⁶⁹ but nothing prevents AMCPs from doing so. Whereas BIAs could only *recommend* that authorisation be subject to conditions,²⁷⁰ AMCPs potentially have greater control over the arrangements since the responsible body may *only* authorise them if the AMCP agrees the LPS conditions are met.²⁷¹

Despite the potential strengths of AMCPs, weaknesses remain. Roger Hargreaves, a retired social worker and DoLS policy lead, notes that the statutory restriction on 'day to day' involvement in care does not preclude some degree of involvement in underlying decisions²⁷², although the Code may go further. The biggest concern is whether referrals to AMCPs will be made where a person's wishes and feelings are unclear, contested, or potential objections are suppressed by medication, institutionalisation or fear of rocking the boat. Those detained for treatment for mental disorder in NHS hospitals are especially unlikely to be referred to an AMCP, because if they *are* regarded as objecting then they would generally be ineligible for the LPS.

²⁶¹ See for example the evidence to the Public Bill Committee of the National DoLS Leads, available at: <u>https://publications.parliament.uk/pa/cm201719/cmpublic/MentalCapacity/memo/MCAB02.pdf</u>.

²⁶² MCA Sched AA1 s24(2)(d).

 $^{^{263}}$ MCA Sched AA1 s24(2)(c). This was inserted on Report following debates in the Public Bill Committee in the House of Commons.

²⁶⁴ Law Commission, 'Impact Assessment: Mental Capacity and Detention' (LAWCOM0055, 2017) 33.

²⁶⁵ MCA Sched AA1 s25(1).

²⁶⁶ MCA Sch AA1 s25(2).

²⁶⁷ 'Final Government Response to the Law Commission's review of Deprivation of Liberty Safeguards and Mental Capacity', n 87. Response to recommendation 20.

²⁶⁸ MCA Sched AA1 s25(2)(b).

²⁶⁹ Law Com No 372 (n71) at [10.51].

²⁷⁰ MCA Sched A1 s 52(2).

²⁷¹ MCA Sched AA1 s18(f) (for authorisation via responsible bodies), s19(e) (where authorised via the care home arrangements).

²⁷² Written evidence of Roger Hargreaves (MCAB04) to the Public Bill Committee, available at: <u>https://publications.parliament.uk/pa/cm201719/cmpublic/MentalCapacity/memo/MCAB04.htm</u>

C. The Duration of Authorisations

Article 5(1) requires reviews at 'reasonable intervals' to ensure the criteria for detention continue to be met.²⁷³ The supervisory body may specify a maximum duration of 12 months for a DoLS authorisation. Once expired, fresh authorisation must be sought, with the full complement of assessments and procedures. Consultees told the Law Commission this incurred 'significant costs' yet amounted to a 'rubber stamping exercise' when a person's condition was stable.²⁷⁴ The LPS introduce the option to 'renew' or vary an authorisation, indefinitely, without necessarily undertaking the full battery of assessments and determinations.

D. Renewals, Variations and Reviews

An initial LPS authorisation may last up to twelve months,²⁷⁵ then be renewed for a further twelve months and thereafter for periods of up to three years.²⁷⁶ Responsible bodies may renew the authorisation if they are satisfied that 'the authorisation conditions continue to be met', 'that it is unlikely that there will be any significant change in the cared-for person's condition during the renewal period which would affect whether those conditions are met', and they have carried out a fresh consultation under the consultation duty.²⁷⁷ Provided the responsible body is satisfied of the foregoing, they may also choose to renew on the basis of a written statement from the care home manager, where the care home carries out the consultation.²⁷⁸

The LPS also allow authorisations to be 'varied', provided the responsible body is satisfied both that a fresh consultation has been carried out by the responsible body or care home manager, and 'that it is reasonable to make the variation'.²⁷⁹

An authorisation ceases to have effect if the responsible body 'believes or ought reasonably to suspect that any of the authorisation conditions are not met'.²⁸⁰ Responsible bodies must specify a program of reviews of the authorisation,²⁸¹ and must additionally review an authorisation if it is varied, 'if a reasonable request is made by a person with an interest in the arrangements', if the cared-for person becomes subject to a regime of the MHA or receives inpatient treatment for mental disorder, or where the reviewer becomes aware of objections by the cared-for person but the original pre-authorisation review was not by an AMCP.²⁸² The review may be carried out by the responsible body, or by the care home manager.²⁸³

²⁸¹ MCA Sched AA1 s27(1)(b) and s38(2).

²⁷³ *Winterwerp*, n 115, at [55].

²⁷⁴ Mental Capacity and Deprivation of Liberty - Consultation Analysis', n 186, [11.30].

²⁷⁵ MCA Sched AA1 s29.

²⁷⁶ MCA Sched AA1 s32.

²⁷⁷ MCA Sched AA1 s33 and s34.

²⁷⁸ MCA Sched AA1 s33 and s35.

²⁷⁹ MCA Sched AA1 s37.

²⁸⁰ MCA Sched AA1 s29(4).

²⁸² MCA Sched AA1 s38(3).

²⁸³ MCA Sched AA1 s38(1).

There is no statutory requirement for fresh medical or capacity assessments, or 'necessary and proportionate' determinations for renewals, variations or reviews. This is potentially a matter of serious concern given that authorisation may be renewed indefinitely and variations to an authorisation may potentially involve significant changes. The Law Commission²⁸⁴ and the government²⁸⁵ anticipated that most reviews would require a fresh necessary and proportionate determination, and this may be recommended in the Code. Guidance will be needed on the point beyond which it is not 'reasonable' to deal with changes without a fresh authorisation, with the full battery of assessments and determinations.

The LPS renewal process is roughly analogous to the approach taken under the MHA. However, the timescales for renewals under the MHA are much shorter (initially after six months and thereafter every 12 months), and MHA renewals require a report by the responsible clinician to the hospital managers.²⁸⁶ Under the LPS, statutory requirements for independence (of reviewers) and regulations concerning qualifications or experience do not apply to renewals or reviews unless AMCPs carry them out. In the MHA context, further protection is offered by other available safeguards, not least automatic periodic reviews by a tribunal; equivalent safeguards are far weaker under the LPS. The 'adjusted' LPS therefore provide for indefinite detention with very limited independent oversight.

E. Interim Authorisations and Emergencies

The MCA only protects against liability for deprivation of liberty where a standard or urgent²⁸⁷ DoLS authorisation is in place, or where court authorisation is being sought or has been granted.²⁸⁸ This creates potential gaps in protection against liability for care and treatment providers. Providers waiting longer than two weeks for a standard authorisation (as most currently will) are in theory exposed to liability, and the MCA does not provide for deprivation of liberty in emergency situations where it is not feasible to make a DoLS or court application.²⁸⁹

The LPS offer interim protection against liability whilst the responsible body is carrying out functions under the LPS 'with a view to determining' whether to authorise the arrangements, or a care home has taken 'reasonable steps' to notify the responsible body of any such arrangements.²⁹⁰ There is also emergency protection against liability for those undertaking 'vital acts' to prevent 'a serious deterioration in P's condition', provided there is a reasonable belief that the person lacks capacity and it would not be 'reasonably practicable' to make an application for the person to be detained under the LPS or Part 2 of the MHA.²⁹¹

²⁸⁴ Law Commission impact assessment, n 261, 31.

²⁸⁵ 'Impact Assessment: Mental Capacity (Amendment) Bill' (2018), n 123, at [12.19]; 'Impact Assessment: Mental Capacity (Amendment) Bill' (2019), n 5, [12.31] –[12.32].

²⁸⁶ MHA s20.

²⁸⁷ Under the DoLS, managing authorities can issue an 'urgent authorisation' for up to two weeks whilst awaiting a standard authorisation from the supervisory body, MCA Sch A1 Part 5.
²⁸⁸ MCA s4A (prior to 2019 amendments).

²⁸⁹ A. Ruck Keene and others, '*Deprivation of liberty in the hospital setting*' (39 Essex Chambers Guidance Note, 2018) at [45] – [50] at: https://www.39essex.com/mental-capacity-guidance-note-deprivation-liberty-hospital-setting/.

²⁹⁰ MCA s4B(7)(b).

²⁹¹ MCA s4B(2)-(6)(b).

The Law Commission recommended against imposing a time limit on interim authorisations lest responsible bodies aimed for a maximum time.²⁹² Opposition amendments to limit emergency provisions to 14 days were rejected by the government on the same grounds,²⁹³ but guidance will be provided in the Code.²⁹⁴ Of particular concern is the absence of any clear commitment to legal aid for challenges pending authorisation.²⁹⁵

F. Rights of Challenge

Article 5(4) rights to a court review of detention are a fundamental safeguard against arbitrary detention. Rights of challenge are especially important under article 5 when – as under DoLS, LPS and the MHA –detention is initiated without involving the courts.²⁹⁶ Under article 5(4) *everyone* who is deprived of their liberty is entitled 'to take proceedings by which the lawfulness of his detention shall be decided speedily by a court'. This must be 'accessible to the person', and 'practical and effective'.²⁹⁷ 'Special procedural safeguards' may be needed to 'protect the interests' of those who are 'not fully capable of acting for themselves'.²⁹⁸

States have a margin of appreciation over how this is realised.²⁹⁹ The mechanism employed by the MHA is an automatic periodic referral to a tribunal,³⁰⁰ to counteract for what Gostin called 'the burden of coming forward' in initiating an appeal.³⁰¹ The Law Commission considered this³⁰² but it would have had tremendous resource implications because of the scale of detention under LPS.³⁰³

Alternatively, states might 'empower or even require' someone to act on the person's behalf.³⁰⁴ Both DoLS and the LPS adopt this approach through complex provisions for representation and advocacy. However, this approach raises the risk that representatives may decline to act on the person's behalf if they view the detention as in the person's best interests or regard a challenge as futile. The ECtHR has held that rights of appeal must not

²⁹² Law Com No 372 (n 71), Recommendation 15.33.

²⁹³ Hansard, HC Public Bill Committee (6th Sitting) col 173-78, n 100 and see Division 22.

²⁹⁴ Hansard, HL Series 5 (Committee Stage 1st Sitting) col 1848, no 184.

²⁹⁵ V. Butler-Cole and A. Boukraa, *'LPS-challenges and criticisms'* (39 Essex Chambers, 2019) https://1f2ca7mxjow42e65q49871m1-wpengine.netdna-ssl.com/wp-content/uploads/2019/04/Liberty-Protection-Safeguards-the-new-law-Criticisms.pdf.

²⁹⁶ D.D. v Lithuania, n 15, at [164]; Kędzior v Poland, n 60, at [76]; Mihailovs v Latvia, n 60, [155].

²⁹⁷ *MH v UK* (2014) 58 E.H.R.R. 35; [2014] M.H.L.R. 249; BAILII 2013 ECHR, at [75].

²⁹⁸ This principle was first established in *Winterwerp*, n 115, at [60], and is reiterated in most subsequent cases concerning rights of appeal against mental health detention.

²⁹⁹ *MH v UK*, n 297, at [75].

³⁰⁰ MHA s68.

³⁰¹ L. Gostin, *A Human Condition* (A MIND Special Report, 1975).

³⁰² Law Com CP 222, n53, Question 11-5

³⁰³ Law Commission, Impact Assessment: Mental Capacity and Detention (LAWCOM0044, 2015), see assumptions on page 30.

³⁰⁴ *MH v UK*, n 297.

depend on the goodwill or discretion of third parties³⁰⁵; there must be a clear *duty* to assist.³⁰⁶

A refusal to assist in bringing an appeal cannot be justified by prospects of success³⁰⁷ In *AJ v A Local Authority* ³⁰⁸ the Court of Protection held that 'there is no place in Article 5(4) for a best interests decision about the exercise of that right since that would potentially prevent the involvement of the court'.³⁰⁹ If a detained person is unable to enlist assistance to appeal, then article 5(4) may be violated.³¹⁰ This approach mirrors the *Neary* dictum that a person is 'not only entitled but must be *enabled'* to appeal.³¹¹

G. Representation and Advocacy

Under both the DoLS and the LPS the primary responsibility for 'enabling' rights of challenge fall on informal representatives – RPRs under the DoLS and 'appropriate persons' under the LPS. These will generally be friends or relatives of the person. Difficulties arise if they are unwilling, unable or unclear about obligations to enable rights of challenge. Friends and relatives may also find the court appeal process daunting or bewildering – an octogenarian RPR described it as 'complex and harrowing'.³¹² Others, like Steven Neary's father, may be scared of rocking the boat when reliant on the responsible body to provide care or treatment. In *AJ* the Court of Protection held that RPRs must be both willing and able to assist the person in exercising rights of challenge.³¹³ Close relatives or friends who supported or helped set up the arrangements may therefore be inappropriate because of their clear conflict of interest in challenging them.³¹⁴ This is likely to be a particular concern for privately arranged care for many older people. Responsible bodies are obliged to monitor the RPR and terminate their appointment if they fail to fulfil this representation role.³¹⁵

The provisions for representation and advocacy under both the DoLS and LPS are extremely complex and are depicted in Fig 2 (for DoLS) and Fig 3 (for LPS). There are some important differences between the two schemes. The DoLS require that a person is represented by an RPR or an IMCA, or both, in all circumstances. The same cannot be said for the LPS: as Fig 3 shows, there are various circumstances where a detained person may have nobody representing them. The DoLS also guarantees to the detained person a freestanding unconditional right to request an IMCA, however under the LPS if the responsible body is satisfied there is an 'appropriate person' to represent the cared-for person, their right to

³⁰⁵ *Stanev v Bulgaria*, n 15, at [174]; *Lashin v Russia* (App 33117/02); [2014] M.H.L.R. 109; BAILII [2012] ECHR 63, at [121]; *DD v Lithuania*, n 15, at [166]; *Shtukaturov v Russia* (2012) 54 E.H.R.R. 27; [2008] M.H.L.R. 238; BAILII [2008] ECHR 223, at [124]; *Sýkora v The Czech Republic* (App 23419/07); [2013] M.H.L.R. 283; BAILII [2012] ECHR 1960, at [179]; *MH v UK*, n 297, at [92], [94].

³⁰⁶ *MH v UK,* n297, at [94]

³⁰⁷ *Winterwerp*, n 115, at [64]. See also: *Waite v UK* (2003) 36 E.H.R.R. 54; [2003] Prison L.R. 160; BAILII [2002] ECHR 804.

³⁰⁸ AJ v A Local Authority [2015] Fam. 291; [2015] EWCOP 5.

³⁰⁹ Ibid, at [88].

³¹⁰ Storck v Germany (2005) 43 EHRR 96, at [118]; [2005] M.H.L.R. 211. MH v UK, n 297, at [95].

³¹¹ Neary, n39, at [202].

³¹² 'Mental Capacity Act 2005: post-legislative scrutiny', n 36, at [287].

³¹³ *AJ*, n 308, at [80] – [86], [89].

³¹⁴ Ibid, at [137].

³¹⁵ Ibid, at [139].

request an IMCA in effect transfers to the appropriate person. Under the DoLS, the provisions for appointing an IMCA are based on situations where otherwise the person would be unrepresented³¹⁶, or where an (unpaid) RPR and the detained person are likely to, or already have, failed to exercise rights of challenge when it would be 'reasonable' to do so.³¹⁷ This means that under the DoLS if there is an indication that the person might wish to exercise rights of appeal and the RPR is not assisting them, the supervisory body must appoint an IMCA to assist them. However, under the LPS, duties to appoint an IMCA are based on capacity and best interests determinations, ³¹⁸ creating a clear risk of concluding that it is not in a person's 'best interests' to be provided with advocacy support to exercise rights of challenge.

Under the DoLS, supervisory bodies 'must appoint' an IMCA where the relevant duties are engaged,³¹⁹ but under the LPS responsible bodies must only take 'reasonable steps' to do so. There are therefore numerous situations under the LPS where best interests decisions, a failure to appoint an IMCA, or a failure to ensure representatives are both willing and able to challenge the detention potentially stand between a person being *entitled* to appeal and their being *enabled* to do so.

The risk that a person will be unable to exercise rights of challenge under article 5(4) is, if anything, further increased under the LPS in comparison with the existing problems under the DoLS.

 $^{^{\}rm 316}$ MCA s39A and MCA s39C.

³¹⁷ MCA s39D.

³¹⁸ This is modelled on similar provisions under the Care Act 2014, which may be appropriate for enabling involvement in care planning but which are not necessarily apt for securing rights of challenge. ³¹⁹ MCA s39A-s39D.

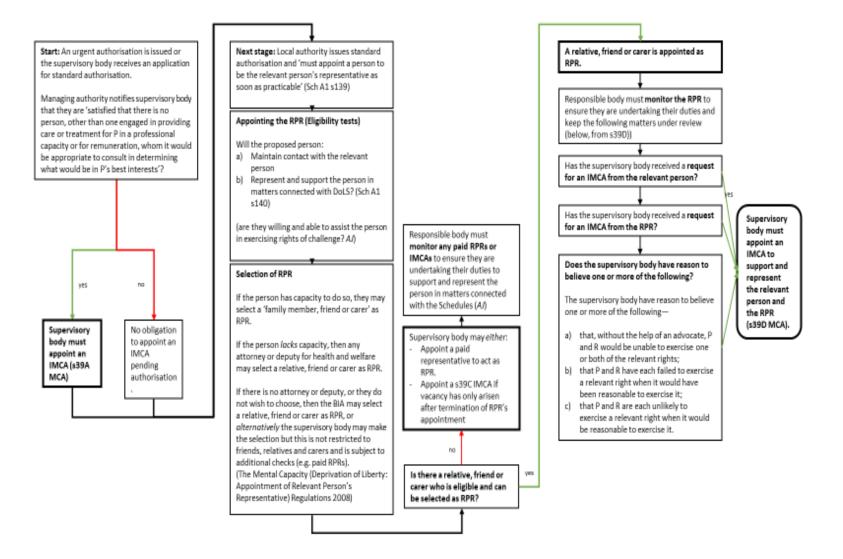


Figure 2 Schematic depiction of provision for advocacy and representation under the DoLS

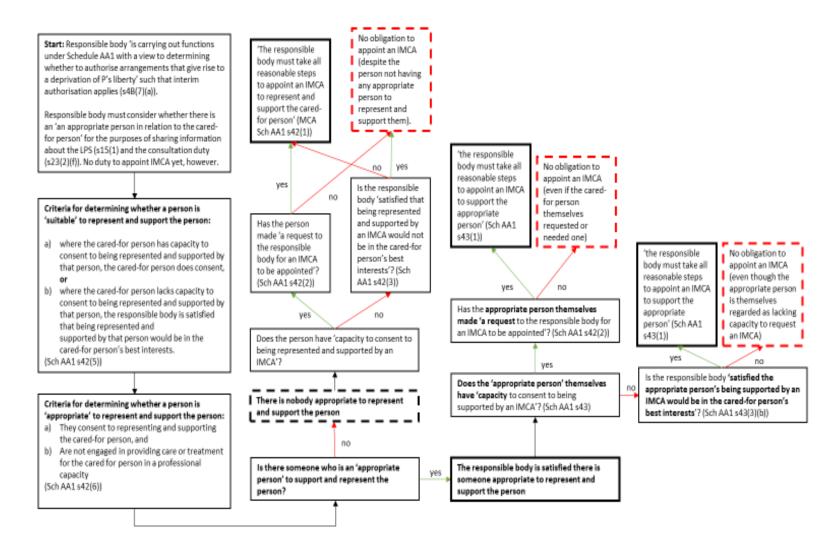


Figure 3 Schematic depiction of provisions for advocacy and representation under the LPS

Given the sheer complexity and gaps in both schemes it may be preferable to place the primary duty to enable rights of challenge on responsible bodies, instead of their serving as a 'fallback' where representatives have failed to do so. However, this was not considered by the Law Commission, and although a provision to this effect was inserted into the Bill in the Lords³²⁰ it was removed by a later government amendment. The government's approach was that detained persons and their relatives were of course 'entitled' to appeal but that recourse to courts should be avoided.³²¹ The question of whether a detained person would be *enabled* to appeal when they wished to do so was not addressed. The Law Commission had envisioned an automatic opt-out advocacy scheme, meaning the majority of people would receive expert assistance and advice on rights of challenge.³²² However, the government was concerned about the 'imposition' of advocacy and felt 'support from family and friends may be more appropriate and beneficial'.³²³ Thus the 2019 amendments reverted to more limited scheme of independent advocacy, prioritising the putative preferences of families over enabling rights of challenge.

H. Rights to Information

Rights of challenge can only operate effectively if people are informed of their rights.³²⁴ Thus Article 5(2) contains a duty to inform a person promptly and 'in a language which he understands' of the reasons why they have been deprived of their liberty.³²⁵ Detaining authorities must take 'reasonable steps' to impart this information³²⁶ – and where the person would not be able to understand it should be communicated to others able to represent their interests.³²⁷

The DoLS require the managing authority of the care home or hospital to inform the detained person about the authorisation and their rights,³²⁸ whilst the supervisory body must give copies of the authorisation documentation to those representing the detained person, and 'every interested person consulted by the best interests assessor.'³²⁹ The Law Commission did not discuss rights to information in their consultation and they did not appear initially in the 2018 Bill. This was raised as a concern by stakeholders and peers in the Lords. Bizarrely, the Minister at one point suggested that people could make subject access requests for this information under the GDPR,³³⁰ implying a fundamental lack of understanding of the nature of this safeguard.

³²⁸ MCA Sched A1 s 59.

³²⁰ This formed part of the 'rights to information' amendment inserted into the Lords. The relevant clause (s13(5) of the Bill as brought forward from the Lords) read 'The responsible body must ensure that cases are referred to court when the cared-for person's right to a court review is engaged.'

³²¹ Hansard, HL Series 5 col 371, n 196.

³²² Law Com No 372 (n 71) [12.40].

³²³ 'Mental Capacity and Deprivation of Liberty - Consultation Analysis', n186, [8.7].

 ³²⁴ Van Der Leer v The Netherlands [1990] 12 E.H.R.R. 567, at [27]; X v United Kingdom (1982) 4 E.H.R.R.
 188; LM v Slovenia (App 32863/05); [2019] M.H.L.R. 67; BAILII [2014] ECHR 608, at [1452].
 ³²⁵ Ibid.

³²⁶ *ZH v Hungary* (App 28973/11); [2014] M.H.L.R. 1; BAILII [2012] ECHR 1891, at [41].

³²⁷ Ibid; LM v Slovenia n 324; X v UK (App no 6998/75) [1980] ECHR Report of the Commission (Adopted on

¹⁶ July 1980), see also related proceedings before ECtHR (1982) 4 E.H.R.R. 188

³²⁹ MCA Sched A1 s57.

³³⁰ Hansard, HL Series 5 col 337 no 196 (The Lord O'Shaughnessy).

The Lords inserted an amendment containing rights to information into the Bill³³¹, which was accepted in principle but redrafted by the government in the Commons. The LPS now contain a three-stage information duty. Responsible bodies must publish general information about the authorisation process and people's rights under the LPS scheme, in formats that are 'accessible to, and appropriate to the needs of, cared-for persons and appropriate persons'.³³² Once arrangements 'are proposed', the responsible body 'must as soon as practicable take such steps as are practicable to ensure that' the cared-for person and any appropriate person understands the nature of the arrangements, the effect of authorisation, and core rights including reviews and challenge.³³³ After authorisation, copies of the authorisation record must be given to the cared-for person and any IMCA or appropriate person representing them.³³⁴

In some respects, the LPS adopt a more sophisticated approach to rights to information than the DoLS, with potential for higher quality *accessible* general information than exists presently. However, unlike the DoLS, a person who is consulted during the LPS process is not entitled to a copy of the authorisation record unless they are the 'appropriate person'. This means friends and family may struggle to access the authorisation record if not considered 'appropriate' to represent the person.

I. Court or Tribunal

Under the DoLS, an 'appeal' against detention is made through an application to the Court of Protection to review a DoLS authorisation under s21A MCA. As outlined above, there are significant concerns that this process is not being initiated when it should be – with the appeal rate currently standing at around 1 per cent. The government anticipates the rate of appeal will fall to 0.5 per cent of authorisations under the LPS, on the questionable basis that AMCPs will act as mediators in disputes.³³⁵

This fractional difference in estimated rates of appeal may seem trifling but holds the key to understanding the fundamental weakness in the scheme: the cost of challenges in the Court of Protection. In 2015 the median cost to a supervisory body of a s21A appeal was around £10,000, but could exceed £100,000 in complex cases, whilst the median cost of a legal aid certificate for either P or the RPR was £7,288 and the mean was £14,665.³³⁶ The sheer scale of the LPS, coupled with the very high cost of appeals, meant that depressing the estimated rate of appeal a mere 0.5 per cent shaved over £35m off the estimated cost of the entire scheme,³³⁷ a substantial proportion of the claimed £200m savings. Increasing rates of appeal beyond the already concerningly low rates under the DoLS would have wiped out any savings for the entire LPS scheme.

³³¹ This is contained in Sched AA1 s13 in the version of the Bill dated 12 December 2018 (Bill 303).

³³² MCA Sched AA1 s14.

³³³ MCA Sched AA1 s15.

³³⁴ MCA Sched AA1 s16.

³³⁵ 'Impact Assessment: Mental Capacity (Amendment) Bill' (2018) (n 123), at [12.32].

³³⁶ L Series, P Fennell and J Doughty, n25.

³³⁷ The estimated costs for 0.5 per cent of LPS authorisations resulting in an appeal was £12.77m in legal aid costs, costs of £18.25 to responsible bodies and costs of £4.56m to the Official Solicitor. 'Impact Assessment: Mental Capacity (Amendment) Bill' (2018), n 123, at [12.32] – [12.37].

The complex reasons for the high costs of Court of Protection litigation are beyond the scope of this paper but appear to have exerted a chilling effect on improving rights of challenge under the LPS. The solution, of course, is to reform the Court of Protection itself – addressing other associated concerns including delay, accessibility and participation in the proceedings.³³⁸ Throughout the history of the MCA and the DoLS, the idea of a tribunal to adjudicate disputes has been debated, and well supported at consultation by those favouring an informal, accessible and efficient form of dispute resolution.³³⁹

The Law Commission initially favoured a tribunal under the LPS,³⁴⁰ as did the majority of consultees, but this was opposed by Court of Protection stakeholders.³⁴¹ However, in their final report the Commission noted difficulties separating out LPS appeals from wider health and welfare matters which remained within the jurisdiction of the Court of Protection. This concern tacitly acknowledges the difficulties outlined above in separating out the 'arrangements' authorised under the LPS from the underlying care and treatment decisions made under the MCA. Devolution of the mental health tribunals in Wales also presented difficulties. The Commission called for a further review of the appropriate judicial body for LPS appeals.³⁴² The JCHR also recommended the government consider a tribunal or reform of the Court of Protection.³⁴³ However, the promised review is still awaited³⁴⁴ and so the forum for appeal under the LPS remains the unreformed Court of Protection under a new provision – s21ZA.

J. Reviewing the 'Arrangements'

The troubled distinction between underlying care and treatment decisions made under the MCA, and the 'arrangements' to enable these, surfaces again in relation to court reviews. Challenges to decisions made under the main provisions of the MCA are rare,³⁴⁵ in part because of restrictions on financial eligibility for legal aid. Following *Cheshire West*, a number of challenges were brought under s21A. Many related to ancillary matters such as a person's capacity to make decisions around sex or contact,³⁴⁶ and even serious medical treatment decisions such as the withdrawal of artificial nutrition and hydration from people with severe brain injuries.³⁴⁷ In *Director of Legal Aid Casework & Ors v Briggs*³⁴⁸ the Court of Appeal ruled that this was an illegitimate use of legal aid for s21A challenges, but held that matters like 'contact' still fell within the ambit of DoLS appeals. It seems quite possible

³³⁹ E.g. Law Commission, Mentally Incapacitated Adults (Law Com No 231, 1995) at [10.3] – [10.8]; 'Protecting the Vulnerable: the "Bournewood" Consultation: Summary of Responses', n 31, at [31]-[36].

³³⁸ L Series, P Fennell and J Doughty, n 25.

³⁴⁰ Law Com CP 222, n 53, Provisional proposals 11-1 – 11-4.

³⁴¹ 'Mental Capacity and Deprivation of Liberty - Consultation Analysis', n 186, Chapter 10.

³⁴² Law Com No 372 (n 71) Recommendation 34.

³⁴³ Joint Committee on Human Rights, The Right to Freedom and Safety, n65, at [64-5]

³⁴⁴ Department of Health and Social Care, 'The Government's Response to The Joint Committee on Human Rights 7th and 12th Reports (2019)', at [1.17], at: https://www.parliament.uk/documents/joint-committees/human-rights/Govt-response-7-12-JCHR.pdf.

³⁴⁵ L. Series, P. Fennell and J. Doughty, n 25; L. Series, P. Fennell and J. Doughty, 'The Participation of P in Welfare Cases in the Court of Protection' (Report for the Nuffield Foundation, Cardiff University, 2017) at: http://orca.cf.ac.uk/98448/.

³⁴⁶ L. Series, P. Fennell and J. Doughty, n 25.

³⁴⁷ J. Cowley, '*How the DoLS can give voice to people with minimal consciousness'* (Community Care 27 January 2017) at: <u>http://www.communitycare.co.uk/2017/01/27/dols-can-give-voice-people-minimal-consciousness/</u>.

³⁴⁸ Director of Legal Aid Casework & Ors v Briggs [2017] EWCA Civ 1169; [2018] Fam. 63.

the Legal Aid Agency may make further attempts to restrict the nature of challenges that can be brought under s21ZA, relying upon the 'bright line' distinction between care and treatment decisions and the arrangements emphasised in connection with the LPS.

K. The Definition of Deprivation of Liberty

Although it was hoped that *Cheshire West* would definitively answer the question 'what *is* a deprivation of liberty?', there continued to be pressure for a statutory definition. Some respondents to the Law Commission's consultation hoped to reverse *Cheshire West*.³⁴⁹ The Law Commission, whilst sympathetic, concluded this was 'misguided' since it could create gaps between the LPS scheme and the interpretation of article 5 by the courts under the Human Rights Act 1998 (HRA).³⁵⁰

The JCHR was also troubled by the consequences of *Cheshire West*, and particularly concerned by the application of the 'acid test' in domestic settings. Echoing its earlier call for a statutory definition the JCHR considered two possibilities.³⁵¹ They concluded that a 'causative' approach based *R (Ferreira) v HM Senior Coroner for Inner South London,³⁵²* which holds that if the person's 'underlying condition was the cause' of their not being free to leave this does not engage article 5, could give rise to difficulties in interpretation and be viewed as discriminatory.³⁵³ The second approach, which found more favour, tackled an element of deprivation of liberty not considered by the Supreme Court in *Cheshire West*: whether a person has given a 'valid consent' to their confinement. ³⁵⁴ Basing its recommendation on a submission from Alex Ruck Keene³⁵⁵ (who worked at the Law Commission on the LPS proposals) the Committee proposed a broader approach to 'valid consent' than the MCA's binary test of mental capacity.³⁵⁶ This, they suggested, was supported by the CRPD Committee's rejection of the binaries of 'mental incapacity'.³⁵⁷

A draft amendment specified that for the purposes of determining whether a person is deprived of their liberty under the LPS, the cared-for person should be considered to have given a 'valid consent' if they are 'capable of expressing their wishes and feelings (verbally or otherwise)', they had expressed 'their persistent contentment' with the arrangements, there was 'no coercion involved' in their implementation, and this was confirmed in writing by two professionals (one independent of the person's care).³⁵⁸ This CRPD-influenced proposal could have resolved some of the more jarring outcomes of *Cheshire West*, such

committee/the-right-to-freedom-and-safety-reform-of-the-deprivation-of-liberty-

safequards/written/80869.html.

³⁴⁹ Law Com No 372, n 71, [5.36-7]

³⁵⁰ Ibid, [5.37].

³⁵¹ JCHR, The Right to Freedom and Safety: Reform of the Deprivation of Liberty Safeguards, n 65, Chapter 5.

³⁵² [2017] EWCA Civ 31; [2018] Q.B. 487; [2017] Inquest L.R. 118; [2017] M.H.L.R. 258.

³⁵³ Twelfth Report of Session 2017–19, 'Legislative Scrutiny: Mental Capacity (Amendment) Bill' (HC 1662 HL 208) at [24].

³⁵⁴ See *Storck v Germany*, n 310, at [74].

³⁵⁵ Written evidence from A. Ruck Keene (DOL0120) submitted to the JCHR's inquiry into 'The Right to Freedom and Safety' (n 65), at: http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/human-rights-

³⁵⁶ JCHR, n 65, at [43-4]

³⁵⁷ Committee on the Rights of Persons with Disabilities, *General comment No. 1 (2014) Article 12: Equal recognition before the law* (UN Doc CRPD/C/GC/1).

³⁵⁸ JCHR, n 353, 12-13.

as the conclusion that Steven Neary is deprived of his liberty in his own home, where he actively wishes to live, whilst still providing procedural safeguards.³⁵⁹ It was tabled by Lord Woolf,³⁶⁰ but rejected by the government on the basis that it conflicted with the position under the ECHR and would create a 'gap' in protection under the LPS scheme.³⁶¹

Initially the Government accepted the Law Commission's recommendation against a statutory definition of deprivation of liberty.³⁶² However, under pressure from stakeholders and the JCHR the government published its own statutory definition of deprivation of liberty only days before the Public Bill Committee in the House of Commons.³⁶³ That definition was resoundingly criticised by stakeholders.³⁶⁴ It would have excluded arrangements where a person's ability to come and go from the place of their confinement was only temporary and potentially subject to permission seeking requirements, in direct contradiction of ECHR case law.³⁶⁵ It created latitude to escape scrutiny under the LPS by asserting that 'if the person expressed a wish to leave the person would be enabled to do so' – an approach that was rejected by the courts in both *Bournewood* and *Cheshire West*.³⁶⁶ The government's statutory definition was rejected by the House of Commons.

The final position agreed by both houses is that the 2019 amendments do not define deprivation of liberty, however guidance on those arrangements falling within scope of the LPS must be given in the Code of Practice, which must be reviewed within three years of coming into force and every five years thereafter.³⁶⁸ This approach, whilst no doubt unsatisfactory to those hoping to reverse *Cheshire West*, at least has the merit of not creating a constitutional nightmare for any court faced with conflicting interpretations of deprivation of liberty from the ECtHR, the Supreme Court and Parliament. The Code has more space for detail and nuance, and can be revised as case law develops. Nor does this approach preclude a legal challenge on what constitutes a 'valid consent' under the LPS, in the manner advocated for by the JCHR.

³⁵⁹ L Series (n 73).

³⁶⁰ Hansard, HL Series 5 col 250, n 197.

³⁶¹ Ibid, col 252 (The Lord O'Shaughnessy).

³⁶² 'Final Government Response to the Law Commission's review of Deprivation of Liberty Safeguards and Mental Capacity', n87, Response to recommendation 2. However, see also 'Annex A: Law Commission recommendations and Government Responses', n 87.

³⁶³ This can be found in the amendment paper dated 13 February 2019 on the Bill's parliamentary webpage: <u>https://services.parliament.uk/Bills/2017-19/mentalcapacityamendment/documents.html</u>.

³⁶⁴ See submissions to the Public Bill Committee from, e.g. Court of Protection Practitioners' Association, Doughty Street Chambers, Independent Age, Irwin Mitchell, Jess Flanagan (solicitor), Lucy Bright BIA), Lucy Series, Royal College of Psychiatrists, Roger Laidlaw (DoLS lead). The Royal College of Nursing, however, did support the government's proposed definition. At: <u>https://services.parliament.uk/Bills/2017-19/mentalcapacityamendment/committees/houseofcommonspublicbillcommitteeonthementalcapacityamend mentbillhl201719.html.</u>

³⁶⁵ *Stanev v Bulgaria*, n15.

³⁶⁶ *HL v UK*, n27, at [46], [86], [91]; *Surrey County Council v MEG & MIG v Anor* [2010] EWHC 785 (Fam), at [233]; M.H.L.R. 108 [2011].

³⁶⁷ Available in the amendments dated 3 April 2019 on the Bill's website (HL Bill 171).

³⁶⁸ MCA s42, as amended by MCAA s4.

VI. CONCLUSION

The Government's aim in the 2019 amendments to the MCA was to 'reform a broken and bureaucratic DoLS system', ³⁶⁹ provide 'proportionate' safeguards, increase flexibility, reduce complexity, and save £200m. The final Act is a different beast from the heavily criticised Bill introduced in July 2018, but it also differs from the Law Commission's proposals, which rested on improvements to the operation of the MCA, and much wider access to independent advocacy. Have the 2019 amendments achieved the government's aims, or should we agree with Baroness Murphy's assessment that Parliament has failed in its task?³⁷⁰

For those hoping to reverse *Cheshire West*, or concerned that the LPS will now pursue people 'in their own homes'³⁷¹, the 2019 amendments will disappoint. The LPS will provide safeguards that are currently entirely absent for people in settings such as supported living, and potentially improve access to justice through expanding the number of people eligible for legal aid via s21ZA challenges. Yet people in care homes and hospitals will lose layers of protection that the DoLS deliver in theory (although often not in reality). The scheme is highly vulnerable to human rights challenges, particularly around its provisions for representation, renewals and appeals, unless creatively patched up by the Code and the courts, as the DoLS themselves were.

The LPS attempt to secure article 5 compliance on an unprecedented scale by giving responsible bodies considerable discretion in how they deliver the safeguards. This flexibility introduces both complexity and risk. Some responsible bodies will no doubt use the LPS as they have the DoLS – to scrutinise and address restrictive practices and resolve disputes. Others will be less vigilant, and the next generation of *Neary* type litigation will consider how responsible bodies exercise their considerable discretion over assessments, determinations, renewals, reviews and fundamental safeguards including representation, advocacy and appeals. The risk remains that some people who are deprived of their liberty will not receive any safeguards at all. Even following *Cheshire West* there is considerable variability in the age standardised rates of DoLS applications across supervisory bodies, raising the possibility that some supervisory bodies are more proactive than others in securing article 5 safeguards.³⁷²

The LPS foreground the wishes and feelings of the person in a way that the DoLS often failed to do. 'Objections' is the weight bearing concept for the crucial safeguard of AMCP review. Courts and practitioners will have to grapple with the complexities of working out what a person wants, and what it means to 'object', when one's methods of communication are (at least to others) unclear or disputed, or even suppressed by one's circumstances. This is not the 'will and preferences' paradigm exhorted in connection with the CRPD, but it is a step in that direction.

At the heart of the DoLS and the LPS lurks an anxiety, about the kinds of power that are exercised within caregiving relationships, particularly where the care recipient is unlikely to

³⁶⁹ Hansard, HL Series 5 col 612, n 1 (The Baroness Blackwood of North Oxford).

³⁷⁰ Ibid, col 616.

³⁷¹ Ibid.

³⁷² NHS Digital (2019); (n 11).

be able to alert others to problems. It is doubtful that article 5 is the best mechanism for addressing this in some of the circumstances where the LPS will now apply.³⁷³ But there were few other available vehicles for securing independent scrutiny and challenge under the MCA, and no sign of a government seeking to remedy this. *Bournewood* and *Cheshire West* held a gun to the government's head,³⁷⁴ and the LPS was the reply.

We are left with our unanswered question: what are these safeguards *for*? Are they, as Baroness Murphy suggests, addressing 'a problem we did not know we had', instigated by the judiciary³⁷⁵? The circular answer of article 5 compliance does not help us. We might ask what article 5 is protecting Steven Neary from today, living happily in his own home? Telling thousands of families that they are detaining their relatives feels like political dynamite at a time when human rights are increasingly vulnerable.³⁷⁶ Yet there are very real concerns about coercion and restrictive practices in a broad range of care settings, with limited alternative scrutiny, and few realistic avenues for disabled people and families to challenge decisions made under the MCA. Whether the LPS will assist in addressing the substantive issues, or merely draw a veil of legitimacy over the 'arrangements', remains to be seen.

POSTSCRIPT

This article was written in 2019, when we inhabited another world, before the coronavirus pandemic of 2020 and the UK lockdown. Although the UK government has introduced 'easements' to the MHA in response to the coronavirus Act, it has not done so for the MCA or the DoLS. Expectations that people in care homes will be 'isolated' in their rooms, and the imposition of 'lockdown' measures raise specific issues for the MCA and the DoLS that have not as yet been addressed.³⁷⁷ The likelihood is that many more people are now effectively deprived of their liberty in care homes and other care settings – often unlawfully – in response to the pandemic. It is also likely that work on the new Codes of Practice and regulations, and implementation of the LPS, will be significantly delayed by this crisis.

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³⁷³ L Series (n 73).

³⁷⁴ An observation of solicitor Richard Jones, a seasoned critic of the DoLS, in response to: A. Ruck Keene, 'Cheshire West: The Supreme Court's Right Hook' (Mental Capacity Law and Policy 19 March 2014) <u>http://www.mentalcapacitylawandpolicy.org.uk/cheshire-west-the-supreme-courts-right-</u>

hook/#comment-13

³⁷⁵ Hansard, HL Series 5 col 1097 n 89.

 ³⁷⁶ E.g. J. Sumption, 'Lecture 3: Human rights and wrongs' (The Reith Lectures, BBC Radio 4, 4 June 2019).
 ³⁷⁷ Alex Ruck Keene, 'Capacity in the time of Coronavirus', (2020) International Journal of Law and Psychiatry, DOI: 101560.

EMPOWERING YOUNG PEOPLE: MULTI-DISCIPLINARY EXPRESSIVE INTERVENTIONS UTILISING DIAMOND9 EVALUATIVE METHODS TO ENCOURAGE AGENCY IN YOUTH JUSTICE

"Listening to the honest, unfiltered voices of children and young people in the secure estate is of great importance." (User Voice 2018, 4)

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ABSTRACT

The article adopts a mixed method approach to evaluating sports and arts-based interventions within Secure Children's Homes in England and Wales; an underresearched area of the criminal justice system. The research adopts the innovative Diamond9 model and semi-structured interviews to evaluate the study. This is the first time the model has been adopted within a Secure Children's Home. The results provide an original insight into the voice of this currently underrepresented demographic of the Secure Estate, and highlight future approaches to evaluating rehabilitative models for this hard to reach group.

Keywords: Dance interventions; Diamond9; Secure Children's Homes; Sports interventions; Young People.

I. INTRODUCTION

Recent research on arts and sports in the (adult) criminal justice system suggest arts and sports projects can have a positive impact on offenders. Arts programmes have been shown to help increase offender's self-esteem, communication skills and selfworth (Allen et al. 2004, Miles & Clarke 2006, Parker et al. 2014, Wilson et al. 2009, Wilson & Caulfield 2009). Arts- and sports-based programmes have commonly been employed to improve prisoners' overall learning capacity and motivation, enhance self-efficacy, help offenders explore and develop prosocial identities and positive relationships with others and act as a 'catalyst' for positive psychological and attitudinal changes and therefore contribute, directly and indirectly, to desistance from further offending.

The research presented herein utilises a mixed method approach to evaluating sports and arts-based interventions within a Secure Children's Homes (SCHs) in England and Wales, adopting the Diamond9 model and semi-structured interviews, considered further below. This is the first time the model has been adopted within a Secure Children's Home; an under-researched area of the criminal justice system. Accordingly, the results provide an original insight into the voice of this currently underrepresented demographic of the Secure Estate. The Secure Estate

incorporates: SCHs, Secure Training Centres (STC), and Young Offender Institutions (YOI).

Secure Children's Homes are locked institutions for young people aged between 10 and 17. SCHs accommodate some of society's most complex and vulnerable young people, yet they have evaded sustained academic attention. These young people can be categorised into 2 groups: - (i) young people placed by the Youth Justice Board as a consequence of conviction for offending; and, (ii) young people in the care of a local authority accommodated under section 25 of the Children Act 1989 as part of the local authority's general duty to safeguard and promote the welfare of the child. Andow and Byrne (2018, 46) highlight that "children entering a secure environment on welfare and justice legislative orders are broadly similar in terms of their sociodemographic characteristics and background experiences...[but] the same clear overlaps are not seen with children detained on mental health grounds." Differences exist in terms of familial demographic and childhood experiences (Andow and Byrne, 2018, p.50). Research suggests that that 60% of children in the criminal justice system have significant speech, language or communication difficulties, 30% have a learning disability, 10% suffer from anxiety disorders and 5% have symptoms of psychosis (Bryan et al. 2007, Hughes et al. 2012). The association between speech and language disorders and behaviour difficulties is well established (Humber and Snow 2001; Tomblin et al. 2000). Communication problems tend to be labelled as behaviour problems and difficulties in understanding make young people very vulnerable in relation to education (Hooper at al. 2003). In comparison to the general and adult population, young offenders exhibit much higher rates of: learning disability (post-traumatic stress disorder; attention deficit hyperactivity disorder (ADHD); and other psychiatric disorders, notably conduct disorder (Royal College of Psychiatrists 2006).

The article and the project provide data which bridges an extant gap across research conducted in adult prisons, and youth offender institutions. Such data collection engages a unique set of challenges arising out of the composition of Secure Units.

The aim of this ongoing project is to examine whether dance and sports-based programmes enable young people to develop a pro-social identity, as well as contribute to building positive social networks. Arthur's (2005, 2007, 2017) research indicates that children involved in crime, particularly where that involvement is persistent, have often had difficult, deprived backgrounds and serious multiple problems in terms of their school achievement, psychological health and drug abuse. Every study of the personal and social experiences of young people in custody reveals that they have almost universally endured various kinds of abuse, neglect, deprivation and misfortune (Arthur 2016). Children in custody are far more likely than the general population to have been in local authority care, to have suffered family breakdown or loss, to be homeless or insecurely housed and to have experienced child abuse. These children are the most disadvantaged, have the poorest educational experiences and are more likely to suffer from poor health, including mental health and substance misuse (Arthur 2010). Between 65-78 per cent of young people in the secure estate have had a period of non-attendance at school (Gyateng et al. 2013, 39); over 53 per cent of young people in custody meet the threshold for conduct disorder (Fazel et al. 2008) and 60 per cent have speech and communication difficulties which significantly impacts on the ability of these children to engage with mainstream educational approaches (Royal College of Speech & Language Therapists 2009, 8). Surveys indicate that 18 per cent suffer from depression and 10 per cent have anxiety disorders (Fazel et al. 2008).

II. YOUNG PEOPLE AND THE PRO-SOCIAL IDENTITY

Desistance theorists have identified the importance for offenders of a 'hook for change', something that will engage them and enable them to develop a pro-social identity, as well as contribute to building positive social networks. Two master themes for success were identified from the literature (Millward and Senker 2012): dissociating from an offender identity and authoring a new non-offender identity. Children and young people who offend "need to develop a coherent, pro-social identity for themselves" (Maruna 2001, p.6) if positive outcomes are to be achieved. Young people's identities are "fluid and changeable" (CLINKS 2013, p.3-4); this fluidity creates opportunities to develop interventions focused on facilitating healing, growth, and identity transformation. These opportunities ought to operate as a catalyst for change in the lives of children in conflict with the law. Effective intervention programmes should ultimately result in "the young person shifting their identity away from one that is conducive to offending to one that promotes a crimefree life, social inclusion and wellbeing" (Beyond Youth Custody 2017, p.24). Interventions should, therefore, impact upon a young person's emotional and psychological well-being (Wilson and Caulfield 2009), on their anger and aggression (Blacker et al. 2008), on their engagement with further education and training (Wilson and Caulfield 2009) and on reducing the risk of reoffending (Cox and Gelsthorpe, 2008).

Research suggests a medium for change is not necessarily tools or programmes but rather the existence of a trusting, empathic and consistent relationship between children and professionals (Creaney 2018, France and Homel 2006). As Lord notes, children and young people are most likely to "express emotions in empathic therapeutic relationships, [and] when they have positive perceptions of [their workers]" (Lord 2016, p.116). Such constructive relationships between youth justice professionals and young people, where both parties are equal, can help to facilitate positive outcomes (Drake et al. 2014). If positive relationships have been established, children can "engender a sense of personal loyalty and accountability" (CLINKS 2013, 5).

Collaborative child/practitioner partnerships, premised on "empathy, warmth and genuineness..." (Hudson and Sheldon 2000, 65) can help to build relationality, and allow trust to develop (Hughes et al. 2014, 6). In addition, custody-based cognitive skills programmes for young offenders can lead to a reduction in future reconviction (Cann et al 2005). In particular, leisure-time activities can be used as part of strategies within both custodial and community settings to inspire positive change in marginalised young people and alleviate offending or anti-social behaviour (Lewis and Meek 2012a, Morgan and Parker 2017).

The North East of England is an important site for this research, given the proportionately high numbers of children in care compared with the rest of the UK (80-92 children in care in the North East per 10,000 children under 18, compared with national rates of between 60 - 62 per 10,000 children). 30% of children in Newcastle live in poverty compared to an English average of 20.1% (Newcastle City Council 2017). Children of lone parents, disabled children and those from certain (but not all) ethnic minority backgrounds are at greater risk of living in poverty (Newcastle City Council 2017). In 2011, 52.3% of children in the North-East of England left school with 5 or more GCSEs or equivalent at grades A*-C including English and maths (Newcastle City Council 2017). This was below the national average (58.3%). Academic achievement among young people living in deprived areas is lower than the average (Newcastle City Council 2017). The highest regional prevalence of kinship care (1.7%) in the UK was seen in the North East. Kinship care is defined as an instance where a child was growing up in the care of a relative but in the absence of parent/s. Kinship placements are privately arranged between relatives, where no private law orders are made and where kinship carers are not approved foster carers (Wijedasa 2015).

Finding a voice

The research findings at the present stage, outlined below, are modest, but significant in providing important data, which bridges a gap in the literature. There is "limited research from within the Children and Young People Secure Estate" generally (User Voice 2018). The majority of existing literature focuses on the benefits of recreational activities in adult prisons, young offender institutions, and youth training centres. In that context, few dance and "sports-based interventions, particularly for the youngest prisoners in the secure estate, have been evaluated" (Parker et al. 2014). There is a dearth of evaluative study relating to the voice of young people in SCHs (Andow and Byrne, 2018, p46).

Andrews and Andrews evaluated the benefits of sport-based interventions in a SCH, utilising a "participant observation" model, designed to tell "two stories", that of the young people and staff, through "the researcher's [*sic*] personal narrative" (Andrews and Andrews 2003, 535). Ellis explained, however, that "there are only a handful [of studies] which consider the views of children in secure children's homes", and those studies emphasise the policy, practice and efficacy of SCHs in terms of intervention (Ellis 2016, 1556).

Several recent evaluative studies have highlighted the "user voice" in relation to specific issues pertinent to the Secure Estate. For example, "Spice and the Secure Estate" (User Voice 2018); "Safeguarding and the Secure Estate" (Children's Commissioner 2011); and, "Restraint and the Secure Estate" (User Voice 2018). In the former study, User Voice collected important data from young people across the Secure Estate, including SCHs, using a variety of data collection methods. Despite this research, User Voice highlighted some of the challenges faced in conducting data collection in SCHs. For example, one SCH refused to allow focus groups to take place without security staff present, and this impaired the "independence and authenticity of the information collected" (User Voice 2018, 40).

Similar concerns were raised in Andow's (2020) ethnographic study of a SCH, where she witnessed young people and staff "working together to perform a misleadingly harmonious 'institutional display' [to OFSTED], motivated by a shared sense of institutional identity", despite significant complaints from both groups regarding the operation and management of the Secure Children's Unit. The User Voice (2018, 40) Study also opted not to include SCHs in surveys; "resources for the surveys were focused on the STCs (Secure Training Centres) and two YOIs (Young Offender Institutions) as the population sizes are much greater and provided greater opportunity to engage more [children and young people] CYP" (User Voice 2018, 42). The smaller size of SCHs is recognised as a benefit in terms of their operation (Secure Accommodation Network 2014), but it results in low sample sizes in research and, as such, resources are frequently directed towards the comparably higher numbers in STCs and YOIs. In respect of sample sizes in SCHs, eleven young people from SCHs were engaged in the latter two studies.

Ellis' (2016, 1556) recent "ethnographic" research goes beyond the studies outlined above by providing "an in-depth picture of the 'everyday' for the [female] children living in a secure children's home." The work undertaken in the present study advances the literature by including both male and female participants in a mixedmethod evaluative study utilising intensive dance and sports-based intervention programmes provided by an external provider within a SCH.

Drake et al. (2014) note that if effective child/practitioner relationships are to be built then children's voices need to be heard and acted upon. This ongoing project aims to give a voice to children and address the power balance between children and state authorities. The goal is to understand the child's vantage point as valid and unique. As Alderson argues, "To involve children more directly in research can rescue them from silence and exclusion, and from being represented, by default, as passive objects" (Alderson 2004, 142). Methods which rely solely on verbal and written competence and "provide limited access to the emotional and symbolic aspects of children's experiences and media-related modes of expression" have been criticised (Bragg 2007, 36). Researching the views and voice of the child has burgeoned over the past 25 years as understanding about children's agency, competence, and participation in society have changed. Across diverse fields of study, researchers have been investigating how best to elicit information from children about their experiences, preferences, perceptions, sensations, attributions, thoughts, and feelings (Saywitz et al. 2010). These types of investigations are common in consumer, child care, and educational research, and studies of children's experiences online using the internet and social networking sites. They are used in the health sector to understand what children know about everyday health and wellbeing, illnesses and treatment management, and to understand children's perceptions of pain and the effects of pain medications.

Concurrent with this proliferation in research, there is a growing recognition that children are knowledgeable about their own needs and experiences. Consequently, traditional notions of children and childhood have been re-examined. The nearly universal acceptance of the United Nations Convention on the Rights of the Child (CRC) (1989) sets a legal benchmark for children's participation in decision-making about matters that affect their own lives. In concert with near-unanimous support of the United Nations CRC and shifts in conceptualizations of the "child" and "childhood," research, policy, and theory make clear the need to better articulate the levels of participation that may be made available to children –

"The voices of children themselves must be prominent in [the] exploration of what is going on in their lives—we must approach children as knowing subjects" (Children's Rights International 2005, 27).

Article 12 of the United Nations CRC recognises the young person as an independent holder of rights and reflects a deeper appreciation of the autonomy of the child. MacKenzie defines autonomy in the following terms: "[t]he principle of respect for autonomy ... gives rise to an obligation to try to empathically engage with the other's experience, to imagine what the other person's situation is like for her, given her cares, values and concerns" (MacKenzie 2008, 512). At the core of Article 12 is a conception of children as articulate social actors who have much to say about the world, as people who can be encouraged to speak out through the adoption of participatory methods of research (James 2007). A commitment to conducting research with children and young people, rather than about them requires researchers to develop techniques "to break down the power imbalance between adults and children, and ... creat[e] space which enables children to speak up and be heard" (O'Kane 2008, 126). However, Warshak contends that "most procedures for soliciting children's preferences do not reliably elicit information on their best interests and do not give children a meaningful voice in decision making" (Warshak 2003). Some authors argue that accessing children's views is a "difficult enterprise" (Sharp 2002, Woods, 2000) that poses methodological challenges for the researcher (Downe 2001, 166). Socio-cultural psychologists have also questioned the dominance of traditional developmental approaches to researching children. They assert that children appear less competent when they are subjected to clinical interviews, tests and surveys in experimental settings than when observed in their everyday social environments (Vygotsky 1978, Hogan 2005). Research concerned with understanding children's views and experiences needs a methodological approach that shows and enables children's competencies within their everyday social settings (Alderson 2004, Kellett and Ding 2004). Consequently a range of multi-sensory methods such as arts and sports activities, the use of cameras, audio recordings, child-led tours and mapmaking have been developed which shift the balance away from the written or spoken word (Clark et al. 2003) and potentially allow a wider range of children to participate in research (Davis and Watson 2000).

III. METHODOLOGY

A rigorous and innovative mixed method design was adopted to explore participant viewpoints on the way in which the young people made "sense of their experiences and the world in which they live" (Holloway 1997, 1) and in which the young people's participation in the research is foregrounded and acknowledged (James 2007, 262). This approach emphasised "giving a voice" to a "hard to reach" group of young people to allow them the opportunity to share their experiential knowledge and lived experiences and fill the "gap" in qualitative research undertaken on young

peoples' experiences of a SCH and their ability to cope with life outside of the SCH. An innovative methodology called the Diamond9 was used to examine whether a small-scale intensive dance based intervention in a SCH could confer psycho-social benefits on this population of young people. The second phase of the project, engaging a sports-based intervention is considered further below. The initial phase of the project allowed young participants to explore ways of expressing emotions through cross-art form collaborations. Responses were monitored and analysed to develop effective evaluation methods and to clearly evidence how the objectives developing and maintaining hope, acquiring social and human capital, fostering personal and social strengths and resources - contribute to desistence agendas. The project aimed to provide the young participants with the tools needed to cope with life outside of the SCH and to reduce their capacity for reoffending. This approach to improving outcomes for young people aimed to develop an enhanced model for early intervention to meet the multiple and complex needs of young people in a way, which reduces the burden on criminal justice and community safety resources.

A. Organisation of the Programme

The research team worked with an external dance company to provide the dance element of the programme. The programme ran for one week, with the data collection taking place during the week of the programme (Diamond9) and two weeks after it had concluded (interviews). Any young person who was resident in the SCH was allowed to take part in the programme, unless the SCH took the view that it was not appropriate. The possible reasons for exclusion from the programme were primarily welfare-focused, where due to fluctuating mental health issues or behavioural issues it was inappropriate for the young person to be involved and/or where the young person declined to be involved. The research team viewed it extremely important that each young person should have this opportunity, even if no data was gained from them.

As the young people would only be able to take part in either dance lessons or an alternative art and creative writing sessions, a taster day the week prior to the programme was organised. There were two evenings of taster sessions, so the young people could try all sessions and then decide which they wanted to participate in. All of those who were involved in teaching the young people attended and took part. A member of the research team also attended the dance taster session, with the aim of introducing themselves to the young people so that they would be familiar with them when asked to participate in the Diamond9 and interviews. After the taster days, the young people who wanted to participate let the staff know and a list was provided to the research team. It was made clear via the consent forms and in session briefings that engagement was optional, and that the young people could withdraw their consent at any time. Members of the research team were present during the week but did not take part in the creative arts sessions. It was important that the young people were familiar and felt comfortable to talk with them, but the researchers wanted the young people to enjoy the sessions rather than being concerned that they were being monitored.

The work undertaken by the young people in relation to both activities contributed to a final performance. This meant that the young people were working towards an end goal, rather than simply learning how to dance or create art. The dance performance was performed by one young person, who completed all of the Diamond9 evaluations, discussed below, and the dance teachers. The students who took part in the art sessions made costumes for the dancers. They could then see their work used in the final performance and how the programme and final performance linked together. For example, during the arts sessions, aboriginal masks were made which were worn by the dancers when performing. The masks also served another purpose, as the SCH wanted to film the performance so the young people could review it and see their achievements. The faces of the young people could not be recorded and the masks addressed this issue. The recording did not leave the SCH. The final performance was attended by other young people in the SCH who had not taken part in the programme and staff working in the SCH. It was a positive end to the programme and allowed the young people to showcase their work. Those who participated in the programme were presented with certificates.

B. Ethical approval

All members of the research team contributed to the ethical approval application, and ethical approval was obtained and approved from the Faculty of Business and Law Research Ethics Committee at Northumbria University, on 16th May 2018, and the Local Authority of the Secure Children's Home. Northumbria University is a member of Newcastle Safeguarding Children Partnership (NSCP) and are required to follow the policies are procedures. The NSCP brings together partner agencies across the city to ensure there is a joined-up approach to safequarding and promoting the welfare of children. Its work crosses the boundaries between the statutory, voluntary and independent sectors and builds upon the best practice achieved by the Area Child Protection Committee. As the project involved vulnerable children, much consideration was given to minimising any detrimental effects. The research team met regularly with staff from the SCH to discuss any issues and how to address them, and all of the data collection methods, and their contents, were approved by staff. The main issue was how to record consent from the young people in a way which ensured that all information was confidential and anonymous, as the team were not permitted to take anything the children had written on outside of the unit, nor could recordings on electronic devices be made. The list of young people the research team were provided with only contained the initials of those who wanted to participate and the "house" they belonged to; the young people are grouped into residential groups or houses within the SCH. It was decided that the research team would explain the project and any ethical considerations to the young person, including withdrawal from the project and anonymity, and if they were happy to participate they would tick next to their initials. This sheet was kept in the SCH and only accessible to the staff working with us on the project and the researchers. This maintained confidentiality, as the only staff who were aware of participation were the ones who were working with us and present during the data collection, as was a safeguarding requirement for the researchers' safety. This approach to consent demonstrates our commitment to viewing the young people involved as reliable, voluntary and competent participants in research (Farrell 2016, 226). All data was collected, processed, retained, stored, and disposed of in accordance with the Data Protection Act 1998. The data storage followed legally defined criteria, and ensured that all uses to which the data was put during the research were consented to by the participant. The identities of the study's participants was protected and anonymised to preserve confidentiality. All information that could be referred to individuals was excluded/redacted before storing (in computerised form) and presenting the data. All computer files were saved with a password and then encrypted using winzip. The research team were never left alone with a young person, due to safety, and a member of staff from the SCH was always present. Staff knew of any issues with the young person and any "triggers" which could cause them to behave inappropriately. The staff also helped explain to the young person what the project was about and what they had to do. The staff at the SCH were extremely helpful. If any issues arose, the young people were able to discuss those issues with their key workers and other professionals available in the SCH.

C. Methodology - The Diamond9

The data collection and evaluation used the "Diamond9" collection method, which allows each participant to rank their engagement with the project in terms of emotional response. This is an innovative research method developed from research in primary education, which produces a hierarchy validated by the contemporaneous group discussion and further unpacked and confirmed by interviews. The Diamond9 encourages discussion about the relative importance of certain factors to the participants and is a "thinking skills tool", which encourages and facilitates discussion (Clark et al. 2013). The Diamond9 facilitated a qualitative, inclusive and childcentred approach to researching "with" young people rather than research being done "to" them (Nind 2014). The use of both quantitative and qualitative methods allows for the development of a richer dataset as it creates the conditions for easier comparison between participants while also keeping their experiences personal to them and highlighting these differences. It creates a space for the young participants to talk about the issues that most affect them and allows for the young person's agenda to take precedence. This method of data collection has not been previously used with an under-researched population, such as, the young people residing at the SCH.

The Diamond9 is a tool used to rank different categories of emotional statements. The young people involved were presented with a board with a diamond shape on it and eight cards with emotional states written on them, for example, "I feel more confident" and "I feel frustrated with my life". The young people were also then asked to provide one emotion not included on the eight cards, to write it on a blank card and to place the card on the board. They were asked to rank the emotional states in the order of how they are experienced, for example, the emotion they experience most strongly at the top of the board and the emotion they experience least at the bottom and to organise the other emotions accordingly in between. Any emotional states which were placed on the same row had the same level of experience. Due to ethical considerations, the young people completed each Diamond9 individually, but the researchers emphasise that this exercise also works

well in a group setting. Members of the research team took written notes of the conversations around the placements of the cards. If some of the young people chose to take part in the evaluation exercise as an individual, they were asked between two to four questions about why they have ranked the cards in that particular order. Once the Diamond9 was complete, the member of the research team recorded the final placement of the cards with a hand drawn diagram. The research team ensured that the young people engaging in the Diamond9 evaluation exercise were not identifiable within the research records. The exercise took approximately 5 minutes to complete, depending on the person involved; and was repeated at the start of the creative arts programme, the middle and the end. The placement of the cards are accorded a numerical value during the data analysis; larger numerical values represent the higher placement of cards, and accordingly, the greater importance of the card's placement, displayed on Figure 1. According numerical values in this way allows for the generation of easily digestible data and the ability to create mean figures.

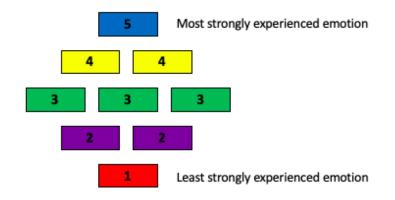


Figure 1 – Diagram showing the layout of the Diamond9 and the value attached to the placement of emotional statements for quantitative analysis

The Diamond9 allowed the research team to generate a rich data source, collected over 3 sessions during the one-week programme. The first session took place on the morning the course started (Monday), prior to any dance lessons, the second in the middle of the week (Wednesday), and the last at the conclusion of the course, after the final performance to the rest of the SCH (Friday). The number of young people who participated varied throughout the week. At the first data collection session, we had six participants. For the second and third data collection session, we only had one participant, whose results are displayed and discussed below. This was mainly due to the young people either not wanting to do the Diamond9 again, or being unable to, e.g. behavioural issues. All of the young people involved were between the age of 11-17. The young person who undertook the complete Diamond9 session was female, but we had a mix of genders during the first session.

The data allowed the research team to analyse the emotional response to the dance programme as an effective mode of expression. The Diamond9 revealed a depth of engagement that other methods would not necessarily generate. For example, the research team were able to monitor, in real time, the full extent of engagement from the young people, with each member of the team; follow up interviews allowed for full integration of the pilot, and provided an opportunity for reflection. The data was captured two weeks following the project by the research team. During this week, four individual interviews were conducted with young people who had started the course and had completed the first Diamond9 session. Again, this was a mix if genders, with three females and one male participating in the interview. A member of staff from the SCH was present during these interviews, and though the young people were given the option for them not to be, none expressed their wish for this. The questions asked of the young people focused around which sessions they did/did not enjoy, if they felt that they were able to express themselves during these sessions (if so, how; how they felt afterwards and why), if they noticed a difference in how they felt before the programme and afterwards, and whether they thought this experience would be helpful to them in the future.

There were also interviews conducted with two members of staff at the SCH, who had worked with the young people during the intervention week. Questions explored their impression of the dance and creative arts programme on the young people and the difficulties which are faced by SCH at this time. Two members of staff have confirmed that the Diamond9 method has now been fully integrated into other programmes of work undertaken by the SCH.

D. Methodological issues

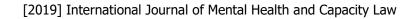
There were some difficulties with the methodology for this project, which ought to be noted. These difficulties were not due to lack of planning and communication with the SCH, but rather the unpredictable nature of these kinds of accommodations. Firstly, not all of the young people who were willing to take part were able to on the first day of the project. There had been an incident in one of the houses and the young people were not able to leave. This excluded some of the sample, which the research team would otherwise have had access to. The young people did, however, still participate in the programme and one volunteered to participate in an interview after the programme had concluded. Secondly, whilst multiple young people conducted the Diamond9 on the first day of the programme, some decided not to complete the other Diamond9s or were not able to participate on the days of data collection. This meant that the research team lost access to those young people for the purposes of Diamond9 evaluation, but some did take part in the interview. Lastly, we had issues during the first round of data collection with the Diamond9s. The plan, which was encouraged by the staff at the SCH, was to take a picture of the completed Diamond9s (which would not breach confidentiality) on a camera owned by them, which would be kept on the premises. The pictures would then be transferred to us. On the day, the SCH had some staffing issues, which meant that we had less time with each young person to collect the data. The researchers took pictures of the completed Diamon9s on that day, and attempted to take a written note of the placement of the cards, but due to the rush it was not possible to complete the notes. Further, the picture of the first Diamond9s were never sent to us by the SCH, though requested several times, and due to incomplete notes, we did not have a complete first Diamond9 for the data presented below.

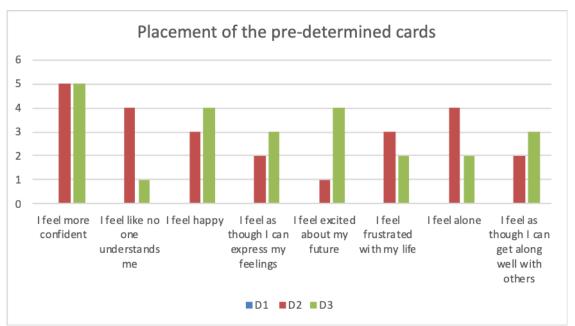
It is important in any research to be transparent and honest about the data collection process, and any issues which arose, to be able to assess the quality and reliability of the result. We had various issues during the data collection process, which were to do with how difficult it can be to collect data in a SCH, due to staffing issues, confidentiality, and the young people themselves. This is not uncommon in these kinds of settings and, though there are not many studies of this kind, Andow (2020) reported similar issues with the management of a SCH in her research. Whilst we are not able to present a full Diamond9, due to the missing photograph, we are able to present the data from the middle and the end of the week, along with the interview data from both young people and staff at the SCH.

This is a small data set, but the authors believe that this is sufficient to show some influence of the creative arts programme on young people and a reliable pilot study to develop for future projects, detailed below. Our approach contrasts with other approaches that often begin with predictions and aim to identify causality from an "outsider" perspective (Millward 2006), and provides a compliment to important quantitative findings on youth offending. A small number of intensively analysed cases are typical in qualitative work of hard to reach young people (Smith and Eatough 2006). For example, Millward and Senker (2012) recruited three male participants from one youth offending service (YOS) in their study of how male young offenders on community orders made sense of their offending behaviour. The small number of participants allowed the researchers to engage in an in-depth study of what it means to be an offender on a community order, with the view of generating insights into effective rehabilitation.

IV. FINDINGS

The findings and discussion are outlined in this section. The data presents some connection between the creative arts programme and the positive emotions felt by the young people. The Diamond9 results presented and discussed were completed by one young person who took part in the dance element of the programme and participated for the whole week. No other full Diamond9s were completed by any other young people during the data collection.

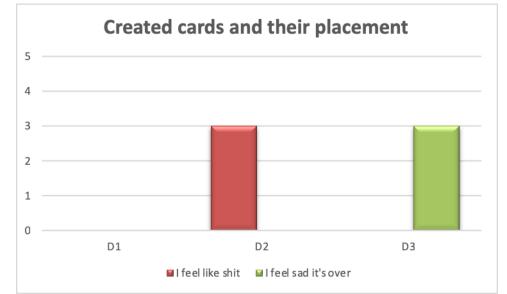




Graph 1 – Graph showing the placement of predetermined Diamond9 emotional statements

As stated above, there were some issues around gaining all of the data collected from the secure unit. We did not get the data from the first Diamond9 and, thus, it is not presented on this graph. There was some change apparent over the week of the creative arts programme. To reiterate, the first session took place on the morning the course started (Monday), prior to any dance lessons, the second in the middle of the week (Wednesday), and the last at the conclusion of the course, after the final performance to the rest of the SCH (Friday). During this young person's first data collection session, the researcher had started to make a note of the card placement, before the next young people were brought in to do their session, but they were brought in early, and this disrupted any notes taken. They were unable to complete the notes on the placement, as they needed to remove the cards to maintain the confidentiality of the placement from other young people. What is clear from the notes is that in the first Diamond9, "I feel more confident" was not placed in the top of the board and, therefore, this card rose to the top placement during the second and third Diamond9 session. During the second Diamond9, the participant stated that this was, "because of the dancing". From the second to the third Diamond9, "I feel excited about my future" rose significantly. This participant indicated that they wanted to continue with dance lessons and the programme clearly had an effect on how they considered their future. Other positive emotional statements also rose in strength of feeling over the course of the programme, such as, "I feel happy" and "I feel as though I can get along well with others." They did not rise significantly, but overall the more positive statements increased. This is supported by anecdotal comments made by a member of staff, who said that they noticed, once the young people became comfortable with the dance, that they seemed more confident afterwards and enjoyed focusing on something positive, rather than the attention on them being negative.

The negative statements decreased in strength over the programme. Emotional statements, such as, "I feel like no one understands me" and "I feel alone" dropped significantly and were perceived to be less strong emotions. When asked during the interview whether they felt as though they were able to express themselves during the creative arts sessions, this participant responded saying, "Yes, I could express emotions in the dance. One move I made up, like an angry step (stamping foot) ended up in the final performance. It felt good to express yourself." The creative element of the dance classes allowed this young person to express themselves in a way which may not have been possible in their usual activities in the SCH. A member of staff in their interview noted that this participant has, since the programme ran, put more detail and attention into tasks given in the SCH, such as, art work.



Graph 2 – Graph showing the emotional statement cards created during the Diamond9 and their placement

The tone of the creative cards changed over the course of the programme. Even in the middle of the programme the young person was still not feeling positive and made a card of "I feel like shit". The final Diamond9, which was conducted immediately after the final performance, displayed the effect of the week on this young person. They were emotional after the programme had concluded and said that they "felt sad it's over". They felt as though they had made friends with the dance teachers and enjoyed getting up each morning to participate. They were upset that they would not have these dance lessons anymore, but also that they potentially would not see those who ran the programme again. It was very moving for the researchers to see the impact on this young person and the change in the created cards was reflected in their interview:

It took me away from arguments in the house, gave me some space. I was so happy doing it and was upset when it was over. I'm glad I've got the memory of it and what they taught me. It upped my confidence. I used to get angry and punch things. I don't feel as angry as much – I think the week helped. It was not difficult before, but I got away from arguments. Clearly the young person who participated in the dance programme for the whole week felt it had made a difference to their time in the SCH and potentially to their future. It allowed them space away from their normal routine in their house, which they could feel frustrated in and misbehave with negative emotions. The result is consistent with the literature on how interventions should impact a young person's emotional and psychological well-being (Wilson et al. 2009) and their anger and aggression (Blacker 2008).

This participant did believe that the programme would be beneficial to them in the future, but especially because to "tell people what I did – you can do things in here [the SCH]". It may be that this course was not something they had expected to have been able to have taken part in whilst they were in the SCH and they felt it was something they could share with people when they left.

Not all of the participants who were interviewed were this positive about the effects of the programme. A participant who had taken part in the arts and creative writing programme stated, when asked if they noticed a difference to how they felt prior to the creative art sessions compared to afterwards, that they felt the same than before, but in a good way and in a happy mood. They enjoyed the arts sessions, which were different to what they had done in school and will continue with art in the future. This intervention indicates an impact on engagement with further education and training (Wilson et al. 2009). Others who took part sporadically did not report a difference in their emotions during and after the programme had taken place. One participant stated that they felt no different after they had taken part in a dance class even though they, "sometimes [find] it difficult to express myself, but I'm not sure if the dance classes helped". They did say, however, that the dance classes had made them feel more confident than they had before, but they were not sure why. The final participant in interview said that they had enjoyed the dance classes, but it did not change the way they expressed themselves and there was no difference from before they participated. They did not feel as though they expressed themselves through dancing and did not think it would be beneficial to their future.

Overall, it appears that the young people who participated more in the programme benefitted more from it. This could have been because of the relationships they developed with the dance teachers and the feeling that they were part of something from outside the SCH. It could also have been that consistent participation will have developed more of a change than intermittent participation, whereby the full effects of the programme may not have been experienced. This was indicated during an interview with a member of staff, they stated that the young person who had taken part in the final dance performance was "like a different person", but the others were "half and half". It could, however, be that not all young people connected with creative arts, whether that be dance, art or creative writing, particularly if they did not feel talented in this area. This connection may be influenced by the self-image of a young person and whether the activity is thought of as something which will improve their image. A member of staff did note that when attempting to engage a young person with an activity it is "all about how they are perceived by other people" and they may be engaged for a couple of hours and then not want to continue. This is why the research team would like to replicate this study with a

different programme activity, discussed further below. The authors are unable to draw conclusions regarding the lasting effects of the pilot study and the impact on reducing the risk of reoffending (Cox and Gelsthorpe 2008). To be able to highlight this impact a longitudinal study would need to be conducted, which the research team will consider for the future.

During interviews, staff highlighted the skills the young people developed during the week. This included teamwork and interpersonal skills, both with each other and with those running the programme. One staff member noted that the rules the dance team enforced, which could not be broken, ensured consistency, which is something needed in the SCH. The other staff member noted the use of communication skills and how the young people interacted and "networked" with those running the programme. The ability to interact with new people for a longer period of time seemed to advance their skills, both generally and within the activity which they took part in.

The researchers also asked staff members generally about their experience of working in a Secure Children's Unit and the issues they currently face. One staff member noted that money can sometimes be an issue, especially when providing programmes like the one in this study. They did, however, note that if this programme indicated a positive outcome then this funding may become more available to Secure Children's Units. The other member of staff said that conflicts with the young people in different houses is an issue, so organising large activities like this programme can be difficult. Both staff members noted that the creative arts generally were becoming less prominent in the SCH, even though they did engage with music and art on a regular basis, but that they should be continued for young people, due to the benefits mentioned.

Using the Diamond9

The Diamond9 proved to be a useful tool for the pilot study. The research team were able to collect data at vital points of the programme, to measure the effect of the creative arts sessions. The ability to collect data quickly which is easily comparable would have been more difficult with more traditional methods, such as, formal interviews. The method allowed the young people to become part of the research, to create something and give them more of a voice, which was an aim of the project. The Diamond9 departs from methods which rely on verbal and written competence, as criticised by Bragg, and offers those researching with children an alternative way to elicit information from young people (Bragg 2007). The Diamond9 created the space for the young people to express their emotions and opinions, providing them with some power and control over the research process and a way to conduct research *with* the young people (O'Kane 2008).

Conducting interviews with the staff on the effects of the programme on the young people provided an insightful input to the results. Children can appear less competent when they are subjected to clinical interviews etc., than when observed in their everyday social environments (Vygotsky 1978, Donaldson 1978, Bronfenbrenner 1979, Hogan 2005). Discussing the programme with the staff who

were present during the week and observing the young people they work with provided additional depth to the findings.

V. NEXT STAGES-EXTENDING THE METHODOLOGY

Growing the data-set

This project is an initial Pilot project, and it is the intention of the research team to broaden the scope of the initial dance-based intervention, and, accordingly, grow the data-set. The research team are in the process of developing the data-set by engaging in the second stage of the project with the SCH. This second stage is designed to develop the original study in light of feedback from the young people, recent government initiatives to develop Sports-based programmes across the youth justice system, and also recognising that some of the young people might have already participated in the original study (Ministry of Justice 2018. Sports-based interventions have frequently been identified as a form of best practice generating a positive response from both staff and young people (User Voice 2018). During the second stage, the SCH will be revisited to engage in a programme of activity utilising sport rather than dance. We will use sports such as boxing, touch rugby, football and yoga as a vehicle to help young people develop important life skills (including coping, educational, employability and other skills.

The second stage of the project is a collaboration across Northumbria Sports Foundation, the research team within Northumbria Law School, and the SCH. The Northumbria Sport Foundation (reg. 1111675) provides sporting opportunities to develop people and communities, focusing upon the North East of England. Whilst the Foundation is linked to Northumbria University, it is structurally and financially independent. The second stage builds upon the original Pilot Study in several key ways, and is designed to engage staff and key workers at the SCH throughout the programme. The revised model will utilise pre-and-post evaluative meeting(s) with staff at the SCH. The pre-and-post meeting(s) will identify what staff seek to achieve from the project, and is designed to ensure that both staff and young people engage as active learners in the process as a means of breaking down barriers to communication. These meetings will follow the "ROAMEF - Rationale, Objectives, Appraisal, Monitoring, Evaluation, Feedback" evaluation cycle (HM Treasury 2018). This development should assist in engaging staff in the authorship of the programme, in addition to ensuring that the needs of both staff and the young people are met. Full ethical clearance will be sought from Northumbria University and the guidance from the British Psychological Society will be adhered to.

At a more practical level, the above change should reduce staff rotation during the programme; an issue which researchers and staff at the SCH recognised as having potentially impacted on the level of engagement with the semi-structured interviews and the initial Pilot Study, more generally. During interview, a member of staff based at the SCH suggested that the programme might operate more successfully if the SCH staff that were involved were "more organised and consistent for the week for both sessions...". The member of staff said that "dealing with [the project] and

sorting... it died out when I wasn't at work, as I was there for the first half of the days".

The ROAMEF evaluative cycle seeks to engage staff at every stage of the process and to consider whether goals identified by staff during the pre-assessment have been met, in addition to discussing how to further develop the evaluative study. The Diamond9 tool utilised during the initial stage has been developed in response to feedback by staff and young people at the SCH, and the reflections and observations of the research team. For example, the emotional statement cards have been modified to reflect wellbeing concepts as a measurement. The research team felt as though the emotional statement cards used in the pilot study were effective, but did not measure a wider range of emotions and functions that we now wish to capture. The interviews are also being developed in light of the findings in the first study, and the recommendations identified above. For example, the research team noticed a theme of the week was the young people enjoying visits and classes from external providers, rather than internal staff delivering courses. The interviews with both staff and young people will focus more heavily on the benefits of external providers coming into the Secure Unit than it was in the pilot study. We are also considering conducting interviews with the staff who run the external courses, to gain their insights into working with the young people and in a Secure Unit. A less formal approach to this method of data gathering is likely to generate a better response; the gathering of data via semi-structured interviews is designed to replicate more casual conversations than a structured interview; shorter interviews are also likely to generate a better response (Andrews and Andrews 2003, 537).

VI. CONCLUSION

This article has provided an overview of a successful research pilot programme on the use of an arts-based intervention in a SCH in England and Wales, utilising the Diamond9 as an evaluative tool to place the young person's voice at the centre of the analysis. Research to date highlights the importance of adopting a child-centred approach to intervention models to engage young people and to break down barriers relating to perceptions of authority and lack of individual autonomy. The arts-based programme ensured that the young people involved were able to make a choice regarding the programme, and/or whether or not to engage in evaluative exercises. The data collected via the Diamond9 mixed method evaluative approach and semistructured interviews presented some interesting findings relating to the experiences of young people and staff who engaged in the programme, and the benefits associated with such programmes.

The study represents the first time the Diamond9 model has been adopted within a SCH. As explained, SCHs represent an under-researched area of the criminal justice system; this might be due to, in part, the more complex demographic in SCHs, and, in part, that resources are directed towards larger institutions where research may have greater generalisability. In this respect, the results, though modest, provide an original insight into the voice of this currently underrepresented demographic of the Secure Estate, and highlight the benefits of arts-based programmes in such settings.

The follow-up study has been developed in light of feedback from the young people, and staff, in addition to current government initiatives in relation to rehabilitative programmes in the youth estate. The second study, at the same SCH, involves an intensive sports-based programme, utilising the ROAMEF evaluative cycle to support staff, the Diamond9 evaluative method, and enhanced semi-structured interviews engaging both staff and young people. The study will help to refine the programme, and will provide important comparative data for further analysis.

This article is part; the presentation of the results of a somewhat modest but important evaluation of the use of arts-based interventions in SCHs; and, part an invitation for interested stakeholders and potential collaborators to contact the authors to discuss the possibility of developing and replicating this important study at international level.

References

Alderson, P. 2004 'Ethics' in S. Fraser, V. Lewis, M. Kellett and C. Robinson (eds.) *Doing Research with Children and Young People* London: Sage.

Allen, K., Shaw, P., Hall, J. 2004 *The art of rehabilitation: attitudes to offender's involvement in the arts.* London: Esmee Fairburn Foundation.

Andow, C., "Outsider Inspections of Closed Institutions: An Insider Ethnographic View of Institutional Display" Sage Publishing (2020) 1-16.

Andow, C., and Byrne. B., "Family characteristics and experiences of children entering secure settings" in *National Association for Youth Justice Compendium of Papers* (2018) available at: <<u>https://thenayj.org.uk/wp-</u> <u>content/uploads/2019/02/NAYJ-Child-friendly-youth-justice-May-18.pdf</u>> accessed 17 March 2020

Andrews, J. P., and G. J. Andrews. 2003. "Life in a Secure Unit: The Rehabilitation of Young People Through the Use of Sport." *Social Science and Medicine* 56 (3): 531–550.

Arthur, R. 2005 "Punishing Parents for the Crimes of their Children" *Howard Journal of Criminal Justice* 44(3): 233-253.

Arthur, R. 2007 *Family Life and Youth Offending: Home is where the hurt is* London: Routledge.

Arthur, R. 2010 "Protecting the best interests of the child: A comparative analysis of the youth justice systems in Ireland, England and Scotland" *International Journal of Children's Rights* 18(2): 217-231.

Arthur, R. 2016 "Exploring childhood, criminal responsibility and the evolving capacities of the child" *Northern Ireland Legal Quarterly* 67(3): 269-28;

Arthur, R. 2017 *Moral Foundations of the English Youth Justice System* London: Routledge.

Beyond Youth Custody 2017) *Now all I care about is my future" Supporting the shift* – *Framework for the effective resettlement of young people leaving custody* London: BYC.

Blacker, J., Watson, A., Beech, A. 2008 A combined drama-based and CBT approach to working with self-reported anger aggression *Criminal Behaviour and Mental Health* 18: 129-137.

Bragg, S. 2007 *Consulting Young People: A Report for Creative Partnerships* London: Lithosphere.

Bronfenbrenner, U. 1979 *The Ecology of Human Development: Experiments by Nature and Design* Cambridge MA: Harvard University Press.

Bryan, K., Freer, J. and Furlong, C. 2009. 'Language and communication difficulties in juvenile offenders', *International Journal of Language and Communication Disorders* 42(5): 505.

Cann, J., Falshaw, L. and Friendship, C. 2005. "Understanding 'What Works': Accredited Cognitive Skills Programmes for Young Offenders". *Youth Justice*, 5(3): 165-179.

Cheliotis, L and Jordanoska, A. 2016 'The arts of desistance: assessing the role of arts-based programmes in reducing reoffending', *The Howard Journal of Crime & Justice*, 55(1-2): 25-41.

Children's Commissioner 2011 *Young People's Views on Safeguarding and the Secure Estate* London: Youth Justice Board.

Children's Rights International 2005 *Newsletter* Sydney: Children's Rights International.

Clark, J., Laing, K., Tiplady, L., Woolner, P. 2013 *Making connections: theory and practice of using visual methods to aid participation in research* Newcastle: Research Centre for Learning and Teaching.

CLINKS 2013 *Introducing Desistance: A guide for voluntary, community and social enterprise(VCSE) sector organisations* London: CLINKS.

Cox, A. and Gelsthorpe, L. 2008 *Beats and bars – music in prisons: An evaluation* London: The Irene Taylor Trust.

Creaney, S. 2018 "Children's voices – are we listening? Progressing peer mentoring in the youth justice system" *Child Care in Practice* DOI: 10.1080/13575279.2018.1521381.

Davis, J. M. and Watson, N. 2000 "Disabled Children's Rights in Every Day Life: Problematising Notions of Competency and Promoting Self-Empowerment" *International Journal of Children's Rights* 8: 211-228.

Douglas, N., Plugge, E. 2008 "The health needs of imprisoned female juvenile offenders: The views of the young women prisoners and youth justice professionals", *International Journal of Prisoner Health*, 4(2): 66-76.

Downe, P. 2001 "Playing with Names: How Children Create Identities in Self in Anthropological Research" *Anthropologica* 43: 165-177.

Drake, D., Fergusson, R., and Briggs, D. (2014). "Hearing new voices: Re-viewing youth justice policy through practitioners' relationships with young people". *Youth Justice*, 14(1): 22-39.

Ellis, K.H. 2016 "'He's got some nasty impression of me he has': Listening to Children in the Secure Estate", *The British Journal of Social Work*, 46(6): 1553–1567.

Farrell, A. 2016 "Ethical responsibilities in early childhood education and care". In Ailwood, J., Boyd, W., Theobold, M. (eds.) *Understanding early childhood education and care in Australia: practices and perspectives* Sydney, Allen & Unwin.

Fazel, S., Doll, H., Långström, N. 2008 "Mental Disorders Among Adolescents in Juvenile Detention and Correctional Facilities: A Systematic Review and Metaregression Analysis of 25 Surveys" *Journal of the American Academy of Child and Adolescent Psychiatry* 47(9): 1010-1019.

France, A. and Homel, R. 2006 "Societal access routes and developmental pathways: Putting social structure and young people's voice into the analysis pathways into and out of crime". *Australian and New Zealand of Criminology* 39(3): 287–294.

Gyateng, T., Moretti, A., May, T., Turnbull, P. 2013 *Needs and Interventions* London: Youth Justice Board.

HM Treasury 2018 *The Green Book: Appraisal and Evaluation in Central Government* London: The Stationery Office.

Hogan, D. 2005 "Researching "The Child" in Developmental Psychology" In S. Greene and D. Hogan (eds.) *Researching Children's Experiences* London: Sage Publications Ltd.

Holloway, I. 1997 Basic concepts for qualitative research. Oxford: Blackwell Science.

Hooper, S.J., Roberts, J.E., Zeisel, S.A. and Poe, M. (2003) 'Core language predictors of behavioural functioning in early elementary school children: Concurrent and longitudinal findings' *Behavioral Disorders* 29(1):10.

Hough, M and Park, A. (2002) 'How Malleable are Attitudes to Crime and Punishment? Findings from a British Deliberative Poll', pp. 163-184 in J. Roberts and M. Hough (eds) *Changing Attitudes to Punishment: Public Opinion, Crime and Justice*. Cullopmton: Willan;

Hough, M. and Roberts, J.V. (2004) *Youth Crime and Youth Justice: Public Perception in England and Wales* Bristol: The Policy Press

Hudson, B. L. and Sheldon, B. 2000. "The cognitive-behavioural approach". In M. Davies (Ed.), *Encyclopaedia of social work*. Oxford: Oxford University Press.

Hughes, G., Cooper, C., Gormally, S. and Rippingale, J. 2014. "The state of youth work in austerity England – reclaiming the ability to 'care'". *Youth and Policy*, 113: 1–14.

Hughes, N., Williams, H., Chitsabesan, P., Davies, R. and Mounce, L. 2012. "Nobody made the connection: the prevalence of Neurodisability in young people who offend". London: Office of the Children's Commissioner.

Humber, E. and Snow, P.C. 2001. "The language processing and production skills of juvenile offenders: a pilot investigation" *Psychiatry, Psychology and Law* 8(1): 1.

Independent Commission on Youth Crime and Antisocial Behaviour 2010 *Time for a fresh start*. London: The Police Foundation.

James, A. 2007 "Giving voice to children's voices: practices and problems, pitfalls and potentials", *American Anthropologist* 109(2): 261-272.

Kellett, M. and Ding, S. 2004 'Middle Childhood' in S. Fraser, V. Lewis, M. Kellett and C. Robinson (eds.) *Doing Research with Children and Young People* London: Sage Publications Ltd.

Kendall, M. 2003 "Designing a research project: randomised controlled trials and their principles" *Emerg Med J* 20:164–168.

Lammy, D. 2017 *The Lammy Review: An independent review into the treatment of Black, Asian and Minority Ethnic individuals in the Criminal Justice System* London: TSO.

Lee, P. 2018 "Why train young offenders to fight? Because it can improve their lives " *The Guardian*, July 7th. [2019] International Journal of Mental Health and Capacity Law

<<u>https://www.theguardian.com/commentisfree/2018/jul/07/young-offenders-boxing-martial-arts-fight-sport</u>> accessed 18th February 2019

Lewis, G., and R. Meek. 2012a. "The Role of Sport in Reducing Offending Among Young Men in Prison: Assessing the Evidence Base." *Forensic Update* 107: 12–18.

Lewis, G., and R. Meek. 2012b. "Sport and physical education across the secure estate: an exploration of policy and practice", *Criminal Justice Matters*, 90(1): 32-34.

Lord, A. 2016 "Integrating risk, the good lives model and recovery for mentally disordered sexual offenders". *Journal of Sexual Aggression*, 22(1): 107–122.

MacKenzie, C. 2008 "Relational autonomy, normative authority and perfectionism" *J Soc Phil* 39: 512-533.

Maruna, S. 2001 *Making good: How ex-convicts reform and rebuild their lives*. Washington, DC: American Psychological Association Books.

Meek, R. 2018 *Government Response to A Sporting Chance* London: Ministry of Justice

Miles, A. and Clarke, R. 2006 *The arts in criminal justice: A study of research feasibility* Manchester: University of Manchester Centre for Research on socio cultural change.

Millward, L. 2006 "The transition to motherhood in an organizational context: an interpretative phenomenological analysis", *Journal of Occupational and Organisational Psychology*, 79(3): 315-33.

Millward, L. and Senker, S. 2001. "Self-determination in rehabilitation: a qualitative case study of three young offenders on community orders". *British Journal of Forensic Practice*, 14(3):,204-216.

Millward, L., & Senker, S. 2012 "Self-determination in rehabilitation: a qualitative case study of three young offenders on community orders". *British Journal of Forensic Practice*, 14(3): 204-216.

Ministry of Justice 2018 *Government Response to A Sporting Chance* London: Ministry of Justice.

Ministry of Justice and Social Development 2016. *Youth Justice Secure Residences: A report on the international evidence to guide best practice and service delivery* (Wellington: Ministry of Social Development)

Morgan, H., and Parker, A.. 2017. "Generating 'Recognition', 'Acceptance' and Social Inclusion in Marginalised Youth Populations: The Potential of Sports-Based Interventions." *Journal of Youth Studies* 20 (8): 1028–1043.

Newcastle City Council 2017 Equality Statistics, Research and Information <u>https://www.newcastle.gov.uk/your-council-and-democracy/statistics-and-census-information/equality-statistics-research-and-information</u>

Nind, M. 2014 "Inclusive research and inclusive education: why connecting them makes sense for 'teachers and learners' democratic development of education". *Cambridge Journal of Education* 44(4): 525-540.

Ofsted 2009 *Life in secure care A report by the Children's Rights Director for England* London: Ofsted.

O'Kane, C. 2008 "The development of participatory techniques: facilitating children's views about decisions which affect them", in Christensen, P., James, A. (eds.) *Research with children: perspectives and practices*. 2nd ed. Routledge: London, 125-155.

Parker, A., Meek, R. and Lewis, G. 2014 "Sport in a youth prison: male young offenders' experiences of a sporting intervention" *Journal of Youth Studies* 17(3): 381-396.

Roberts, J. and Hough, M. 2005 "Sentencing Young Offenders: Public Opinion in England and Wales", *Criminal Justice*, 5(3): 211-232

Royal College of Psychiatrists. 2006. "Child Defendants" (Occasional paper OP56) London: Royal College of Psychiatrists.

Royal College of Speech & Language Therapists 2009 *Locked up and Locked out: Communication is the key* Cardiff: Wales Justice Coalition.

Sacco, R. 1991. "Legal Formats: A Dynamic Approach to Comparative Law" *American Journal of Comparative Law* 39(1): 1-34.

Saywitz, K., Camparo, L.B., Romanoff, A. 2010 "Interviewing children in custody cases: implications of research and policy for practice", *Behavioural Sciences and the Law*, 28: 542-562

Secure Accommodation Network 2014 *Achieving Outcomes and Value for Money in Secure Children's Homes* London: Justice Studio.

Sharp, L.A. 2002 *The Sacrificed Generation: Youth, History and the Colonized Mind in Madagascar* Berkeley: University of California Press.

Smith, J. A., & Eatough, V. 2006 "Interpretative phenomenological analysis". In G. M. Breakwell, S. Hammond, C. Fife-Schaw, & J. A. Smith (Ed.), *Research Methods in Psychology* (pp. 322–341). London: Sage.

Taylor, J., Shostak, L., Rogers, A. and Mitchell, P. 2018 "Rethinking mental health provision in the secure estate for children and young people: a framework for integrated care (SECURE STAIRS)", Safer Communities, 17(4): 193-201.

Tomblin, B.J., Zhang, X., Buckwater, P. and Catts, H. 2000. 'The association of reading disability, behavioural disorders and language impairment among second-grade children' *Journal of child psychology and psychiatry* 41(4): 473

Trevor, J. 2010 "Public Opinion, Politics and the Response to Youth Crime" in D.J. Smith (ed.) *A New Response to Youth Crime*. Cullompton: Willan.

User Voice. 2018. *Young People Talk Spice and the Secure Estate* London: User Voice.

Vergara, A.T., Kathuria, P., Woodmass, K., Janke, R. and Wells, S.J. 2016 "Effectiveness of Culturally Appropriate Adaptations to Juvenile Justice Services" *J Juv Justice* 5(2): 85–103.

Vygotsky, L. S. 1978 *Mind in Society* Cambridge MA: Harvard University Press.

Warshak, R. 2003. "Payoffs and pitfalls of listening to children" *Family Relations*, 52: 373–384.

Wijedasa, D. 2015 *Characteristics of children living with relatives in England: Part 1* Bristol: University of Bristol Press.

Wilson, D., Caulfield, L.S. 2009 "Freedom of Expression" *Public Service Review: Home Affairs* 20: 64-65.

Wilson, D., Caulfield, L.S., Atherton, S. 2009 "Good vibrations: the long-term impact of a prison based music project" *The Prison Service Journal* 182: 27-32.

Woods, P. 2000 "Reviewed Work: Research with Children: Perspectives and Practices by Pia Christensen and Allison James" *British Journal of Educational Studies* 48 (3): 344-345.

THE STATE'S OBLIGATION TO PROTECT LIFE AND HEALTH OF VULNERABLE ADULTS – THE ORDER OF 26 JULY 2016 OF THE GERMAN FEDERAL CONSTITUTIONAL COURT IN THE LIGHT OF CRPD AND ECHR

ELISABETH RATHEMACHER

I. INTRODUCTION

The principles of self-determination in medical matters and to respect people's decision not to be treated are implemented in German health law.¹ The law concerning medical treatment applies equally to people with mental illnesses. Yet, there are also protective measures for cases of significant risks to others or oneself. The German law offers legal possibilities for forced medical treatment² and forced hospitalization to protect life and health of adults with serious mental illnesses that lead to impaired decision-making capacity and the denial of medical treatment.³

However, from the perspective of German fundamental law as well as human rights, the interference with physical integrity and self-determination to prevent self-damage is a difficult issue and has led to landmark decisions on national level concerning forced medical treatment.⁴ In the decision of the 26th of July 2016,⁵ the German Federal Constitutional Court (BVerfG) as Germany's institution to interpret fundamental rights, defined a duty of the state to protect vulnerable adults and therefore to use protective measures. This includes medical treatment against the natural will⁶ under narrowly defined preconditions as a last resort.⁷ Deviating from former court decisions, the German Court did not decide about the permissibility of a treatment to regain the capacity to consent, but a somatic treatment to save the patient's life. In its reasoning the court considered the UN Committee on the Rights of Persons with Disabilities' reports and guidelines, as well as the case law of the European Court of Human Rights (ECtHR). As already stated in a previous order on forced medical treatment, the court

¹ As for example in the §§ 630a-630h BGB (German Civil Code) dealing with the treatment contract or § 1901a BGB which deals with the advance directive for health care.

² The terms 'involuntary medical treatment' and 'forced medical treatment' are used synonymously in this report and refer to a medical treatment against the will of a person. This treatment can either be of somatic or psychiatric nature. The term 'involuntary treatment' has no common definition in international law, see European Union Agency for Fundamental Rights, 'Involuntary placement and involuntary treatment of persons with mental health problems', 2012, p. 9, available at <u>https://fra.europa.eu/sites/default/files/involuntary-placement-and-involuntary-treatment-of-persons-with-mental-health-problems en.pdf</u> (last accessed 22nd Dec. 2019).

³ On the basis of the federal adult protection law see § 1906 and § 1906a BGB; on the basis of public law there are 16 different mental health acts concerning the treatment of mentally ill people.

⁴ BVerfG, Order of the Second Senate of 23 March 2011 – 2 BvR 882/09 = BVerfGE 128, 282 = NJW 2011, 2113; BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15 = BVerfGE 142, 313 = BVerfG NJW 2017, 53.

⁵ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, available in English at <u>https://www.bundesverfassungsgericht.de/e/ls20160726 1bvl000815en.html</u> (last accessed 28th Dec. 2019).

⁶ "Treatment against the natural will" is the German definition for involuntary medical treatment.

⁷ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 71.

saw no contradiction in protective measures by the state including forced medical treatment as a last resort to the mentioned human rights treaties.⁸

However, the legitimacy of involuntary measures as involuntary hospitalization and forced medical treatment is discussed on international level as well.⁹ Whether involuntary measures should be completely banned against the background of the human rights treaties or whether they only require strict regulation is still controversially considered.¹⁰ Especially the United Nations Convention on Rights of Persons with Disabilities¹¹ (CRPD) encourages to rethink and discuss existing laws and practices concerning involuntary measures.¹² Perspectives, especially on 'will and preferences' Art. 12 (4) CRPD thereby differ considerably.¹³

¹⁰ Compiling the opinions of human rights stakeholders such as the Special Rapporteur on the rights of persons with disabilities and other human rights experts who encourages the abolition of involuntary treatment and placement, 'Mental health and human rights, Report of the United Nations High Commissioner for Human Rights', UN Doc. A/HRC/39/36 of 24th July 2018. Furthermore, the 'Statement by the Committee on the Rights of Persons with Disabilities to oppose the Draft Additional Protocol to the Oviedo Convention', Sept. 2018, available at

⁸ BVerfG, Order of the Second Senate of 23 March 2011 – 2 BvR 882/09, para 52; for further information on the case see footnote 46.

⁹ Overview of the different UN Committee positions S. Gurbai and W. Martin, 'Is Involuntary Placement and Non-Consensual Treatment Ever Compliant with UN Human Rights Standards?', available at <u>https://autonomy.essex.ac.uk/wp-content/uploads/2018/01/EAP-UN-Survey.pdf</u> (last accessed 20th Dec. 2019); older report from the European point of view, European Union Agency for Fundamental Rights, 'Involuntary placement and involuntary treatment of persons with mental health problems', 2012, p. 9, available at <u>https://fra.europa.eu/sites/default/files/involuntary-placement-and-involuntarytreatment-of-persons-with-mental-health-problems en.pdf</u> (last accessed 22nd Dec. 2019).

https://www.ohchr.org/Documents/HRBodies/CRPD/Statements/StatementOviedo CRPD20th.docx (last accessed 28th Dec. 2019) stresses that the legitimacy of involuntary treatment and placement opposes Art. 14, 17 and 25 CRPD. Also, for the abolition of regulations allowing involuntary treatment and placement in its latest report, the UN Committee on the Rights of Persons with Disabilities, 'Concluding observations on the combined second and third periodic reports of Spain', UN Doc. CRPD/C/ESP/CO/2-3, para 26-30. More moderate view on involuntary treatment: Human Rights Committee, UN Doc. CCPR/C/AZE/CO/4 no. 13 ("psychiatric confinement is applied only as a measure of last resort and for the shortest appropriate period of time and that the confinement is strictly necessary and proportionate for the purpose of protecting the individuals in question from serious harm or from preventing injury to others"); Council of Europe: 'Draft Additional Protocol concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment', DH-BIO/INF (2018) 7, see Art. 10 and 11.

¹¹ The United Nations Convention on the Rights of Persons with Disabilities (CRPD) passed by the general assembly of the United Nations 13th December 2006.

¹² E. Flynn, 'Disability, Deprivation Of Liberty and Human Rights Norms: Reconciling European and International Approaches', International Journal of Mental Health and Capacity Law, 2016, [75-101]; P. Cuenca Gómez, M. Barranco Avilés and P. Rodríguez des Pozo, 'Psychosocial Disability And Deprivation Of Liberty: Reviewing The Case Of Qatar In The Light Of The Convention On The Rights Of Persons With Disabilities', International Journal of Mental Health and Capacity Law, 2018, [55-77]; P. Fennell, in: I. Bantekas & M. Stein & D. Anastasiou (edit.), 'The UN Convention on the Rights of Persons with Disabilities: a commentary', Oxford University Press, 2018, Art. 15, [437-442]; Favorizing a strict abolition of involuntary measures: T. Minkowitz, 'Abolishing mental health laws to comply with the Convention on the Rights of Persons with Disabilities', in: B. McSherry, P. Weller (edit.), 'Rethinking Rights-Based Mental Health Laws' Oxford and Portland', Hart Publishing, 2010, [151–177].

¹³ G. Szmukler, "Capacity", "best interest", "will and preferences" and the UN Convention on the Rights of Persons with Disabilities', World Psychiatry, 2019, [34-41]; For example, some interpretations divide the term "will and preferences", giving "will" and "preference" different values in the will determination process. See A. Ward and P. Curk, "Respecting 'will': Viscount Stair and online shopping", BtPrax, 2019, [54-58]; A. Arstein-Kerslake & E. Flynn, ' The General Comment on Article 12 of the Convention on the

Human rights are mandatory guidelines for national law. But the texts of treaties as CRPD and ECHR often do not provide solutions to specific problems and need interpretation. However, the practical application of incorporated international law in national cases and the interpretation of indefinite terminology is often up to national courts.¹⁴ Therefore, besides international institutions, the national courts play an important role in interpreting human rights by applying them¹⁵ and it is worthwhile to have a closer look at national decisions considering international human rights treaties.

This report intends to explain the case and arguments of the BVerfG in the order of the 26^{th} July 2016 in the context of CRPD and ECHR. The relationship to the interpretations of the CRPD Committee and the ECtHR case-law will be addressed in particular.

II. THE COURT'S CASE WITHIN THE CONTEXT OF GERMAN ADULT PROTECTION LAW

A. A brief introduction to German adult protection law

Germany has got a two-tiered legal system for the protection of adults. One tier is based on private mandates as the enduring power of attorney (Vorsorgevollmacht), which is a fully equivalent, private alternative to the second tier, the statutory system *Rechtliche Betreuung*.¹⁶ The German "*Betreuung*" is an instrument for the legal protection of adults in need of help. It ensures the exercising and protecting of the rights of the adult by appointing a legal representative by court order without incapacitating the adult or restricting legal capacity. Measures of protection for an adult are dealt with by a special court (a department of the local court), the "Betreuungsgericht,", hereafter referred to as guardianship court. The "Betreuer" (court-appointed legal representative) takes care of the specific matters assigned to him in the individual case and is obliged to respect the will and preferences of the adult, § 1901 (3) German Civil Code (BGB). It is only as a last resort, i.e. if advising and assisting the adult proves unsuccessful, that the court-appointed legal representative may use his power to represent the adult in his or her affairs. The affected person remains able to give consent, even though he or she might have a legal representative for matters of health care.

Rights of Persons with Disabilities: a roadmap for equality before the law', The International Journal of Human Rights 20(4), [471-490].

¹⁴ There are differences in incorporation of international law. Germany has incorporated the CRPD as a federal law.

¹⁵ On the different roles of national courts in applying international humanitarian law, S. Weill, 'The Role of National Courts in Applying International Humanitarian Law', Oxford University Press, 2014.

¹⁶ "Betreuung" is an instrument for the legal protection of adults by appointing a legal representative by court order without incapacitation, for further English explanation of the term see <u>https://www.wcag2016.de/fileadmin/Mediendatenbank WCAG/Tagungsmaterialien/Glossar.pdf</u> (last accessed 28th Dec. 2019); The law of "Betreuung" is based on the principles of necessity and autonomy. Voluntary (private) measures such as a continuing power of attorney for health care have priority, see § 1896 (2) BGB.

According to the law, with the exception of emergency cases, every medical treatment requires the informed consent of the patient. Doubts on the adult's capacity to consent have to be verified for each medical intervention by the physician. Due to mental illness, a patient might not understand the importance or consequences of treatment and thus cannot give informed consent. In this case his legal representative has to consent for him (§ 630d (1) BGB) if he does not have an advance directive in health care (§ 1901a (1) BGB) consenting or disagreeing with the needed medical treatment.

The ultimate limit of these regulations is the *natural will* of the adult. The term '*natural will*' in the context of the court implies any wish or will that is consciously expressed without necessarily being legally effective in terms of not having the capacity to consent.¹⁷ Any medical treatment against the natural will of a patient is characterized as involuntary medical treatment¹⁸ and therefore needs to accomplish the legal requirements and approval by court. Therefore, only in exceptional cases and under very strict conditions, German law allows forced medical treatment.¹⁹

Due to the federalist system, there are rules on forced medical treatment and deprivation of liberty regulated in the adult protection law *Betreuung* as well as in the Mental Health Acts of the 16 individual German states. These state laws do not require a consent of a legal representative and can concern a threat to the safety of others as well.²⁰ The Mental Health Acts differ in detail, usually apply to urgent cases and are not covered by the addressed BVerfG's decision.²¹

B. The case

The case dealt with by the BVerfG concerned a woman who suffered from a schizoaffective psychosis. She was under supervision of the German statutory adult protection system "*Betreuung*". Her court-appointed legal representative was assigned to manage matters of health care for her.²² She was accommodated in a care facility, where she refused to take medication for her autoimmune disorder and expressed the intent to commit suicide. After having been transferred to a closed dementia unit with the approval of the guardianship court, her illnesses were treated against her natural will on the basis of multiple court orders. At the hospital it was discovered that she also suffered from breast cancer. At this point she was physically weakened to such an extent, that she could neither leave the hospital, nor did she want to leave.

¹⁸ This can either be psychiatric or somatic treatment.

¹⁷ For an English explanation see A. Ward, 'A major step forward in CRPD compliance by the German Federal Constitutional Court?', Mental Capacity Law Newsletter, (70), Nov. 2016, 22, [30]; G. Szmukler, 'The UN Convention on the Rights of Persons with Disabilities: 'Rights, will and preferences' in relation to mental health disabilities' International Journal of Law and Psychiatry, (54), 2017, 90, [92].

¹⁹ See § 1906 BGB (old version), which respects the requirements set by BVerfG, Order of the Second Senate of 23 March 2011 – 2 BvR 882/09; BVerfG, Order of the Second Senate of 12 October 2011 – 2 BvR 633/11 = BVerfGE 129, 269 = NJW 2011, 3571.

²⁰ According to several decisions of the BVerfG, these regulations had to be reviewed and are mostly subject to revision to new standards.

 $^{^{21}}$ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 71 the court refers to "persons under custodianship".

²² There is no distinction between psychiatric and somatic matters of health care in Germany.

The woman was considered unable to give her consent to the medical treatment for the breast cancer. But she was able to express her natural will and communicated that she did not wish to be treated. Therefore, her court-appointed legal representative applied to the guardianship court for the extension of the patient's forced hospitalization and for involuntary medical measures to treat the cancer. The guardianship court denied the application because the woman did not want to leave the hospital and therefore did not meet the legal requirements for forced hospitalization. For that reason, she could not be subject to coercive medical treatment.

In German law, the natural will of the patient limits the possibility for the legal representative to decide on a treatment²³ and can only be overruled, if the requirements for the use of involuntary medical treatment are met.²⁴ At the time of the order, § 1906 (3) BGB (old version) listed the requirements which are necessary for the approval of the guardianship court.

The medical (psychiatric or somatic) treatment has to be necessary to prevent a threatening considerable damage to health and the rejection of the treatment by the patient has to be grounded on a psychiatric illness or a mental health disability.²⁵ Serious efforts have to be made to convince the patient to be treated voluntarily. The medical intervention needs to be the only possibility to prevent serious health damage and the expected profit has to outweigh the possible impairments. The crux of the case was that the provisions of § 1906 (3) BGB (old version) did not distinguish between the requirements of forced hospitalization and involuntary treatment. Hence, the law demanded in addition to other criteria the involuntary hospitalization of a patient when he was treated against his natural will.

The criteria for the court's approval for forced hospitalization, § 1906 (1) BGB²⁶ are not met if there is no deprivation of liberty, i.e. the hospitalization is not against or without the will of the person concerned and the patient stays in hospital voluntarily.²⁷ Thus, involuntary medical treatment was limited to patients who rejected hospitalization.

In the sequence of proceedings, the BVerfG was engaged with the case having to decide about the compatibility of the current regulation with the German Constitution which necessarily required involuntary accommodation and therefore was preventing the woman from being treated.

The woman was not treated for her breast cancer and died before the court could decide about § 1906 (3) BGB. Whether the woman should have been treated

²³ See § 1904 BGB.

²⁴ Forced treatment against the free will of a person is not possible.

²⁵ § 1906 (3) BGB (old version).

²⁶The legal representative can apply for forced hospitalization for two reasons. Firstly, if the patient may seriously endanger his health or life because of a psychiatric illness. Secondly, if to prevent a serious health damage or death a treatment is necessary which needs a hospitalization which the patient refuses because of a psychiatric illness, see § 1906 (1) No. 1 and 2 BGB.

²⁷ BGH, Order of 1 July 2015 - XII ZB 89/15 = FamRZ 2015, 1484, para 18-19; BGH, Order of 23 January 2008 - XII ZB 185/07 = FamRZ 2008, 866, para 19-20.

involuntarily, was not decided by the court, as this was not the relevant question. This would have implied further investigation of the requirements of involuntary medical treatment as the original will of the woman on the treatment of her breast cancer.

III. KEY POINTS OF THE COURT'S DECISION

A. The state's duty to protect

The judges decided that not having a regulation to treat people with a court-appointed legal representative in need of a medical treatment who cannot recognise the necessity of a medical measure or who cannot act in accordance with this realisation violates the state's duty of protection of the right to life and physical integrity under Art. 2 (2) sentence 1 German Constitutional Law.²⁸

In its reasoning the court explained the origin of the state's "duty to protect". The court claimed that the constitutionally guaranteed right to life and physical integrity does not only guarantee a subjective defensive right of the individual against the state but sets up objective values that demand duties of protection on part of the state, to protect and support the life of individuals.²⁹

This usually undefined duty of the state takes a specific form if individuals meet the requirements for the appointment of a legal representative and are not able to recognize the necessity of a medical treatment or cannot act in this awareness due to their mental illness.³⁰ As ultima ratio, a medical examination and treatment against the natural will of the individual must be possible.³¹

Even though the court refers to individuals with the need of a court-appointed legal representative, this decision is also applicable to adults with a legal representative under an enduring power of attorney (*Vorsorgevollmacht*) who has been determined by the adult himself to decide on matters of deprivation of liberty and involuntary medical treatment.³²

Despite the aforementioned safeguard function of the right to life, involuntary medical treatment still conflicts with the person's right to self-determination and the right to physical integrity.³³ Generally, under German Constitutional Law all people are free to deal with their own health – the BVerfG called it the "freedom to illness".³⁴ To medically treat somebody because it is assumed the best out of an objective third party view would interfere with the general right of personality (Art. 2 (1) in conjunction with Art. 1 (1) German Constitutional Law).³⁵ This strictly implies that a treatment against the

²⁸ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 66-68.

²⁹ Ibid, para 68-69.

³⁰ Ibid, para 71.

³¹ Ibid, para 71.

³² See § 1906 (5) and § 1906a (5) BGB.

³³ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 74.

³⁴ BVerfG, Order of the Second Senate of 23 March 2011 – 2 BvR 882/09, para 19; BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 74.

³⁵ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 74.

free will³⁶ is impossible, because the free will is prior to the state's duty of protection.³⁷ But the person's right to self-determination and right to physical integrity can be interfered with by law in cases of serious threats to the health of persons who are unable to protect themselves. For those cases the state has to provide the possibility of involuntary medical treatment under certain conditions.³⁸

This requires the absence of free will, i.e. a missing competence to decide about necessary treatments due to a mental disorder or illness.³⁹ Additionally, the medical treatment needs to be necessary to avoid a serious threat to the person's health or life and must not be associated with dangerous treatment risks.⁴⁰ Most importantly, there must not be any reason to believe that the refusal of the treatment reflects the original free will of the person.⁴¹ The *original free will*⁴² is a former effectively expressed legal will e.g. by advance directives for health care. The court stressed that this process is a matter of balancing the rights in every individual case and the natural will has to be taken into account when deciding about involuntary treatment.⁴³ Moreover, firm procedural safeguards are necessary to ensure coercive treatment will only be used in the cases described above.⁴⁴

B. The compatibility of involuntary medical treatment with obligations under international law

The court reflected arguments of the interpreting sources of the CRPD and the European Convention on Human Rights (ECHR) concluding that coercive medical treatment is compatible with Germany's obligations under international law.⁴⁵

The BVerfG stated that its rulings on involuntary medical treatment are in line with the CRPD, including Art. 12 CRPD (equal recognition before the law). Thus, they confirmed their statement on Art. 12 CRPD which was already specified in a previous order on the prerequisites for compulsory medical treatment of a forensic patient.⁴⁶ The court affirmed that the CRPD aims at safeguarding and strengthening the autonomy of persons with disabilities. However, they saw no general prohibition of measures which are conducted against the natural will in case the capability of self-determination is

³⁶ 'Free will' means that the will is competent und legally effective in the matter concerned; for an English explanation see A. Ward, 'A major step forward in CRPD compliance by the German Federal Constitutional Court?', Mental Capacity Law Newsletter, (70), Nov. 2016, 22 [30].

³⁷ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 75.

³⁸ Ibid, para 80.

³⁹ Ibid, para 78-79.

⁴⁰ Ibid, para 80.

⁴¹ Ibid, para 82.

 ⁴² For an English explanation of the term see A. Ward, 'A major step forward in CRPD compliance by the German Federal Constitutional Court?', Mental Capacity Law Newsletter, (70), Nov. 2016, 22 [30].
 ⁴³ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 82.

⁴⁴ Ibid, para 84.

⁴⁵ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 87.

⁴⁶ BVerfG, Order of the Second Senate 23 March 2011 – 2 BvR 882/09. The court decided that the approval of forced medical treatment is not included in the approval of forced hospitalization. They decided that involuntary medical treatment strictly requires that the person accommodated is incapable of understanding the severity of his/her illness and the necessity of treatment measures or of acting in accordance with his or her understanding due to the illness.

limited. On the basis of Art. 12 (4) CRPD, the BVerfG concluded that measures against the natural will of the person must be possible, as long as suitable safeguards are implemented by the state.⁴⁷

The court also justified its decision with regard to the reports of the UN Committee on the Rights of Persons with Disabilities (CRPD Committee)⁴⁸. In the court's opinion the CRPD Committee does not impose binding decisions on how to interpret the treaty upon the member states,⁴⁹ but its reports have to be considered and dealt with in an argumentative way.⁵⁰ They admitted that the CRPD Committee criticized the German adult protection law in its *Concluding observations on the initial report of Germany* in 2015.⁵¹ The CRPD Committee recommends in line with the *General comment No. 1* in 2014⁵² on Art. 12 CRPD that all forms of substituted decision-making should be replaced by systems of supported decision-making.⁵³ Yet, the court underlined that the CRPD Committee remained vague. It did not refer to this special case addressed by the court and thus did not exclude involuntary medical treatment for this situation.⁵⁴

The court also referred to the CRPD Committee's interpretation of Art. 14 CRPD (Liberty and security of the person) in its *Guidelines on article 14 of the CRPD*.⁵⁵ The BVerfG assumed that the spirit of the CRPD cannot possibly deny people who cannot form a free will any help. Therefore, the court stated that in their opinion the CRPD is not opposed to coercive treatment if it is strictly regulated.⁵⁶ Additionally, the court emphasised that due to the German adult protection law, the will and the - if necessary - "supported will" of the patient have priority as demanded by the CRPD Committee.⁵⁷ The court summarised that even taking the CRPD committee's arguments into account, there is no good reason under the text and spirit of the CRPD to abandon such persons to their fate, and to conclude that the CRPD is opposed to compulsory medical treatment where this is constitutionally required under strictly regulated circumstances.⁵⁸

According to the BVerfG the state's obligation to protect and therefore use coercive medical treatment as ultima ratio is also in accordance with the ECHR and the case law of the ECtHR.⁵⁹ They referred to the ECtHR's jurisprudence on Art. 8 ECHR which

 $^{^{47}}$ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 88 citing BVerfG, Order of the Second Senate of 23 March 2011 – 2 BvR 882/09.

⁴⁸ Concerning the function of the United Nations Committee on the Rights of Persons with Disabilities see part IV.

⁴⁹ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 90 with further references.

⁵⁰ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 90.

⁵¹ CRPD Committee, Concluding observations on the initial report of Germany (2015), UN Doc. CRPD/C/DEU/CO/1.

⁵² CRPD Committee, General comment No. 1 (2014), UN Doc. CRPD/C/GC/1.

⁵³ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 91.

⁵⁴ Ibid.

⁵⁵ CRPD Committee, Guidelines on article 14 of the CRPD adopted during the Committee's 14th session, September 2015, Annex to the Report of the Committee on the Rights of Persons with Disabilities, UN Doc. A/72/55.

⁵⁶ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 91.

⁵⁷ Ibid, para 91.

⁵⁸ Ibid, para 91.

⁵⁹ Ibid, para 92.

provides the right to respect one's private life and therefore to live in selfdetermination, as well as on the right to life, Art. 2 ECHR.⁶⁰ The court stressed that the ECtHR gives the states a margin of appreciation to which extent the right to live in self-determination and to harm one's health may be granted.⁶¹ The ECtHR demands that decisions which may lead to serious harm or death may only be accepted if the adult has a free will and is of sound mind.⁶² Otherwise the ECtHR states, that keeping a person from risking his or her life is manifested in Art. 2 ECHR as a duty of the state.⁶³ The state has to take care that there are sufficient regulatory arrangements which ensure that an individual's decision of not being treated is based on a free will.⁶⁴ Therefore, the BVerfG concluded that the ECtHR's interpretation of Art. 2 and Art. 8 ECHR does not contradict their own assumptions.⁶⁵

IV. DISCUSSION OF THE COURT'S ARGUMENTS

A. Arguments concerning CRPD compliance

Although the court assumed that its results are in conformity with the CRPD, some parts of the German adult protection law, especially concerning forced medical treatment, are controversial.⁶⁶ In particular, the compliance with the CRPD is in question. This was notably expressed by the CRPD Committee in the *Concluding observations on the initial report of Germany*.⁶⁷ Therefore, the various arguments raised by the BVerfG shall be discussed in the light of the CRPD. In addition, the court's understanding of the CRPD Committee's statements shall be explained.

The CRPD was adopted to ensure that people with disabilities receive equal enjoyment of the basic rights, Art. 1 CRPD. In Germany the CRPD has the force of law and helps to determine the scope of fundamental human rights.⁶⁸ According to Art. 4 CRPD the

⁶⁰ Ibid, para 93 with reference to Pretty v UK (App no 2346/02) ECHR 2002-III, 155 [194], para 62-63. Pretty v UK deals with the legislative position on assisted suicide.

⁶¹ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 93 with reference to Lambert and others v France (App no. 46043/14) ECHR 2015-III, 67 [117], para 148. The case of Lambert and others was about the range of the state's obligation according to Art. 2 ECHR.

 $^{^{62}}$ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 94; for the requirements of "unsound mind" see Winterwerp v the Netherlands (App no 6301/73) ECHR Series A no. 33; Winterwerp v the Netherlands is a landmark decision on Art. 5 ECHR naming the minimum criteria for the lawful detention of people with "unsound mind".

⁶³ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 94 with reference to Lambert and others v France (App no. 46043/14) ECHR 2015-III, 67 [114], para 140; dealing with the question whether it is an individual right to decide to end one's life Haas v Switzerland (App no 31322/07) ECHR 2011-I, 95 [117], para 54; Arskaya v Ukraine (App no 45076/05) (ECHR 5th December 2013), para 69-70; Arskaya v Ukraine deals with the state's obligation to ensure adequate health-care regulations, concerning decision-making capacity of the patient.

⁶⁴ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 94 with reference to Arskaya v Ukraine (App no 45076/05) (ECHR 5th December 2013), para 69-70, 88.

⁶⁵ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 95.

⁶⁶ S. Schmahl, 'Menschenrechtliche Sicht auf die Zwangsbehandlung von Erwachsenen bei Selbstgefährdung', in: D. Coester-Waltjen et al. (edit.), 'Zwangsbehandlung bei Selbstgefährdung', Universitätsverlag Göttingen, 2016, [43-53]; D. Kuch, 'Wohltätiger Zwang', DÖV, 2019, 723, [730-732]; P. Masuch and C. Gmati, 'Zwangsbehandlung nach dem Gesetz zur Regelung der betreuungsrechtlichen Einwilligung in eine ärztliche Zwangsmaßnahme und UN-Behindertenrechtskonvention', NZS, 2013, 521.
⁶⁷ UN Doc. CRPD/C/DEU/CO/1, para 25.

⁶⁸ Incorporated in German Federal Law in 2008, see BGBI. II, 2008, p. 1419.

Convention's rights have to be respected in legislation and jurisprudence of the national courts.

The CRPD Committee is a safeguard implemented by the treaty itself (Art. 34 CRPD), which gives advice and evaluates the state reports on legal basis of Art. 36 (1) CRPD. The countries report about their progress implementing the CRPD to the CRPD Committee, which evaluates the measures and gives general recommendations (as demanded by Art. 35 CRPD). An optional protocol, which was signed by Germany as well, gives the Committee the authority to examine individual complaints about state's violations of the Convention, however, without the ability to sanction them.⁶⁹

In several decisions, the BVerfG already confirmed that it does not consider the statements of the CRPD Committee as binding, neither on international nor national courts.⁷⁰ Regardless of the content of the UN Committee's statements, the BVerfG's view seems plausible. Primarily, the interpretation of the treaty is the duty of the member states and has to focus on the treaty's intention, Art. 31 (1) Vienna Convention⁷¹. In addition, the competence of committees developed by human rights treaties is not uniformly valued.⁷² Therefore, the CRPD Committee as an organ implemented by the treaty itself, does not necessarily provide an obligatory interpretation of the CRPD. In Germany, the CRPD is implemented in national law and is reviewed within the national jurisdictions. Unlike the ECHR, the CRPD is not reviewed by an international court like the ECtHR who may take binding decisions. The committee cannot be accorded the same status. Their interpretations (such as the concluding observations) are not legally binding, they only "shall make [...] suggestions and general recommendations" Art. 36 (1) CRPD.⁷³ Yet, the CRPD Committee plays an important role in the unification of interpretation and the supervision of implementation. Therefore, as said by the court, their argumentation is important and has to be well considered.⁷⁴

The question remains whether the considerations of the BVerfG concerning the justification of involuntary medical treatment for vulnerable adults comply with the CRPD. The CRPD Committee's interpretation clearly rejects any form of restricting autonomy and especially involuntary medical treatment as a form of substituted decision-making.⁷⁵ The *General comment No. 1* on the interpretation of the CRPD articles criticized involuntary medical treatment, declaring it to be in violation of Art.

⁶⁹ See Art. 6 and 7 of the Optional Protocol to the Convention on the Rights of Persons with Disabilities. ⁷⁰ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 90; confirmatory BVerfG, Order of the Second Senate of 24 July 2018 – 2 BvR 309/15, 2 BvR 502/16, para 90-91 = BVerfGE 149, 293.

⁷¹ Vienna Convention on the Law of Treaties, opened for signature Vienna 23 May 1969 and entered into force in Germany, 20 August 1987.

⁷² See A. Ward, 'A major step forward in CRPD compliance by the German Federal Constitutional Court?', Mental Capacity Law Newsletter, (70), Nov. 2016, 22 [26] with reference to HRC, General Comment No 33, UN Doc. CCPR/C/GC/33 of 5 November 2008, para 13.

⁷³ G. Szmukler, 'The UN Convention on the Rights of Persons with Disabilities: 'Rights, will and preferences' in relation to mental health disabilities', International Journal of Law and Psychiatry (54), 2017, 90 [91] speaks of the CRPD Committee's interpretations as 'authoritative' but not 'legally binding'. ⁷⁴ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 90.

⁷⁵ UN Doc. CRPD/C/GC/1, para 7, 9, 42; UN Doc. CRPD/C/DEU/CO/1, para 26, 37-38.

17⁷⁶, Art. 15⁷⁷, Art. 16⁷⁸ and Art. 12 of the Convention.⁷⁹ The CRPD Committee insists that all medical interventions relating to physical or mental integrity shall be based on the free and informed consent of the individual.⁸⁰ They attested the member states a "general failure to understand"⁸¹ the treaty's intention on supported decision-making and requested to make alternative assistance available.⁸²

Furthermore, the CRPD Committee presented their opinion on the German rules on compulsory medical treatment and the German adult protection law in their *Concluding observations on the initial report of Germany* in 2015.⁸³ The legal instrument of "*Betreuung*⁷⁸⁴ was declared incompatible with the CRPD.⁸⁵ They criticized the use of compulsory treatment and recommended the elimination of all forms of substituted decision-making.⁸⁶

Despite the CRPD Committee's obvious position on involuntary treatment, the BVerfG asserted that the CRPD Committee did not consider the special situation addressed in the order.⁸⁷ Looking at the CRPD Committee's reports, this can be confirmed. They did not explicitly focus on people with serious mental illnesses which are in a life-threatening condition. Furthermore, they did not state that the member states have to accept the death of persons with impaired decision-making capacity.

The BVerfG also affirmed that its argumentation complies with the CRPD Committee's guidelines regarding the interpretation of Art. 14 CRPD.⁸⁸ The guidelines declare that during deprivation of liberty there shall be no medical measures for the protection of health without the free and informed consent of the person concerned.⁸⁹ Therefore, the BVerfG concluded that the CRPD Committee demands the state to abandon coercive treatment.⁹⁰ However, the court assumed that the CRPD Committee's statement cannot exclude people who cannot give their consent from access to medical treatment.⁹¹ The CRPD Committee itself has seen a need for exceptions in cases when no will can be determined, such like a coma. In such cases, the "best interpretation of will and preferences"⁹² may be applied. To the German Constitutional Court the term

⁷⁶ Protecting the integrity of the person.

⁷⁷ Freedom of torture or cruel, inhuman or degrading treatment or punishment.

⁷⁸ Freedom from exploitation, violence and abuse.

⁷⁹ UN Doc. CRPD/C/GC/1, para 42.

⁸⁰ Ibid, para 41.

⁸¹ UN Doc. CRPD/C/GC/1, para 3.

⁸² UN Doc. CRPD/C/GC/1, para 3, 28-29; Criticising the uncompromising stance of the CRPD Committee S. Schmahl, 'Stellung und Rolle der UN-Behindertenrechtskonvention im Gefüge des universellen Menschenrechtsschutzsystems', in: A. Diekmann et al. (edit.), 'Betreuungsrecht im internationalen Kontext', Eigenverlag Betreuungsgerichtstag e.V., 2017, 82 [89].

⁸³ UN Doc. CRPD/C/DEU/CO/1.

⁸⁴ See footnote 16.

⁸⁵ UN Doc. CRPD/C/DEU/CO/1, para 25.

⁸⁶ Ibid, para 26, 37-38.

⁸⁷ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 91.

⁸⁸ Ibid, para 91 referring to the Guidelines on Art. 14 CRPD.

⁸⁹ Guidelines on article 14 of the CRPD, UN Doc. A/72/55, no. 11.

⁹⁰ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 91.

⁹¹ A. Ward, 'A major step forward in CRPD compliance by the German Federal Constitutional Court?', Mental Capacity Law Newsletter, (70), Nov. 2016, 22 [28-29].

⁹² UN Doc. CRPD/C/GC/1, para 21.

"free and informed consent" in Art. 25 (d) CRPD implies that whether or not the incapability to give the free and informed consent refers to a coma or a mental illness, the treatment should still be given⁹³ if it reflects the *original* or *presumed free will*⁹⁴ of the person.

To understand the BVerfG's interpretation of the CRPD Committee's statements, one must assume that the court's arguments are based on two ideas. Firstly, the court assumes that the rights of the individual, namely Art. 12 and Art. 10 or Art. 25 CRPD respectively, can be weighed against each other under certain circumstances in cases of serious threats to life and health. Secondly, to clarify the stance of the court, one has to assume that there is a distinction between a *natural* and a *free will.*⁹⁵

The fundamental idea of the CRPD is to promote equality and equal treatment of persons with disabilities. Yet, the view of the BVerfG that Art. 12 CRPD is not granted without respecting the other rights of an individual as long as the interventions are objectively justified and proportionate,⁹⁶ is also supported by the convention's text.

Involuntary medical treatment of persons with impaired decision-making capacity is not explicitly prohibited by the CRPD. An earlier draft of the CRPD planned to strictly regulate coercive measures in Art. 17 CRPD.⁹⁷ Though, it was not included in the conventions final text. However, no regulation of involuntary medical treatment does not indicate a prohibition.⁹⁸

Furthermore, the CRPD's aim is to protect life and health of the person as stated in Art. 10 and 25 CRPD. In cases of conflict, those rights have to be carefully considered for the individual.⁹⁹ Therefore, the text of the CRPD does not generally exclude the right to protect the life in favour of guaranteeing autonomy if the person requires support.¹⁰⁰ In the international discussion, too, efforts have been made to find

⁹³ A. Ward, 'A major step forward in CRPD compliance by the German Federal Constitutional Court?', Mental Capacity Law Newsletter, (70), Nov. 2016, 22 [29].

⁹⁴ On the basis of known values which are important to the person, a third person interprets the will and preferences representatively for the concerned person.

⁹⁵ Medical treatment against the free will of the person is not possible.

⁹⁶ V. Lipp, 'Erwachsenenschutz, gesetzliche Vertretung und Artikel 12 UN-BRK', in: V. Aichele (edit.) 'Das Menschenrecht auf gleiche Anerkennung vor dem Recht', Nomos, 2013, 329 [335-336]; R. Marschner, 'Menschen in Krisen: Unterbringung und Zwangsbehandlung in der Psychiatrie', in: V. Aichele (edit.) 'Das Menschenrecht auf gleiche Anerkennung vor dem Recht', Nomos, 2013, 203 [221].

⁹⁷ R. Kayess and P. French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities', HRLR, 2008, 1 [29-30].

⁹⁸ Ibid, [30] R. Kayess and P. French see no opposition by the Ad Hoc Committee to forced medical treatment.

⁹⁹ R. Marschner, 'UN-Konvention über die Rechte von Menschen mit Behinderungen – Auswirkungen auf das Betreuungs- und Unterbringungsrecht', R&P, 2009, 135 [137]; M.C. Freeman et al., 'Reversing hard won victories in the name of human rights: a critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities', Lancet Psychiatry, 2015, [844-850].

¹⁰⁰ Same opinion S. Schmahl, Menschenrechtliche Sicht auf die Zwangsbehandlung von Erwachsenen bei Selbstgefährdung', in: D. Coester-Waltjen et al. (edit.), 'Zwangsbehandlung bei Selbstgefährdung', Universitätsverlag Göttingen, 2016, 43 [52]; P. Masuch and C. Gmati, 'Zwangsbehandlung nach dem Gesetz zur Regelung der betreuungsrechtlichen Einwilligung in eine ärztliche Zwangsmaßnahme und UN-Behindertenrechtskonvention' NZS, 2013, 521 [526].

solutions to these ethical conflict situations.¹⁰¹ Possible state interventions should be disability-neutral.¹⁰²

Furthermore, the safeguard function of Art. 12 (4) CRPD, "the state parties shall ensure that measures taken to exercise legal capacity are appropriate and proportional to the person's rights and interests", indicates that substituted decision-making as a last resort is also covered by the treaties text. In 2011, the BVerfG confirmed that Article 12 CRPD does not forbid measures which limit self-determination in general.¹⁰³ Following this decision, the BVerfG has based its position upon Art. 12 (4) CRPD.¹⁰⁴ It stated that "the context of the provision in Art. 12 (4) CRPD, which expressly relates to measures limiting persons concerned in their legal capacity and agency, proves that the Convention does not prohibit such measures in general, but that it limits their permissibility inter alia by obliging the signatories to the Convention under Art. 12 (4) CRPD to provide for suitable safeguards against conflicts of interests, misuse and disregard, and to ensure proportionality".¹⁰⁵ Thus, the court extended the requirements of Art. 12 (4) CRPD to involuntary medical treatment.

Though in Germany many scholars generally agree that forced medical treatment complies with the CRPD,¹⁰⁶ the interpretations of Art. 12 CRPD differ: For instance, *Lachwitz* limits Art. 12 (4) CRPD to supportive measures provided by Art. 12 (3) CRPD.¹⁰⁷ This would exclude forced medical treatment. It is widely agreed on that Art. 12 (3) CRPD may give a right to support but does not force support upon the person.¹⁰⁸

¹⁰³ BVerfG, Order of the Second Senate of 23 March 2011 – 2 BvR 882/09, para 52-53.

¹⁰⁴ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 88.

¹⁰¹ Giving an overview of the different approaches L. Series and A. Nilsson, in: I. Bantekas & M. Stein & D. Anastasiou (eds), 'The UN Convention on the Rights of Persons with Disabilities: a commentary', Oxford University Press, 2018, Art. 12, 339 [357].

¹⁰² For example, E. Flynn and A. Arstein-Kerslake, 'State intervention in the lives of people with disabilities: the case for a disability-neutral framework', International Journal of Law in Context, (13), 39 [49-52].

¹⁰⁵ Ibid, para 88 with reference to BVerfG, Order of the Second Senate of 23 March 2011 – 2 BvR 882/09, para 52-53.

¹⁰⁶ S. Schmahl, 'Menschenrechtliche Sicht auf die Zwangsbehandlung von Erwachsenen bei Selbstgefährdung', in: D. Coester-Waltjen et al. (edit.), 'Zwangsbehandlung bei Selbstgefährdung', Universitätsverlag Göttingen, 2016, [43-53]; P. Masuch and C. Gmati, 'Zwangsbehandlung nach dem Gesetz zur Regelung der betreuungsrechtlichen Einwilligung in eine ärztliche Zwangsmaßnahme und UN-Behindertenrechtskonvention', NZS, 2013, 521 [526]; V. Lipp, 'Erwachsenenschutz, gesetzliche Vertretung und Artikel 12 UN-BRK' in: V. Aichele (edit.) 'Das Menschenrecht auf gleiche Anerkennung vor dem Recht', Nomos, 2013, 329 [335].

¹⁰⁷ K. Lachwitz, 'Übereinkommen der Vereinten Nationen über die Rechte von Menschen mit Behinderung', BtPrax, 2008, 143 [147]; ibid, 'Funktion und Anwendungsbereich der "Unterstützung" ("support") bei der Ausübung der Rechts-und Handlungsfähigkeit gemäß Artikel 12 UN-BRK – Anforderungen aus der Perspektive von Menschen mit geistiger Behinderung', in: V. Aichele (edit.) 'Das Menschenrecht auf gleiche Anerkennung vor dem Recht', Nomos, 2013, 67 [84-85]; also W. Kaleck, S. Hilbrans and S. Scharmer, Gutachterliche Stellungnahme (2008), [32], available at <u>https://www.diebpe.de/stellungnahme/stellungnahme.pdf</u> (last accessed 28th Dec. 2019.

¹⁰⁸ S. Baufeld, ¹Zur Vereinbarkeit von Zwangseinweisungen und -behandlungen psychisch Kranker mit der UN-Behindertenrechtskonvention¹, R&P, 2009, 167 [172] referring to the word "provide"; K. Lachwitz, ¹Funktion und Anwendungsbereich der "Unterstützung" ("support") bei der Ausübung der Rechts-und Handlungsfähigkeit gemäß Artikel 12 UN-BRK – Anforderungen aus der Perspektive von Menschen mit geistiger Behinderung¹, in: V. Aichele (ed) ¹Das Menschenrecht auf gleiche Anerkennung vor dem Recht¹, Nomos, 2013, 67 [75]; V. Lipp, ¹Erwachsenenschutz, gesetzliche Vertretung und Artikel 12 UN-BRK¹ in: V. Aichele (edit.) ¹Das Menschenrecht auf gleiche Anerkennung vor dem Recht², Nomos,

However, this does not imply that interventions through substituted decision-making cannot be involved as a last resort.¹⁰⁹ As a strict regulation for "unwanted" measures would be much more essential, *Lipp* states that restricting sec. 4 to required measures in Art. 12 (3) CRPD would limit the safeguard function of Art. 12 (4) CRPD enormously.¹¹⁰ Therefore, the requirements of Art. 12 (4) CRPD apply to every intervention in the persons legal capacity.¹¹¹ Even though the CRPD encourages the state to strengthen supported decision-making in the first place, to meet the requirements for appropriate help and to establish safeguards, it does not explicitly exclude involuntary medical treatment.

However, the CRPD Committee does not follow the idea of different qualities of will and does not distinguish between *free* and *natural will*.¹¹² As the free will cannot be scientifically and objectively determined, the fact that the BVerfG does not make any observations on this point, even though their argumentation bases on this assumption, can certainly be criticised.¹¹³ Yet, the system of giving different legal weight to different "qualities" of will also allows an allocation of responsibilities, which protects the individual.¹¹⁴ Not regulating specific standards for the guality of human actions would imply giving legal weight to any kind of human action and make vulnerable people receptive to manipulation. Furthermore, advance statements would be of limited use when the conserved will would contradict the natural will and thus could not be respected when deciding about medical treatment. One also has to take into account that the absence of free will in the sense of the BVerfG does not describe a legal status of a person but the lack of a condition for a legally binding will concerning a particular medical intervention. The legal status of the individual as a person before the law and the legal capacity in general are not questioned. The distinction of free and natural will is therefore not opposed to Art. 12 CRPD.

Even interpretations by researchers with legal backgrounds which are not used to the distinction of *natural* and *free will* still come to similar conclusions as the BVerfG on the basis of Art. 12 (4) CRPD. For example, *Ward and Curk* or *Szmukler* conclude that different interests of the individual must be weighed against each other by dividing the terms "will and preferences", giving "will" and "preference" different value in the will determination process.¹¹⁵

¹¹⁴ J. Neuner, 'Natürlicher und freier Wille', AcP, 2018, 1 [18].

^{2013, 329 [332]} referring to the word "support". Other opinions see forced medical treatment as a part of "support" in Art. 12 (3) CRPD P. Masuch and C. Gmati, 'Zwangsbehandlung nach dem Gesetz zur Regelung der betreuungsrechtlichen Einwilligung in eine ärztliche Zwangsmaßnahme und UN-Behindertenrechtskonvention', NZS, 2013, 521 [526-527].

¹⁰⁹ "Art. 12 [CRPD] does not prohibit substituted decision-making", A. Dhanda, Syracuse Journal of International Law and Commerce 34 (2007), 429, [460-461].

¹¹⁰ V. Lipp, 'Betreuungsrecht und UN-Behindertenrechtskonvention', FamRZ, 2012, 669 [673-674].

¹¹¹ V. Lipp, 'Betreuungsrecht und UN-Behindertenrechtskonvention', FamRZ, 2012, 669 [673-674]. ¹¹² UN Doc. CRPD/C/GC/1, para 13–15.

¹¹³ R. Uerpmann-Wittzack, 'annotation on BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15', FamRZ, 2016, [1746-1747]; general criticism on the term 'natural will' R. Beckmann, 'Der "natürliche Wille" – ein unnatürliches Rechtskonstrukt', JZ, 2013, [604-608].

¹¹⁵ A. Ward and P. Curk, "Respecting 'will': Viscount Stair and online shopping", BtPrax, 2019, [54-58]; G. Szmukler, 'The UN Convention on the Rights of Persons with Disabilities: 'Rights, will and preferences'

B. Arguments concerning ECHR compliance

As the decisions of the ECtHR are binding on the courts of the ECHR parties,¹¹⁶ they are an important variable in national human rights implementation. The interpretation of the ECtHR on Art. 2 and Art. 8 ECHR supports the assumptions of the BVerfG, as explained in more detail below.

Art. 8 ECHR includes the right to make decisions that can be dangerous or harmful to one's health.¹¹⁷ Medical treatment against the free will would violate this freedom even if the denial of treatment may lead to death.¹¹⁸ Art. 2 ECHR provides the right to life. As well as the BVerfG, the ECtHR argued that the right to life obliges the authorities to protect an individual from itself under certain circumstances.¹¹⁹ The ECtHR's requirements for the states to protect life and health of vulnerable adults can be seen in Arskava v. Ukraine.¹²⁰ The ECtHR confirmed that Art. 2 ECHR obligates the state to protect the patient's life.¹²¹ Yet, with respect to Art. 8 ECHR they saw no obligation of the state to prevent an individual from taking his or her own life if the decision has been taken freely and with full understanding.¹²² This implies that if conditions of a sound mind are not met, the duty to protect the individual's life maintains. The ECtHR also criticised that in this particular case no domestic regulations were at hand which sufficiently elaborated the conditions under which refusal to undergo treatment was valid and binding on medical staff.¹²³ They mentioned the necessity to implement a regulatory framework, which shall ensure that a patient's decision-making capacity is objectively evaluated in a fair and proper procedure.¹²⁴

The ECtHR explained that not ensuring adequate health-care regulations which sufficiently elaborate as to whether the rejection of treatment by the patient is valid violates Art. 2 ECHR.¹²⁵ This implies that if the state had considered the patient

in relation to mental health disabilities', International Journal of Law and Psychiatry, (54), 2017, 90 [93-96].

¹¹⁶ Concerning the relationship of German Constitutional law and the ECHR see BVerfGE 111, 307 = BVerfG, Order of the Second Senate of 14 October 2004 – 2 BvR 1481/04, para 30-39; BVerfGE 128, 326 = BVerfG, Judgement of the Second Senate 4 May 2011 – 2 BvR 2365/09, 740/10, 2333/08, 1152/10, 571/10, para 86-90.

¹¹⁷ Arskaya v Ukraine (App no 45076/05) (ECHR 5th December 2013), para 69; Pretty v UK (App no 2346/02) ECHR 2002-III 155 [194], para 63.

¹¹⁸ BVerfG, Order of the First Senate of 26 July 2016 – 1 BvL 8/15, para 93 referring to Lambert and others v France (App no 46043/14) ECHR 2015-III, 67 [109], para 120 and Pretty v UK (App no 2346/02) ECHR 2002-III 155 [194], para 62-63.

¹¹⁹ Thematic Report, Health-related issues in the case-law of the European Court of Human Rights, June 2015, p. 19 referring to Keenan v UK (App no 27229/95) ECHR 2001-III, 93 available at <u>https://www.echr.coe.int/Documents/Research report health.pdf</u> (last accessed 28th Dec. 2019); About the duty of protection by the state concerning denied necessary treatment of a mentally disabled person in a psychiatric institution see Câmpeanu v Rumania (App no 47848/08) (ECHR 17th July 2014), para 130.

¹²⁰ Arskaya v Ukraine (App no 45076/05) (ECHR 5th December 2013).

¹²¹ Ibid, para 62.

¹²² Ibid, para 69.

¹²³ Ibid, para 88.

¹²⁴ Ibid, para 88.

¹²⁵ Ibid, para 69.

incapable of making a valid treatment decision, the patient would have been treated against his wishes to protect his life. As seen in *Herczegfalvy v. Austria*, the ECtHR does not categorically exclude involuntary medical treatment as long as it is therapeutically indicated.¹²⁶

Moreover, the ECtHR as a human rights institution at European level also tends to consider the CRPD as 'relevant international law' in its judgements.¹²⁷ The ECtHR explained its understanding of Art. 12 (4) CRPD in *A.-M.V. v. Finland*¹²⁸: "the applicant's rights, will and preferences were taken into account" as long as the state authorities had properly balanced the right to self-determination and the protection of the health of the person.¹²⁹

Those decisions of the ECtHR indicate that the ECHR demands a state's duty of protection for vulnerable people as well. The ECtHR is not opposed to involuntary medical treatment as long as the countries provide a regulatory framework.¹³⁰ It can be concluded that the order of the BVerfG does not contradict the ECtHR's case-law and therefore complies with the ECHR.

V. IMPACTS ON GERMAN LAW

As a consequence to the order of the BVerfG, § 1906a BGB was introduced in July 2017.¹³¹ Forced hospitalization and involuntary medical treatment are now regulated in two different paragraphs. Involuntary treatment no longer requires forced hospitalization. However, it requires an in-patient stay at a suitable facility which can guarantee the necessary medical standards for the treatment. Furthermore, the law confirms that involuntary medical treatment has to comply with the original will of the patient, for example in an advance directive for health care.¹³² An involuntary medical treatment at home, in ambulatory practices or in nursing homes remains prohibited.

Of course, the order of the BVerfG has been met with varying response in Germany. Some researchers and psychiatrists criticize an expansion of the possibilities for forced

¹²⁶ Herczegfalvy v Austria (App no 10533/83) ECHR Series A no. 244, para 82.

¹²⁷ L. Waddington, 'The Domestication of the Convention on the Rights of Persons with Disabilities', in: A. Waddington and A. Lawson (eds), 'The UN Convention on the Rights of Persons with Disabilities in Practice', Oxford University Press, 2018, 538 [554]; see for example A.-M.V. v Finland (App no 53251/13) (ECHR 23rd March 2017).

¹²⁸ A.-M.V. v Finland (App no 53251/13) (ECHR 23rd March 2017).

¹²⁹ A.-M.V. v Finland (App no 53251/13) (ECHR 23rd March 2017), para 90.

¹³⁰ More restrictive E. Flynn, 'Disability, Deprivation Of Liberty and Human Rights Norms: Reconciling European and International Approaches', International Journal of Mental Health and Capacity Law, 2016, 75 [88-89] who finds that the ECtHR assumes that in specific situations the state has to protect the life of the patient, even though other rights may be restricted, but pledges for a more CRPD-friendly interpretation of the ECHR and the ECtHR decisions.

¹³¹ The current law on compulsory medical treatment is § 1906a BGB, introduced by BGBl. I, 2017, p. 2426.

¹³² See § 1906a (1) No. 3 BGB.

medical treatment.¹³³ Other scholars call for an extension to forced medical treatment without a necessary inpatient stay.¹³⁴

The effects of the new § 1906a BGB will have to be observed.¹³⁵ On the positive side, however, the consideration of advance statements for health care for forced medical treatment was strengthened significantly.¹³⁶ If the patient has denied a somatic or psychiatric treatment in an advance directive for health care that meets the legal requirements such as being able to consent at the time of writing down that statement, the will of the patient has to be respected even though the denial of treatment might lead to death.¹³⁷

VI. CONCLUSION

Even though there are many points of criticism and the decision of the BVerfG contradicts the general trend to interpret the CRPD such as the statements of the CRPD Committee, it can be concluded that the order complies with both, the legal requirements of the CRPD and the ECHR.

Despite the focus on self-determination, the protection of the individual (even against oneself) by the state remains an objective of the human rights treaties. The CRPD does not focus on self-determination alone. Primarily, the treaty's intention is the protection of vulnerable people, including the obligation to balance the rights of the individual in each case.

This approach corresponds to the view of the ECtHR on the ECHR. The ECtHR does not explicitly mention involuntary medical treatment in its judgements, but the state's obligation to protect the life if the patient cannot decide with "sound mind". Thus, it is the logical conclusion that – if not treating violates the patient's right to life – involuntary medical treatment must be possible.

Therefore, in the context of the human rights framework, the BVerfG presents a concrete and solid answer concerning the difficult question on how to deal with people suffering from severe mental illnesses who cannot express a free will and face serious health damage or death. The court's understanding of the CRPD's articles happens in the light of its own national jurisprudence. Yet, it offers impulses on how to interpret them and transfer their contents as Art. 12 (4) CRPD "will and preferences" to practical use. Looking at the current challenge of practical implementation of the CRPD, it is

¹³³ For instance A. Schmidt-Recla, 'Karlsruhe "On Liberty["], MedR, 2017, [92-96]; M. Zinkler, Statement on the draft law on § 1906a BGB, available at <u>http://www.antipsychiatrieverlag.de/artikel/recht/pdf/zinkler-1906a.pdf</u> (last accessed 20th Dec. 2019); earlier publication M. Zinkler, 'Germany without Coercive Treatment in Psychiatry – A 15 Month Real World Experience', (Vol. 5), Laws, 2016, [1-6].

¹³⁴ For instance A. Spickhoff, 'Nach der Reform ist vor der Reform: Zur Neuregelung der Zwangsbehandlung im Zivilrecht', FamRZ, 2017, [1633-1639]; A. Brilla, in: 'Beck'scher Online Grosskommentar BGB', Gsell et al. (edit.), § 1906a, para 14-15.

¹³⁵ According to Art. 7 of 'Gesetz zur Änderung der materiellen Zulässigkeitsvoraussetzungen von ärztlichen Zwangsmaßnahmen und zur Stärkung des Selbstbestimmungsrechts von Betreuten' of 17th July 2017, BGBI. I, 2017, p. 2426, § 1906a BGB will be evaluated in 2020.

¹³⁶ See § 1906a (1) no. 3.

¹³⁷ See § 1906a (1) no. 3 and § 1901a (1) BGB.

quite evident that even if the existing mental health law systems have to be viewed critically, practicable interpretations are targeted.¹³⁸

However, the legal justification of protective measures against the natural will on part of the state will remain of particular interest to legal, medical and ethical researchers, especially, the interpretation of Art. 12 (4) CRPD "will and preferences" as there is not only one way of interpreting the article.¹³⁹ Whichever approach is taken, the focus has to remain on exercising the patient's will.

The BVerfG allows involuntary medical treatment as a last resort, if it is based on the original or presumed will of the adult. An effective way to respect will and preferences in this context, is to strengthen the establishment and use of voluntary measures such as advance directives to determine the original will.¹⁴⁰

In Germany, there is still potential to develop legal and practical concepts to implement the ideas of the CRPD. Since the current periodic state report of Germany draws upon the BVerfG judgment¹⁴¹, the reaction from the CRPD Committee remains to be seen.

¹³⁸ Ideas on practical implementation in hospitals see M. Zinkler, 'Supported Decision Making in the Prevention of Compulsory Interventions in Mental Health Care', Frontiers in Psychiatry, 2019, article 137, [1-3].

¹³⁹ A. Ward and P. Curk, "Respecting 'will': Viscount Stair and online shopping", BtPrax, 2019, [54-58]; G. Szmukler, 'The UN Convention on the Rights of Persons with Disabilities: 'Rights, will and preferences' in relation to mental health disabilities', International Journal of Law and Psychiatry, (54), 2017, [90-97].

¹⁴⁰ On the current status of voluntary measures see, for example, the report by A. Ward, 'Enabling Citizens To Plan For Incapacity', CDCJ(2017)2final; on the challenges of psychiatry specific advance decision-making in particular, G.S. Owen, et al., 'Advance decision-making in mental health – Suggestions for legal reform in England and Wales', International Journal of Law and Psychiatry, 64, 2019, [162-177]; also emphasizing on advance directives as a forward solution F. Mahomed, M. A. Stein and V. Patel, 'Involuntary mental health treatment in the era of the United Nations Convention on the Rights of Persons with Disabilities', PLoS Medicine, October 2018, 1 [5-6]; M. Scholten and J. Gather, 'Adverse consequences of article 12 of the UN Convention on the Rights of Persons with Disabilities and an alternative way forward', J Med Ethics, (44), 2018, 226 [231-232].

¹⁴¹ Federal Ministery of Labour and Social Affairs, Combined second and third periodic report of the Federal Republic of Germany, submitted September 2019, [21], available in English at <u>https://www.gemeinsam-einfach-</u>

machen.de/GEM/DE/AS/UN BRK/Staatenpruefung/Zweite Staatenpruefung/Bericht englisch.pdf? bl ob=publicationFile&v=2 (last accessed 22nd Dec. 2019).

Opinion

ENGAGEMENT AND PARTICIPATION AS A PART OF THE MENTAL WELFARE COMMISSION FOR SCOTLAND

GRAHAM MORGAN MBE*

ABSTRACT

An account of the work of the engagement and participation officers with lived experience as users and carers in the MWC, showing: the history of user and carer involvement in the Commission, the reason for the employment of the present workers and the creation of the department of engagement and participation. Told from the perspective of lived experience of using services, describing the development of the roles to date, the activities carried out to date, especially those connected with mental health law, capacity, and the role of the NPM in safeguarding against cruel and degrading treatment and torture, some assessments of the impact of these activities and a presentation of the personal perspective of using lived experience as an integral part of a professional role.

For a scholarly journal this will be a slightly unconventional article. I'm going to tell you a story. I am going to muse and reflect on why having people with direct experience of mental ill health or direct experience as carers is so important to an organisation such as the Mental Welfare Commission for Scotland. There is a more detailed description of the Commission elsewhere within the journal's pages but—to put it simply—we are there to uphold and protect the rights of people with a mental disorder in Scotland. In fact, we are one of the many organisations that make up the UK National Preventative Mechanism—an institutional framework prescribed under the auspices of the UN Torture Convention—that exists to ensure that people with a mental illness, personality disorder, autism, dementia, learning disability and related conditions are not treated badly, are not abused, and are not trampled on by an uncaring society.

We visit people in hospitals, including the secure hospitals. We visit people at home. We monitor the mental health and incapacity legislation that applies to us. We carry out investigations, promote good practice and influence policy. We keep records of people detained under the Mental Health Act. We do all sorts of things. These are all aimed at ensuring people are not badly treated, while at the same time helping to establish and further promote good practice that lead towards a better quality of life.

We have a network of practitioners who are assigned to different areas of Scotland. They are psychiatrists, social workers and mental health nurses, all of whom use their detailed expert knowledge of policy and practice to influence and comment on what they see.

Unlike some organisations we do not have many formal powers. Decisions about detention are more the province of the Mental Health Tribunal for Scotland. We cannot close a ward, or insist on a change in practice. But we can influence, and we can persuade, and we can be very good at doing this.

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When I first came into post as an Engagement and Participation Officer (Lived Experience) three years ago, I met many advocacy groups and, in discussion with them, found out many of their views about the Commission. First of all, many people's initial reaction was of an organisation that is remote, formal, populated by smart professional people in suits, people they would not necessarily feel comfortable with, people they might, indeed, feel wary of. I will talk more about that later. Another theme from groups was that they wished the Commission had greater powers, could close a ward or even a hospital, and that it could insist on changes being made then and there. This resonated with me because I too often thought that way. I felt that an organisation that is there to safeguard the rights of people like me, and others more vulnerable than me, could only ever be tokenistic if ultimately it could not force bad practice to stop.

But I wonder how change happens? How good practice flourishes? I remember being on a Commission visit to a hospital ward that—quite frankly—was not doing too well, but I also remember the sensitivity with which the nurse practitioners pointed out some of the areas that needed improved and the enthusiasm with which the nurses on that ward, some of whom had little training in mental health, embraced that conversation; they fell upon it almost as if they were hungry for the learning and the good practice that they could implement. So, much as I do sometimes want to shout and stamp my feet, and force change to happen—especially when I see the way some of my friends and colleagues with a mental illness are treated—I can also see that change is almost something that we need to be drawn into; that to create change, we need to want that change to occur and that the bluntness of "You will do this and this and this" can serve sometimes to create only fear and defensiveness.

I have a similar feeling about my job in the Commission. My Engagement and Participation colleague with lived experience as a carer, Kathleen Taylor, and I are here to create a culture change—a shift in working—a different perspective and a different emphasis.

It is easy to see, when the perspective of lived experience is not a daily reality of an organisation, why people may worry about it, may be hesitant; and very easy when we arrived as new, anxious, idealistic people in brand new posts for us to come with a set of assumptions and beliefs about how people would view us. Looking for a negative reaction can be confirmed in an instant if you look out for it, are poised for a silly comment or an offhand dismissal but it takes me back to how change occurs.

Sometimes change occurs by setting aside worries and preconceptions; and needs people like us to help it along. If I had come along as the person I was some years ago I don't think I would have lasted in post for long at all. But with my carer colleague Kathleen, who is both funny and cynical, and is a wonderful person to confide in, we almost became a feature of the dining area in the Commission offices for a time. Eating our lunches, getting to know people, asking questions, enjoying the new people and experiences about us; and maybe—not quite the same as the peer support our practitioners offered to those nurses I mentioned before, but similar—we offered links and connections. We showed that we had mutual aims and that even when we were desperate for change to occur for the communities we had come from, we were also ready to laugh and giggle and learn. In that way, some of the hesitation drops aside and we all gain a better understanding of each other; what we are good at and could well do more of, what we need support with, and where we are better not used in certain areas.

And I must admit I do like this approach. If I had joined the Commission full of anger and full of assumptions about the people who worked there, it would have been hard to create partnerships and to share stories, ideas and thoughts about how we could work together.

But first of all, in this story; lived experience is an essential requirement for the work I do. Now that is one of the strangest skill-sets to find on a job description! To be in a professional world where it is a positive advantage to have a diagnosis of schizophrenia; where to be on a compulsory community treatment order not only conveys credibility but equally an expertise other people want to seek out!

These sort of posts, in what is really quite a formal organisation, need to be set within context, and part of the way I will do this is to do just what my job demands and be open about my lived experience and its place in what might be called the 'user movement'.

I was first referred for psychiatric help when I was 17 and first admitted to hospital when I was twenty or twenty-one.

Middlewood, 36 years ago, was an asylum scheduled for closure. It was a dark forbidding place on the outskirts of Sheffield, set in beautiful grounds but frightening. I remember my bewilderment about being taken there, after an overdose; both at the holes in the walls and the smashed furniture. Some of the bare rooms were just floorboards and dust. The beds crammed next to each other, the noise at night; but also the nurses ---friendly, not in uniform—taking us out to the pub in the evening. And then of course the less attractive sights; the nurse who was assaulted, the patient who was then leaped on by about six male nurses—jagged in the bum—who screamed and screamed through the night before he was taken away. The old ladies from the long-term ward above us who sometimes escaped and rushed into our room; desperate to get at the fag ends we-the more fortunate patients-had left in the ashtrays. The man with no belt, who walked around having to hold his trousers up; he was so emaciated and died not long after I was discharged. The friend I made who had learning disabilities and alcohol problems, who the nurses took to the pub and discharged when he took a drink there; who the next time I saw him was in a homelessness shelter: just two rooms with bare floorboards; the men's possessions piled in bin bags and the corners of the room. A young man kneeling on the floor rocking backwards and forwards while we tried to speak to each other.

That is the setting which drew me into activism and trying to make the world a better place for people like me with a mental illness. In our country there are now hardly any of the old hospitals left and fewer of the bad practices. But these experiences are not some antiquated aspect of care, some curiosity.

Many of the older people who still go into hospital, nowadays, will have both good and very bad memories of treatment in what now seems like a different age—but is actually a scant few years ago—and of course so will many of the staff. The changes that have occurred to combat some of the abuse of the past are, in many ways, recent; the possibility that life will change for the worse again, not an impossible idea.

However, in that setting, when I left hospital in my twenties, I received some very puzzling and mostly silent psychotherapy as follow up. I found, for me, a slight sense of liberation. Here was something clearly unjust, here was something to change, and here was a cause to believe in.

So I became a volunteer in a halfway house for young people with mental health problems, where we met support workers and community development workers who schooled us in the works of RD Laing,¹ Asylum magazine,² and that whole area of alienation and oppression we were just becoming aware of.

We set up a new organisation imbued with many of the values we had been taught. We established a drop-in centre for young people with mental health problems (McMurphys); created, run by and developed by young people with mental health problems. We were intensely suspicious of officials and professionals, and only reluctantly agreed to speak to some of the people in the Council and Health Board who might fund us; refused to allow professionals access to the building, and maybe that anger was justified. Maybe that search for identity, a voice and control, was what we needed; it certainly helped me.

I moved to Scotland, where again with some of the more radical people in the third sector we set up Awareness³, one of the first advocacy groups for people with mental health problems in Scotland. From that, after an interlude as a yacht skipper, followed work with CAPS Independent Advocacy⁴, where I worked to set up advocacy groups across Lothian, helped establish a National user voice for our country, a series of user conferences and also a National user written magazine. We were still strident; dead set on having our voice, not having it adulterated by carers. In fact suspicious of carers. In many ways we still saw people who worked in the NHS as the enemy, with only the occasional allies. We were deeply suspicious of compulsory treatment, aggrieved by our experiences of hospital.

It was in Edinburgh that I had the first of my major hospital admissions. There, I had to line up in a queue for medication, and get stitched up without anaesthetic when I harmed myself.

Then 24 years ago I moved to the Scottish Highlands where again I set up an advocacy group called HUG^5 (action for health), and here my views shifted both because of my treatment and because of the people I met.

All of my work so far had been mainly with radical social workers, progressive planners and policy makers; we sort of knew what we all thought and were expected to think. But in the Highlands, I met with service users who had not been educated and had their consciousness raised. Here I found, when Craig Dunain, Highland's Asylum was due to be shut that many people who had been patients in it did not want this to happen. That if there had to be a new hospital, that they wanted it in the same isolated patch of beautiful

¹ Nick Crossley, 'R. D. Laing and the British anti-psychiatry movement: a socio–historical analysis' (1998) 47 (1) Social Science & Medicine Volume, [877-89]

² Now published by PCCS Books <u>asylummagazine.org/</u>

³ Oor Mad History, Community History and Arts as Advocacy Project based at CAPS

⁴ <u>capsadvocacy.org/</u>

⁵ <u>www.spiritadvocacy.org.uk/about-us/who-we-are</u>

countryside on the edge of town. It was here I met people who said that they were kept alive by medication and that far from being a chemical cosh, it gave them a new life; and also people that had no problem with getting help from a chaplain or going to church to find peace.

A far and hugely liberating cry from the fairly rigid ideals of liberation and oppression that I had grown up with, in my career to work with people with a mental illness to make change for the better for that community.

And that is also where my personal perspective changed, I was admitted a few times to hospital—nearly always under a section—and although there were very clearly times when practice was not as it should be, I also had my own en suite bedroom, had things to do and met people who genuinely seemed to care for me and—much as I still wonder if it was for the best—had my life saved on a number of occasions. Then later, when life became particularly bad, I met a succession of psychiatrists and CPNs who I got on well with and who I found I could trust with aspects of myself I couldn't with anyone else. I met and helped create a community motivated by giving back and providing mutual support where anger was not the driving force for speaking out but creating connection and belonging and finding solutions to what often seemed like insoluble problems. Where the issues we addressed were the ones we found important and not necessarily the emotion laden aspects of treatment that other people thought we should address and lastly where we found that by working together—with professionals, schools, businesses, arts projects—we could often create a change that would never have happened if we had remained in separate and mutually suspicious camps.

And that is why I am now with the Mental Welfare Commission. As I mentioned, I have been sectioned a number of times and know that those sections keep me alive. I am fairly sure that my ten years on a CTO does likewise, and am fascinated and honoured to hear the different stories of my friends and colleagues on that subject; and still slightly surprised at how conservative our community is when you peer beyond the radicalised activists and community of which I used to be and to some extent still am a part of.

I am no longer filled with a harsh anger at my personal treatment and can feel slightly awkward when I meet people with lived experience who, with a straight face, can say that no medical professional can possibly feel empathy with a person with a mental illness.

It seems to me, that as part of that user movement that made the involvement of people with mental health problems in policy and services an everyday expectation, I am now learning that, what may have once needed to be a separate and distinct voice; one which reclaimed its own power has, to some extent, a need to recognise that it is also sometimes an artificial voice and on occasion an unfair one. That most people who work in mental health do so from a personal commitment to improving our lives – most would hardly do it for the money! That it is just as common for a doctor or a social worker or a nurse to develop mental health problems as anyone else and to deliver the very services, we sometimes say, do not acknowledge the lived experience we have. That the need to critique and display our anger sometimes excludes those people who are grateful for and happy about the treatment they have received.

That was a very long introduction to my life and to my motivations, but it is important to set the involvement of people with lived experience in context. The idea of engagement, participation, advocacy, has come from the combined efforts of service users, carers and their allies. It has a rich history and will develop in a variety of ways. For me and many of my friends, that development is about partnership and shared values—whilst I know that for some others the only credible voice rests in a distinct identity and a distinct way of interpreting distress and which often rejects the very concept of mental illness.⁶

Thirty five years ago, we would have been bewildered to be told that the involvement of people with a mental illness in an organisation like the Commission was now a legal consideration – it would have been inconceivable.⁷

And yet over the last few years since the creation of the Mental Health (Care and Treatment) Scotland Act 2003, it has been a requirement in law to have people with lived experience as a part of the Commission. Initially this started with the people with lived experience joining the Commission's Board of Directors and Advisory Committee, and also the employment—for a few days a year—of people with lived experience to take part in some of the Commission visits. Five years ago, following direction from the Commission Board, a Department of Engagement and Participation was created with an executive director employed to create strategies and manage both the present Engagement and Participation officer (lived experience) and the Engagement and Participation officer (lived experience) and the Engagement and Participation officer (lived experience) sits alongside the other directors of the Commission and it is an essential requirement of all staff in this department that they all have personal lived experience. She also has other more general responsibilities within the Commission.

And now for what we actually do in the Commission: what we achieve. How having someone like me at the Commission and someone like Kathleen does, in reality, make us better at safeguarding people with a mental disorder from abuse. This means that the worst aspects of the old asylums will hopefully remain as stories and tales we are happy to have moved on from.

I remember when I worked for HUG and was part of the Millan Committee⁸ (chaired by The Rt. Hon. Bruce Millan) which paved the way for the current Act in Scotland. While my verbal contributions in the meetings were not as they would be now, my presence was an important milestone. In fact, I was rather bewildered by the language, procedure and manner of my fellow committee members, and could never keep up with what ended up as around fifteen bin bags full of dense and complex reading materials in just a couple of years. But I do remember that I was visible, and it was that presence which created a dignity to the process of developing and modifying legislation that justifies the detention of people like me.

In any sphere where it is possible to see people and communities as 'other', when we place them in the societies where decisions are made for and about them— sometimes without

⁶ Helen Spandler, Jill Anderson and Bob Sapey, Madness, distress and the politics of disablement (Bristol, The Policy Press, 2015)

⁷ Schedule 1 Mental Health (Care and Treatment) (Scotland) Act 2003

⁸ Scottish Executive, New Directions: Report on the Review of the Mental Health (Scotland) Act 1984 (SE/2001/26)

their consent or knowledge—it is incredibly hard to perpetuate that difference, that alienation when the person you are alienating is sitting next to you. When you share a train journey, a coffee, a story of how your children are doing.

And so—much as I regret that lack of skill this could imply—being in the Commission, having my post created where it is a matter of public record that I have lived experience creates the same imperative. I now know that many people who work in the Commission have had their own problems and that even more have friends and relatives that they are very close to those who have mental health problems or learning disabilities or dementia. But where that might once have been a private thing, almost something that is obscured by the role of a worker, now it is celebrated and highly visible in Kathleen and myself.

I would like to say that this is a simple awareness raising exercise that doesn't take any effort; that it just occurs and creates change purely because Kathleen and I are visibly in post—but actually it does carry a burden.

It is a burden I willingly carry, and would not have any other way, as a large part of my identity rests in my experience of mental ill health and the services that treat me. But keeping that high profile can be hard and it can be easy to misinterpret reactions from other people.

I come from a tradition where we expected—and experienced—our presence and voice as being something unwelcome; where we saw barriers to everything we were trying to achieve. These barriers were and to an extent are still real, but they can make me hypersensitive. I can worry intensely what people think of me and worry that when I use my personal experience that I am too intense, too inward. I can worry when something I put forward for the intranet or internet does not appear that it is because of my failings or because I have lived experience or because I am incompetent.

Within this is a whole host of issues; the very existence of my post makes this feeling slightly inevitable as our perceived difference is highlighted as a condition of work. The fact that there is no career path, no qualification that I can use to justify my skill base can make me anxious in a work environment with highly qualified professionals. The fact that there is sometimes probably some degree of this perception of 'otherness' coming from our fellow workers, that they may perhaps sometimes be slightly confused by the boundary issues that might potentially exist when working with people who at another time would likely have been their clients and the fact that I do have anxieties and paranoias and worries that seem to be part of my condition which can make me think that people are talking about me, or looking at me negatively or avoiding me. Makes for a possibly heady mix of potential problems.

This is an inevitability that will occur when people are put into jobs like this; but it does not mean that it is wrong to have such jobs or that the worry we have about other people's reactions to us are realistic. I am constantly having people from the Commission reaching out to me and speaking to me and praising me. When my book START⁹ was published, at least ten members of the Commission came to the launch; that is over a fifth of our organisation took time out of their social life to celebrate an achievement of mine.

⁹ Graham Morgan, START (Fledgling Press, Edinburgh 2018)

In this story I have laboured that sense of otherness; it is a real problem but sometimes it comes from within. Sometimes when we have grown into our roles from a sense of alienation, we can occasionally see evidence of hostility that does not exist and neglect to recognise those everyday gestures of welcome that routinely occur each time we come into the office.

Having a line manager who herself has lived experience has also been invaluable for dealing with the anxieties and worries that both Kathleen and I initially had when we came to the Commission.

Some time ago I talked about my role in the Millan Committee, said that my value to some extent just rested on my visibility, but I also remember a reunion of the Committee many years ago where one of the Committee members said that a speech that I gave at an away day completely transformed her ideas around detention and the Mental Health Act.

And that aspect is a wonderful part of my job; there can be few roles where just reflecting on what you have been through in your life—especially when it has been harsh and traumatic—has been prized and sought after. Invariably, when I give speeches, I employ a personal perspective, but equally try, as far as I can, to include the different viewpoints of the Communities and people I work with.

This has been especially the case with some of our national and international work around detention and supported decision making.¹⁰ We have involved a few hundred people in discussions around both our freedom and our capacity and ability to make decisions or be supported to make decisions; as well as just what would avoid decisions being taken out of our hands. This work has very clearly shown that, at least in Scotland, people with lived experience do not easily subscribe to the pronouncements of the UNCRPD around compulsory treatment;¹¹ in fact a considerable majority are opposed to its general comment.

This can be confusing and difficult because there is also a very loud and angry minority of people completely opposed to compulsory treatment.

Balancing these views can be difficult. But to be honest, when I have addressed the United Nations or a number of international conferences it can be a relief to deliver my own personal perspective knowing that it reflects the mainstream opinion in my country; if not in other parts of the international community or user and survivor movement.

¹⁰ See eg: Mental Welfare Commission for Scotland (MWCS), The views of people with lived experience on supported decision making: Service users and carers information (2019); Mental Welfare Commission for Scotland, Seeking Your Views consultation Capacity, Detention, Supported Decision Making and Mental III Health (2019); Craigie, Bach, Gurbai, Kanterd, Kim, Lewis, Morgan, Legal capacity, mental capacity and supported decision-making: Report from a panel event (2019) (62) International journal of law and psychiatry, [160-8]; Jill Stavert, Good Practice Guide – Supported Decision Making (Mental Welfare Commission for Scotland, 2016)

¹¹ Committee on the Rights of Persons with Disabilities, General Comment No 1 (Article 12: Equal recognition before the law), CRPD/C/GC/1, 19 May 2014.

There is, however, a balance to be achieved in telling a personal story; I have recently delivered a speech on care planning at an event we ran to develop good practice.¹² I used my personal experience of care planning to illustrate the fact that so many people I have consulted with seem to feel only a passing connection—or indeed interest—in their care plans, and then used the experience of the people we consulted to finish the talk; there is a power in the real story. That narrative in a speech has an authenticity, but when the final report on our consultation with service users and carers is produced¹³ it will just contain their opinions and not my personal preferences and thoughts.

This is where the other aspect of being a Participation Officer is so important. The majority of my time I am visiting lived experience advocacy groups, self-management and support groups, and also groups of peers using services. At these meetings we find out their opinions on anything from seclusion¹⁴ to legal representation,¹⁵ from the definition of stigma, to the purpose of hospital¹⁶ to the degree of autonomy we want in our lives¹⁷ or carers' experiences of interacting with services¹⁸.

These meetings occur throughout Scotland; in inner city areas, hospitals, remote rural and island areas, in community halls and services and it is here that we are able to both involve people in the Commission's work and find out their views on what we are doing—but also find out their voice on key issues around such things as freedom and detention, right to life, and respect for personal and private life¹⁹ that are of concern to both us and the people we speak with.

We check all our notes with the groups and people we meet with– and from this create papers reflecting the views of carers and people with lived experience. In this situation my role is more specific; I am there to get the discussion going, to record the discussion and to make sure that the final paper is an accurate record and reflection of the meetings that we have held. Although it is not research and is instead a record of a consultation, we have had help from our research officer in the Commission in qualitative analysis of the results of what we do, and do check with people with lived experience that the final report does as far as it can, reflect their views and of course, as part of this, I bring in the decades of experience I have had in facilitating group meetings and in encouraging the diverse range of views that our communities have about their treatment and identity.

Some of the reports we have created around supported decision making have been commented on by various Universities and some have influenced other bodies such as people reviewing the English legislation. Increasingly these reports will become public

¹² Mental Welfare Commission for Scotland (MWCS), Person Centred Care Plans: A Good Practice Guide (2019)

¹³ MWCS, Care plans: how people with lived experience and their friends and family want to be involved, Service users and carers information (2019)

¹⁴ MWCS, Use of Seclusion: A Good Practice Guide (2019)

¹⁵ MWCS, The views of people with lived experience of mental ill health on legal representation (2019).

¹⁶ MWCS, The views of people with lived experience on the purpose of a psychiatric hospital, Service users and carers information (2019).

¹⁷ MWCS, How much we want to keep our autonomy when being cared for, Service users and carers information (2019)

¹⁸ MWCS, Carers' experiences of interacting with services (2020)

¹⁹ Universal Declaration of Human Rights (United Nations [UN]) UN Doc A/RES/217(III) A, UN Doc A/810, 71, GAOR 3rd Session Part I, 71

documents on our website in a section likely to be called `What people tell us'; hopefully they will increasingly influence our own work and wider policy arenas.

Now that we are beyond the purely personal perspective, there are a number of other areas where we try to include the voice and ideas of people with lived experience. Some examples include work around advance statements²⁰ and around our rights.²¹

These were both projects that we, as engagement workers, have been involved in. With advance statements terms of reference, we worked alongside advocacy groups and others to consult on why people so rarely have advance statements; despite governments and Advocacy groups generally saying they are a 'good thing' when we are at risk of having decisions taken out of our hands when we are very ill.

Our report on people's views informed the Commission, but in addition we contributed to the final leaflets that were produced and recruited and supported people with lived experience to be filmed speaking about advance statements in films that were later placed on our website. Now that the advance statement guidance has been produced, we have worked alongside user groups and people with lived experience to deliver training on the subject.

In similar vein, when we are about to be admitted to hospital we can be bewildered about what is happening to us; we can be frightened, confused, anxious but above all we can be ignorant—not knowing what we can do, what we can't do and what can and can't be done with us. In the midst of all this our rights are very important. But at the same time, we may not be in such a position that we either recognise or indeed act on those rights. In order to make some difference in this area, we ran a consultation event aimed primarily at service users and carers to find out what things are important to us during these times and from this came a project where we created a 'Rights Care Pathway' which related and contrasted particular issues we may experience prior to, during and after admission to hospital to the relevant legislation-nationally and internationally-that applies to us. This can vary from anything from the right to have our pets cared for while we are patients, to our right to advocacy or to appeal a section. The Rights Care Pathway was a visual guide. There was also a more detailed report produced on the subject and a series of films created from a lived experience view-point and professional view-point. We also had a few hospital wards piloting projects around improving recognition of our rights when in hospital and distributed the Rights Pathway throughout Scotland, as well as creating a 'Learn Pro' module for professionals. As engagement workers we helped consult service users and carers, were a part of the Planning Group, recruited people to be filmed and recruited people to speak on rights at a launch event. Though we took the pathway and films around user and carer groups these were aimed primarily at professionals. A reflection that rights should be as much or even more of a concern for them when carrying out their job as they are for us; particularly when we do not have them upheld. Generally speaking, the groups we have visited have been enthusiastic about the Rights Care Pathway; feeling it is a very valuable document to use when we are very vulnerable and also of great use to the advocacy projects and groups that they might be a part of. But there is also a degree of cynicism which maybe reflect just how far we have to go and how important the sort of

²⁰ MWCS, Good Practice Guide: Advance Statement Guidance: My Views, My Treatment (2017)

²¹ MWCS, Rights in Mind: A pathway to patients' rights in mental health services (2018)

awareness raising and voice of people with lived experience can be. Some people watching the enthusiasm some of the nurses had on film, for our rights—said that it was great but not something they witnessed in their treatment. Other people commented that it may be great to know what our rights are and to know they are legally enforceable but that actually making them real, in a time of cuts and austerity, was less easy to contemplate.

The Commission has now produced guidance around care plans and seclusion. We consulted people with lived experience and their carers across the country and held two large consultation meetings attended by some users and carers but mainly by professionals where we presented the findings of our meetings with people with lived experience. Despite the large number of people with lived experience who have only a hazy notion of care plans we had little difficulty in finding out views on this and were greatly helped by one of the people with lived experience's paper on how she had taken ownership of her care planning.

With seclusion we had more difficulties. While a massively important subject, it is rarely used and indeed where it is practiced it is sometimes not known as seclusion, so although we were able to get a broad selection of views about how we might feel or how a loved one might feel if they were subject to seclusion; we only managed to get a few concrete examples of what people who had actually experienced it felt about it but did gain more information from Carers in carer groups where the experience of seclusion by family members unfortunately is sometimes a common event.

This is another aspect of the role; the examples we gathered were from people we had built up a good relationship with over the years. This creates a degree of trust in which to be able to talk safely about experiences that can be both traumatic and humiliating and rests to some extent on the links we have established with the user movement.

All these areas of work are around good practice. They are based on rights and legislation and concentrate on times when we may be at our most vulnerable—but they remain guides that we hope will encourage professionals to uphold and promote people's rights, and also for people with lived experience to become aware of.

Slightly more focussed on practice is our visiting program. The Commission routinely visits every psychiatric ward in the country, as well as some other services. The team meets service users, carers and staff, and has access to all the paperwork on the ward. We carry out both announced and unannounced visits and produce public reports with recommendations which we expect wards and hospitals to implement.²² As engagement workers we are a full part of the visiting team, although there is a practical limit to the number of visits we can go on. The combination of practitioners and engagement workers can be very powerful. From a personal perspective, knowing what it is like to have someone within arm's reach of you for week after week, remembering the indignity that can occur when having to share dormitory space, or the sheer boredom that can occur on a ward, gives us a perspective that most practitioners do not have. It also gives us an opportunity. While many patients are happy to talk to practitioners, there are occasions where a connection can be more easily established if a patient knows that we also understand what it is like to be a patient—or know what it is like to have a loved one in hospital. This

²² For local visit reports, see: www.mwcscot.org.uk/publications/local-visit-reports/

connection can make conversation much easier and information about issues on the ward easier to find out. It adds another dimension to our visiting program. We are often used where the team is keen to have as much contact with patients as possible; perhaps because of worries that have been raised prior to our visit. There is sometimes a perception that certain patients are more likely to talk and confide in us than in other people.

An additional aspect of this is our regular round of meetings with user and carer groups. In these meetings we can become aware of particular concerns people have of a certain ward, which has led to further action from practitioners.

We can also be asked to meet with advocacy groups and projects, prior to a visit, in order to check just what exactly the key issues are that we should be looking at. Key to this, has been the work we have carried out with user and carer groups to develop a relationship with them and give the belief that there is some point and value in letting us know when they have worries about a hospital.

This is greatly helped when we can point out areas of work which we know have come about as a direct result of the voice of people with lived experience and their carers— and has led to some very productive and enjoyable meetings with people; despite the difficult subject matter that is being raised and discussed.

As with all our work, being able to contribute both from a lived experience and from a sort of outsider status helps the Commission get a breadth of view and perspective. Being part of a culture that exists in many ways to challenge the status quo—and having had experiences of treatment for mental ill health that have on occasion highlighted just how we should not be treated—is an important complement to the perspective of practitioners; who though professionally critical are nevertheless a part of the very professions that they sometimes scrutinise.

The expertise and depth of experience of the Commission's practitioners is undoubted, as is the power of peer mentoring and critique. But equally, we can come from a perspective where we may highlight issues—and aspects of treatment and ways of seeing people with lived experience—that are not immediately obvious.

In addition, there is considerable variety in how people and communities view mental illness and mental disorder. As Engagement Officers we consciously reach out to try to understand perspectives and experiences that do not fit within a conventional model of how mental distress is viewed. Some of the communities and people who are treated for a mental disorder have had deeply damaging experiences at the hands of the mental health system and in consequence may have such a different understanding of their experience that they become deeply resentful—and maybe antagonistic—towards not only the mental health system writ large, but of organisations such as the Commission. As Engagement Officers, we try—as far as we can—to reach out to such people and communities. Trying to acknowledge that some forms of behaviour and conduct are an inevitable consequence of poor treatment can, on occasion, be difficult; but it is extremely important to us that we take in, as far as possible, the wide variety of voices and perspectives of people with lived experience that exist.

Separate to visits to psychiatric wards are themed visits where we look at a particular issue affecting a particular community or service. We may have been made aware of this issue through calls to our advice line, or through our wider visiting program. Increasingly—through our contact with people with lived experiences—we are being made aware of current issues that, under any system of evaluation, merit deeper investigation.

We are a part of every themed visit and contribute a lived experience perspective to the planning, and the visit itself. We have been involved in visits to medium and low secure hospitals,²³ to acute wards,²⁴ and have played a major part in visits around the experience of people who are homeless and have mental health problems,²⁵ people with dementia in community hospitals²⁶ and people with a diagnosis of Borderline Personality Disorder or EUPD.²⁷ Again our perspective is useful; both in establishing a connection and trust with people, but also in having some idea of what issues people may be facing.

Lived experience, however, does not necessarily mean that we have lived experience of everything people go through and does not—in itself—mean we will be immediately and automatically approachable. For instance, I have never experienced homelessness or incarceration in a secure unit. But just as practitioners may have an expertise in issues that they have no personal experience of, we may have some idea of the issues people experience through our past work with those who have lived experience—people who are carers. One of the things that we concentrate on in themed visits is finding out from people what their priorities are for us to look at in the first place. So when we carried out our visit around people with EUPD, we met with over thirty people—with the diagnosis—initially just to find out what issues were important to them so that we could focus our visit around this and likewise with people with eating disorders or those who experience homelessness and currently with people with experience of prison and mental ill health, or dual diagnosis of mental illness and substance misuse issues.

Our networks that we have established, both in the past and in our current posts, can also be invaluable ways of both advertising a themed visit and of gaining access to people on the actual visit. Increasingly we are now part of the write up of the final report of the visit itself.

These are the main elements of our involvement in the Commission, with particular emphasis on our role in safeguarding the rights of people with a mental disorder. There is talk of involving us in some of the formal investigations that the Commission carries out into failings in care; though we are not involved in casework, apart from by alerting practitioners to issues they might need to know about and follow ups. We are not involved in the advice line, guardianship visits or in leading particular areas of work—although our line manager is a director at the Commission and routinely carries out much of the high level work we have less connection with.

²³ MWCS, Medium and low secure forensic wards: Visit and Monitoring Report (2017)

²⁴ MWCS, Adult acute themed visit report: Visit and Monitoring Report (2017)

²⁵ MWCS, Themed visit to homeless people with mental ill health: Visit and Monitoring Report (2017)

 ²⁶ MWCS, Themed visit to people with dementia in community hospitals: Visit and Monitoring Report (2018)
 ²⁷ MWCS, Living with Borderline Personality Disorder – The experience of people with the diagnosis, families and services in Scotland: Visit and Monitoring Report (2018)

Briefly referred to earlier, is the bit about culture change. We are expected to raise issues that encourage everyone in the Commission to routinely involve people with lived experience—including their carers—in the everyday work they carry out; to respect the differing experiences, views and backgrounds people come from, to recognise what is easily forgotten, that we are working in effect <u>for</u> people with a mental disorder. We may have varied expertise and qualifications but ultimately, we are working to promote the rights of people with a mental disorder and are in many ways accountable to them; just as we are also accountable to Parliament and to our Board of Directors.

Culture change is a complex and difficult aim; the Commission is not aiming to become a user-run organisation per se but is aiming to have lived experience at the centre of what it does. Just as it wants to be an organisation that would want professionals to turn to whenever they have concerns about the rights of people, so does it hope that ultimately people with lived experience feel a sense of belonging and ownership of the Commission. Our presence across Scotland is helping with this, but it is a complicated; just as professionals can mistreat and prejudice against service users and carers so can we, as service users, feel anger and anxiety about people seen as professionals. We may refuse to speak to social workers or psychiatrists, and this is where, as Engagement Officers we bridge a gap; by being people that certain groups are willing to speak with, in contrast to some of our other staff.

Hopefully as time goes by this occasional mismatch in perception and expectation will begin to reduce; why else have these posts if we are not aiming for that? But just as there will always be necessity for an organisation like ours when society sanctions the detention of people—who haven't committed a crime—so too will there always be the possibility of suspicion and conflict when an organisation that is here to protect our rights is run by some of the people who when acting as professionals can take away our freedom; even if this is in the name of providing us with that fundamental right—the right to life.

Our presence challenges the idea that everything is about a power imbalance and that mental health services are inevitably about oppression and restriction. We tread a ground where we acknowledge that there are many, many, different perspectives when looking at mental disorder. That there is definitely abuse and poor treatment and even more definitely, the potential for poor treatment and abuse. But where, in the past, I would have thrown my hands up at this and said 'We will have nothing to do with a system in which we have had such bad experiences', now I feel that the solution to such issues is by dialogue and cooperation and by learning together. It means that I recognise the expertise of professionals and also recognise that the practitioners in the Commission can have a greater understanding of legislation and the rights contained in it than I ever will, but equally that without my voice-and the voice of people like me-the Commission will always run the risk of being a tokenistic gesture .That we need the feedback that Kathleen and I gain from service users and carers and need to act on this, that we need the blog posts and comments I put up on the intranet to remind us all of a lived experience perspective-and the numerous speeches and reports, not only on issues to do with detention but on issues like our rights in the benefits system or experiences in rural areas, or views on restrictions on smoking in hospitals.

I said earlier that nowadays I like the idea of dialogue and co-operation and learning because that is how change happens; but I also said that service users can get frustrated

at our inability to insist on change. The legislation that underpins our organisation makes it a legal requirement to have people with lived experience in the Commission and the last four years have been spent in making it a reality rather than a token gesture—though I think there is still an incredible amount to do. But I can also see the point sometimes of reflecting that legal requirement on our internal working with perhaps correspondingly more powers in the actual work the Commission does. It is a debate that is maybe beyond me, but sometimes—when I witness what some of the people with lived experience go through and what their friends and family experience—there are times when it does seem sad that we can only point out to a Health Board, or Local Council/Authority that they are acting improperly; maybe it would be better if we could require them to make changes, just as service users and carers have told us.

There are of course, lots of issues around this; it would need more resources, it would need legislation, and above all it would need that increased debate about creating change through example and dialogue—and the power of argument—as opposed to telling another organisation that a certain course of action will not be permitted.

Already I swither, I can see the point of both ways of looking at rights and the services we receive. But more than anything, I can see the point of having people like myself and Kathleen in the Commission to raise discussion about issues like this, to wonder if we have enough people with lived experience on our Board of Directors, to wonder if the Advisory Committee is diverse enough, to question the level at which we involve our contacts in the Commission, think always 'Is this being done with the right motives and ethics or is it something that just looks good?'

And do we—as people with lived experience—make a fundamental difference around such things as detention, rights and freedom? I think we do. We have an experience that most people do not, we have a perspective that is essential in any organisation such as this, and the capacity to build connections and create bridges and in some circumstances have a role that cannot be found elsewhere – our discussions on detention and supported decision making really needed to be rooted in and informed by lived experience—just as it can be immensely helpful having a lawyer or psychiatrist influencing national and international practice, it can also be incredibly important to have people whose role it is to help people with direct experience of some of the worst aspects of life; to give expression to that experience and on occasion use their own experience to influence and create what we hope will be a better world for people with a mental disorder.

Just as a small summation of our work, between 2017 and 2019 we have met and reached out to at least 1500 people; attending well over 120 user and carer groups, visiting well over 20 hospitals, and playing a role in more than 40 themed visit events. We have also delivered over 65 presentations—varying from user and carer group meetings to International conferences—contributed to six commission reports and created ten of our own reports documenting our engagement activities.

A few quotes to finish with:

From Commission staff:

'Still sitting at my desk because I started reading your paper and couldn't put it down...I'm completely blown away by your honesty and how you've managed to describe your experience with such heart-rending clarity. I hope in difficult times you realise how much you are valued here too - even if we don't show it and seem a bit stiff compared to former colleagues!! I think the dilemmas you describe – both personally and for others – really get to the heart of what's important and cut through the political speak we seem to tie ourselves in knots with when we start to talk about these rights.'

From advocacy groups:

The new post has contributed directly to Carers feeling more involved with the Commission and more confident to approach it.

Face to face meetings with a number of Carers who are individually or collectively facing very complex issues have been particularly valued. Carers report feeling listened to and understood in a way they had not experienced before

Thanks so much for last night It seemed to me that they appreciated being asked about their experiences on acute wards, and that maybe that was the first time that anyone has taken an interest (which I should've asked, in hindsight!) Hopefully this will be the first of other things to come - it was really inspiring in terms of my own project, and gave me some ideas about what we, as a group, could think about in terms of challenging some of the issues that were raised

From outside agencies:

"Informative and hugely inspirational talk about lived experience. Really beneficial to hear about the experience and impact of detention in reality, the restrictions and differing viewpoints. Really warm and enjoyed listening to you."

Your reports look excellent to me – I really think the focus on supporting people to make their own decisions has great potential to improve people's experience of services and, as you suggest, reduce the need for compulsory intervention. A theme, which is in your report, which we also found to be really important was time – people saying that they felt pressured to make decisions and that more time would have eased that – I've attached the most recent draft of our report too. It's still a draft but I think it reinforces many of your findings.

Opinion - Case Comment

PERSONAL INDEPENDENCE PAYMENTS, MENTAL DISTRESS AND UNIFORM POLICY IN DETERMINING MOBILITY CLAIMS

Zia Akhtar*

ABSTRACT

In December 2018, the Minister of State for Disabled People, Health and Work revealed to Parliament that only 140,000 Personal Independence Payment (PIP) cases had been officially reviewed and cleared for the given year.¹ Disclosure of this meagre number (at the time less than 10 per cent of all applications) was preceded by a decision of the High Court (*RF v Secretary of State* [2017] EWHC 3375) which found that regulations that came into force last year were "blatantly discriminatory" to people who were suffering from mental health problems.

The issue that it brings to the surface is that this is an integrated benefit where the mental health component and the mobility component are overlapping. This has been revealed by the "psychological distress" suffered as a consequence of a lack of mobility of the claimant who has been awarded the benefit. This paper enquires if the PIP is a social security provision that has been injudiciously implemented without sufficient consultation given its anomalies, and it argues for the need for clarity and the application of a set criteria for evaluation. There is also a basis to argue that it should be deemed as an integral mobility and mental health-based benefit with greater regard for the claimant's existing welfare provisions rather than a subjective reliance on the assessor's report.

Keywords: Personal Independence Payment; PIP; mental health; discrimination; mobility; psychological distress, Article 14, paragraph 2.4, descriptor 3 (b) (2).

I. INTRODUCTION

The Department of Works and Pensions (DWP) introduced the Personal Independence Payment (PIP) in January 2017 to replace the Disability Living Allowance. ² The Personal Independence Payment (PIP) is a form of non-contributory social security provision paid to people who have daily living and/or mobility needs, designed to help with the extra costs of living with a long-term illness or disability. They have to be eligible for 3 months and

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¹ Minister of State for Disabled People, Health and Work, Hansard, HC Series 6, Vol 651 col 82-4 WS, (20 Dec 2018), <u>https://hansard.parliament.uk/commons/2018-12-</u>20/debates/18122039000023/PersonalIndependencePayment

² In December 2010, the new coalition Government launched a consultation on the reform of Disability Living Allowance (DLA) (Cm 7984). The ministerial foreword stated: "*We are steadfast in our support for the principles of DLA, as a non-means-tested cash benefit contributing to the extra costs incurred by disabled people. However, we need to ensure that the benefit reflects the needs of disabled people today, rather than in the 1990s. It is time that we had a disability benefit which is easier for individuals to understand and provides clear criteria and consistent awards". Personal Independence Payment will also be a more dynamic benefit – it will take account of changes in individual circumstances and the impact of disabilities, as well as wider changes in society, such as social attitudes and equality legislation."*

need the payment for at least 9 months until they are terminally ill. ³This is a non -means tested benefit which is paid regardless of income, savings, **or** National Insurance contribution record and is a tax-free benefit. It is possible to receive PIP even if a person is working or studying and if a person who is a carer with care needs, it is possible to claim PIP and this will not reduce the Carer's Allowance.⁴

The framework of this benefit includes a daily living component (how your mental health affects your daily life) and, a mobility component (how your mental health affects your ability to travel and make journeys). There has been controversy from the start regarding the claim to this benefit of those who are suffering from the mental health problems which require the support in their lives to cope with the disability. The recent debate has been characterised by the claims of applicants based on the lack of expert guidance of the DWP in dealing with the mental incapacity that impacts on the mobility criteria and that led to review and guidelines set by judges. 5

The PIP regulations fall within the ambit of the Welfare Reform Act (WRA) 2012 and the European Convention on Human Rights (ECHR). The WRA 2012 Part IV contains the parent power for the making of regulations to bring the new PIP scheme into effect. Section 77(2) provides that PIP has two components, namely the daily living component and the mobility component (section 77(2)). Section 79(1) provides that a person is entitled to the mobility component at the standard rate if the person's ability to carry out mobility activities is limited by his or her physical or mental condition. Section 79(2) provides that a person is entitled to the mobility component at the standard rate if the person's ability to carry out mobility activities is severely limited by their physical or mental condition. The "physical or mental condition" is not defined in the Act and Section 79(4) provides that the relevant mobility activities may be prescribed. Section 80(1)(c) and (d) provide that a person's ability to carry out mobility activities is to be determined in accordance with regulations. Regulations made under section 80(3) must provide that the ability to carry out mobility activities is to be determined in accordance with regulations. Regulations made under section 80(3) must provide that the ability to carry out mobility activities is to be determined in accordance with regulations.

The recipients of the Personal Independence Payments are also covered by the Equality Act 2010 which combines previous equality legislation in England, Scotland and Wales and includes a new Public Sector Equality Duty (PSED) that enables protection against form of racial, disability and gender discrimination. This duty combines the previous public sector equality duties into one single duty and extends the areas of discrimination covered.⁷ The PSED have compelled the public authorities to promote equality of

³ Money Advice Service. Personal Independence Payments An Introduction. <u>https://www.moneyadviceservice.org.uk/en/articles/personal-independence-payment-an-introduction#who-can-get-pip</u>

⁴ Personal Independence Payments explained. Scleroderman & Raynauds UK <u>https://www.sruk.co.uk/scleroderma/managing-scleroderma/person-independence-payment-</u> explained/?gclid=EAIaIQobChMI-LG9saKz6AIVRLTtCh0HugtbEAAYAiAAEgJTuPD_BwE

⁵ The first statutory review into PIP was the Independent Review of the Personal Independence Payment Assessment (December 2014) that stated "The latest published data on PIP awards at the time of publishing this Report were to July 2014, when 106,400 were in payment" www.gov.uk/government/publications/ personal-independence-payment-pip- assessments-first-independent-review

⁶ These sections were brought into force on 10 June 2013.

⁷ The previous Public Sector Equality Duties were the Race Equality Duty which came into force in May 2002; the Disability Equality Duty which came into force in December 2006; and the Gender Equality Duty which came into force in April 2007. The General Equality Duty came into force. The Essential Guide to the

opportunity and eliminate discrimination for service users and staff, rather than waiting for individuals to complain.

Section 149(1) of the Act defines what the PSED means in terms of general and specific duties. The Act places "a general duty on the public sector in the exercise of its functions, to have due regard to the need to: eliminate discrimination, harassment, victimisation and any other conduct that is prohibited under the Act, advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it, and foster good relations between people who share a relevant protected characteristic and people who do not".

The aim of these duties is to encourage public bodies to consider how they can positively contribute to the advancement of equality and good relations. Equality considerations should be reflected in the design of policies, the delivery of services, including internal policies and reviews. ⁸ The public bodies are national and local Government bodies carrying out functions for the public and include Government departments such as DWP, HM Revenue and Customs, etc, Local authorities, NHS bodies e.g. hospitals, transport and educational bodies; the police, and other bodies carrying out public functions on behalf of the above. ⁹

Francine Morris, has observed that the "*DWP and its agents are service providers for the purposes of the Equality Act 2010. This means that they must comply with the duties not to discriminate against, harass or victimise individuals and to make reasonable adjustments for disabled people to access their services. This duty applies at every stage of the process from application. The DWP also carries out public functions, and must comply with the Public Sector Equality Duty*".¹⁰

The PSED imposes an obligation to issue a public sector equality statement annually in order to substantiate that it has abided by the norms of this duty. The legal decisions show the extent to which the courts hold the public bodies responsible in maintaining their duty. In *Aaron Hunt v North Somerset Council*¹¹ the local authority was faced with significant reductions in funding based on their budgetary needs to consider making substantial financial savings in respect of providing youth services. This was because the authority decided to 'review youth service provision through promoting non-[council] funded positive activities, supporting transfer of responsibility to towns/parish councils and community groups or closing youth centres as a last resort ([ensuring] targeted youth support will continue for the most vulnerable)'.

The Claimant argued that in approving specific budget reductions, the authority had failed to comply with its PSED to have regard to section 149. The judge overruled these

¹⁰ Francine Morris, The Trials of Welfare Reform (2015) p 6-7 Equality and Human Rights Commission https://www.equalityhumanrights.com/sites/default/files/the trials of welfare reform 0.pdf

¹¹ [2012] EWHC 1928 (Admin)

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 https://www.equalityhumanrights.com/sites/default/files/psed
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⁸ Ibid, p11

⁹ The complete list is in Schedule 19 of the Act. There is also provision for additional bodies specific to Wales (Part 2) and Scotland (Part 3). See www.legislation.gov.uk/ukpga/2010/15/schedule/19

objections and held the evidence showed council members did have due regard to the PSED when they reached their decision to approve the revenue budget. The EIA identified the budget proposals which had a high impact on service-users; it dealt explicitly and in detail with the impact of the reduction in the youth-service budget; it referred explicitly to the impact on a number of the protected characteristics itemised in section 149. Furthermore, it disclosed information on which it based its conclusions and steps to be taken to minimise or mitigate that impact.¹²

There is further evidence that the courts have developed principles in how public bodies should take action to comply with the PSED and the correct approach. In *AA and others v Sandwell Metropolitan Borough Council*¹³ the Sandwell Council introduced minimum two year residency requirements for anyone claiming Council Tax Reduction (CTR) in their area. This excluded three women who were exempted from this waiver and raised judicial review. The High Court struck down the policy on various grounds, including the failure with the PSED under section 149 of the Act.

Mr Justice Hickinbottom ruled the two year residency rule was unlawful on six separate grounds. The Council acted outside its statutory powers, the rule was irrational and discriminated on grounds of race and gender, and the Council failed to hold any consultation or comply with its equality duties. The ruling stated:

94. Section 149 was undoubtedly engaged: indeed, that was well- recognised by the Council, in the way in which it conducted an EIA at various stages before the residence requirement was tabled. However, there is simply no evidence that the Council conducted any assessment at all of the race or gender impact of the residence requirement at or before it adopted the 2013-14 CTR Scheme; and scant evidence that it did so prior to the 2014-15 Scheme. I do not consider that the evidence that there is (e.g. with regard to feedback towards the end of 2013, from wherever it came) is sufficient to show that the Council grappled at all with the effects of the requirement on those with the identified protected characteristics.

95. On the evidence, I cannot but find that the Council was in breach of its section 149 duty. That duty is important; and, had the Council been rigorous in satisfying its obligation to have due regard to the relevant characteristics, then, again, it may not have proceeded with the unlawful course that it followed.

The PIP scheme comes within the ambit of Article 1 of the First Protocol to the ECHR and covers the Article 8 Right to a Private and Family Life. It also engages Article 14, which prohibits discrimination in the enjoyment of Convention rights and the discrimination on a number of grounds in "other status" which includes disability. This is when there is different treatment of people in the same position which will be unlawful if the different treatment cannot be "objectively" justified.

There are some overlapping rules such as for those who may be covered by mobility but fall under the daily living needs such as whether or not a person finds it hard to make a journey because of `overwhelming psychological distress.'¹⁴ The issue that has caused the

¹² Paras 93-94

¹³ CO/633/2014

¹⁴ OPD means distress related to a mental health condition or intellectual or cognitive impairment resulting in a severe anxiety state in which the symptoms are so severe that the person cannot undertake a journey without being overwhelmed. The threshold is a very high one - a claimant who, without prompting, would be left feeling anxious, worried or emotional does not meet it. OPD may occur in conditions such as

most controversy regarding the PIP claim is how will the affect will be determined by the date of the claim and the catalyst on how people with mental health conditions had been discriminated against. From 16 March 2017, new PIP regulations prevented an award of the enhanced PIP mobility rate in cases where someone cannot follow the route of a familiar journey without another person unless it is "for reasons other than psychological distress". This meant that those with serious mental health conditions, who are unable to plan or undertake a journey because of overwhelming psychological distress were only entitled to a lower level of support, if any.

There have been recent issues that have surfaced which have caused the PIP framework to be questioned. The fact that the DWP has allegedly discriminated against people with mental health conditions in the way it has dealt with their PIP claims where the mobility component is under consideration. This includes the disregarding of the evidence relating to mental health and focusing instead on other impairments and made no attempt to seek medical evidence from their GP. There are also allegations that the assessors are not accurate about the assessment of the patient's symptoms and the medication that they are dependent upon.¹⁵

The tribunal has to undertake a complete reconsideration of the issues that are raised by the appeal and, subject to the tribunal's discretion under section 12(8)(a) of the Social Security Act 1998, any other issues that merit consideration. The tribunal must not take account of circumstances that were not obtaining at that time: see section 12(8)(b) of the Social Security Act 1998. Later evidence is admissible, provided that it relates to the time of the decision: R(DLA) 2 and 3^{16}

The argument in this paper is that where psychological distress is concerned there should be a flexible approach towards admitting the expert evidence to be submitted at the tribunal and that this should include evidence of other benefits such as the Employment and Support Allowance (ESA) and the GP records.

II. INTERPRETING 'MOBILITY' IN THE REGULATIONS

The payment of PIP retains the key principles of DLA by providing welfare benefits to help claimants overcome the barriers which prevent disabled people from participating fully in everyday life. It has the objective of a fairer, more consistent and sustainable provision of social security. The intention is that support should be aimed at those disabled people who face the greatest challenges to leading independent lives. In terms of dealing with those who suffer from a disability relating to mobility there are provisions in the Social Security (Personal Independence Payment) Regulations 2013¹⁷. Descriptors c, d and f are relevant for the mobility component of the PIP.

generalised anxiety disorder, panic disorder, dementia or agoraphobia. PIP Assessment Guide Part 2 - The Assessment Criteria DWP 30/9/19.

¹⁵ PIP Assessment report being inaccurate. Scope: Equality for disabled people. 27/9/18. <u>https://community.scope.org.uk/discussion/49756/pip-assessment-report-being-inaccurate</u>Under Section 12 (8) of the Social Security Act the tribunal has to take account of circumstances that were obtaining at the time and the later evidence is only admissible provided that it relates to the time of the decision. RL (DLA) 2 AND 3/01

¹⁶ R(DLA)2/01 (formerly CDLA/2934/1999) states that evidence obtained late must be relevant to circumstances obtaining at the date of decision. See also R(DLA)3/01 (formerly CDLA/4734/1999). ¹⁷ S.I. 2013 No.377

The Claimant is entitled to receive the benefits in these circumstances as follows:

c. For reasons other than psychological distress, cannot plan the route of a journey.

d. For reasons other than psychological distress, cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid.

f. For reasons other than psychological distress, cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid.

Schedule 1 Part 3 contained the table for mobility activities. This provides in the Activity column Planning and following journeys. In the Descriptor column, if a can plan and follow the route of a journey unaided then they get awarded zero points; Descriptor b, Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant. The award is of 4 points; Descriptor c, Cannot plan the route of the journey gains 8 points; Descriptor d, Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid gains 10 points; Descriptor e, Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant gains 10 points; and Descriptor f, Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid gains 12 points.

The Social Security (Personal Independence Payment) Regulations 2013 were amended by para 2(4) of the Social Security (Personal Independence Payment) (Amendment) Regulations 2017¹⁸. Para 2(4) provides:

In the table in Part 3 (mobility activities), in relation to activity 1 (planning and following journeys), in descriptors c, d and f, for "Cannot" substitute "For reasons other than psychological distress, cannot.

These regulations were interpreted by the tribunal reviewing appeals based on the infringements of these rules. In *MH v Secretary of State for Work and Pensions (PIP)*¹⁹ the appeal concerned the approach to the mobility descriptors, particularly mobility activity 1.

The claimant had been found to be unable to undertake any journey because it would cause overwhelming distress to him (descriptor 1(e)) but appealed on the ground that the overwhelming distress he would suffer if he went out meant that he also could not follow the route of a familiar journey without another person (descriptor 1(f)) and that the retching he would experience would make him unable to move more than 50 metres (descriptor 2(c)). The challenge stated the effect of these regulations was that many people with mental health problems and some people with learning disabilities and brain injuries were prevented from accessing the mobility component of PIP, even if their mental illness, learning disability or brain injury was so severe that they were entirely unable to travel, if the reason for this was psychological distress.²⁰

The Upper Tribunal Judges Rowland, Rowley and Hemingway held "that, applying regulation 4(2A)(a), a person who cannot walk along a pavement or cross a road safely by himself because he is at risk of having a fit and so needs supervision to do so, is unable safely to follow a route and satisfies descriptor 1f. We consider that the same analysis

¹⁸ SI 2017 No. 194

¹⁹ [2016] UKUT 531 (AAC)

²⁰ Para 12

applies to a claimant who is unable to follow a route safely because he or she is unaware of dangers due to a sensory or cognitive impairment".²¹

The Upper Tribunal referred to the 'overwhelming' psychological distress and although this term may appear to be setting a high-or difficult-to- meet threshold, in practice, if someone's psychological distress impairs their ability to mobilise outdoors to such an extent that they cannot plan a route, or go there unaccompanied, it should be self-evident that the level of distress is 'overwhelming'. This has had a bearing on later judgments and in the review that the DWP has applied it will apply in the 'anti-test case rule', whereby the outcome of a test case is only applied to other similar cases from the date of the test case judgment.

The Court considered the application of regulation 7 to the application of the requirements in their regulation 4(2A), which provides that a descriptor applies only where it is satisfied on over 50% of the days. The tribunal referred expressly to this requirement when giving its reasons for disallowing (the appellant's) appeal. ²² It is the risk of losing their mobility or such an occurrence which creates the need for her to have supervision in order to be able to carry out the relevant descriptor safely. This meant that descriptors 'c', 'd' and 'f' could be satisfied by claimants by virtue of 'overwhelming psychological distress'. The claimant was eligible to score points under descriptor 1c, 1d or 1f if their inability to follow the route of a familiar journey was caused by psychological distress, even if they had the intellectual capacity to navigate the journey.

In response to this ruling the Government amended the PIP regulations from 16 March 2017, replacing the word 'cannot' in descriptors 'c', 'd' and 'f' with the phrase: 'For reasons other than psychological distress, cannot'. This meant that claimants whose ability to plan and follow journeys was impaired by mental, rather than physical, health problems could only score a maximum of 10 points under descriptor 'e' and it prevented them from an entitlement claim to the enhanced rate of the PIP mobility component.

III. ESSENTIAL PROBLEM WITH PARAGRAPH 2(4)

The concept of psychological distress has been in dispute in the context of the mobility for the descriptors to meet the requirements set out in the legislation. This is of considerable impact for claimants who, within the parameters of the Act, have been assessed as not suffering from psychological distress. There is a risk that public bodies can discriminate against different groups of disabled people, not simply against disabled people as a whole by comparison with non-disabled people.

These are matters that require consideration after the coming into force after the commencement of the substantive provisions of Part 4 of the Welfare Reform Act 2012 and (Regulation 1(2); , he the Human Rights Act 1998 provisions and the consultation by the DWP with the stakeholders before making the regulations. This is because the issue can involve the mental health of the person in terms of their capacity and the need to be mobile with regard to the descriptors in the Mobility component of the allowance.

²¹ Para 37

²² Paras 54 and 55

In *RF v Secretary of State for Work and Pensions (Mind and Equality and Human Rights Commission intervening)*²³ there was a challenge by a judicial review to the <u>Social Security</u> (Personal Independence Payment) (Amendment) Regulations 2017 SI No 194, which excluded claimants from any entitlement to the mobility activity 1 if the cause of meeting the descriptor is psychological distress for descriptors 1c, 1d, and 1f.

Mr Justice Mostyn relied on the following three grounds in support of the application to quash paragraph 2(4) of the 2017 regulations.

i) the 2017 regulations are in breach of the prohibition against discrimination in Article 14 of the European Convention on Human Rights (ECHR), read together with Article 8 and Article 1 Protocol 1;
ii) the 2017 regulations are ultra vires Part 4 of the Welfare Reform Act 2012; and
iii) SoS unlawfully failed to consult prior to making the 2017 regulations.²⁴

Mr Justice Mostyn considered the four-limbed test from *Bank Mellat v HM Treasury*²⁵ when evaluating whether or not the 2017 regulations were in breach of Article 14 ECHR: firstly, the objective of the measure is sufficiently important to justify the limitation of a protected right; secondly, the measure is rationally connected to that objective; thirdly, a less intrusive measure could not have been used without unacceptably compromising the achievement of the objective; and finally, when balancing the severity of the measure's effects on the rights of the persons to whom it applies against the importance of the objective, to the extent that the measure will contribute to its achievement, the former outweighs the latter.²⁶ The Court relied on the judgment in *R. (on the application of MA) v Secretary of State for Work and Pensions*²⁷ that this principle "no doubt that this applies to this social security measure" and that "this reflects the wide margin of appreciation given to national governments when enacting measures with a macro-economic effect". The common factor in these limbs was to be determined according to whether or not the measure is 'manifestly without reasonable foundation'. ²⁸.

The objective of the paragraph 2 (4) was to save on the financial costs of PIP payments but Mr Justice Mostyn concluded that the measure that saving costs alone could not be "objectively justified, and that paragraph 2(4) of the 2017 regulations were manifestly without reasonable foundation" and was ultra vires. ²⁹ The measure failed to achieve a fair balance between the severity of the impact on people experiencing psychological distress and the importance of the objective and quashed it. The other grounds of challenge were also satisfied in that the parent statute did not grant the power to make secondary legislation with this effect, which was incompatible with the purpose of the scheme as defined in the parent statute. There had also been any consultation before the enactment of this measure.³⁰

This was premised on the process of consultation that led to the Welfare Reform Act 2012. This began with the consultation process which the government undertook before enacting

- ²⁴ Para 40
- ²⁵ [2013] UKSC 39
- ²⁶ Para 42
- ²⁷ [2016] UKSC 58
- ²⁸ Para 43
- ²⁹ Para 44
- 30 Para 45

²³ [2017] EWHC 3375 (Admin)

the legislation. The Government published its response to the consultation (Cm 8051) in April 2011. At para 15 on page 4 it proposed: "There will be two components of Personal Independence Payment; a daily living component and a mobility component, each with a standard and enhanced rate."³¹

However, there was no consultation when the process started to receive feedback for the definition of psychological distress. This was stated by the judge when he referred "to written evidence filed by the claimant and the first intervener about what specialist consultees were given to understand, during the period of gestation of these regulations, as to the scope of the "psychological distress" factor. The claimant filed witness statements by Ms Lambert of the National Autistic Society, Mr Butler of Disability Rights UK, Mr Anders of Revolving Doors and Ms Kotova of Inclusion London. The first intervener filed a statement from Mind's director of external relations, Ms Sophie Corlett. All of these people worked at organisations which contributed to the consultation process in the run-up to the 2013 Regulations. None of them recalls being told of an intention to distinguish overwhelming psychological distress from other mental health issues. On the contrary, had the intended distinction been made clear, all of these people would have raised concerns and objections". ³² Mr Justice Mostyn highlighted that the intention of differentiating between individuals with physical and mental health issues was never communicated to 'the outside world' and could not be inferred from either a literal or purposive construction of the original 2013 regulations. The later amendment utilising the secondary legislation was done by legal *fiat* and was not a logically connected to the legislative objective. ³³ The judge referred to Article 19 of the UN Convention on the Rights of Persons with Disabilities, which protects disabled people's right to live independently and be included in the community. ³⁴

Mr Justice Mostyn held that the intention of separating the individuals with physical and mental health issues was never conveyed into the public domain and could not be inferred from the statutory interpretation of the regulations. These were 'blatantly discriminatory' against those with mental health impairments and which cannot objectively be justified. ³⁵ The regulations had been passed into law by secondary legislation. The appellant's claim was supported through amicus curiae interventions by the National Autistic Society, Inclusion London, Revolving Doors and Disability Rights UK. Mind and the Equality and Human Rights Commission (EHRC) intervened in the case as third parties supporting RF's claim.

In August 2017 an inquiry by the UN committee on the Rights of Persons with Disabilities (the committee's first ever inquiry) examined the government's progress in becoming compliant with the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The report found that the UK government is failing to uphold disabled people's rights across a range of areas from education, work and housing to health, transport and social security.³⁶12 These findings were further supported by the report of Philip Alston, the UN

³¹ Para 8

³² Para 24

³³ Para 63

³⁴ Para 61

³⁵ Para 59

³⁶ www.theguardian.com/society/2017/aug/31/un-panel- criticises-uk-failure-to-uphold-disabled-peoplesrights. See also Joseph Rowntree Foundation (2018) UK Poverty 2018: A Comprehensive Analysis of Poverty

Special Rapporteur on extreme poverty and human rights in 2018.³⁷ In January 2018 the Secretary State of Work and Pensions announced that the government would not appeal the High Court's judgment and that it would drop its appeal against the original Upper Tribunal decision (MH v Secretary of State for Work and Pensions [2016]) that had prompted the regulations under challenge. It also undertook to review all the previous cases that had been decided taking this regulation into consideration that had gone against applicants in similar circumstances and to back date claims for payments of individuals effected by the decisions.³⁸

The *MH* approach can be integrated with the *RF* decision because the former referred to the <u>`</u>overwhelming' psychological distress and the later has affirmed that it could be linked to circumstances of mental distress generally. Although this text appears to set a high- or difficult-to- meet threshold, in practice, if someone's psychological distress impairs her/his ability to mobilise outdoors to such an extent s/he cannot plan where s/he is going, or go there unaccompanied, it should be self-evident that the level of her/his distress is `overwhelming'. The DWP has ordered a review which it states would link it to the ruling in *MH*, which implies that it is applying the `anti-test case rule', whereby the outcome of a test case is only applied to other similar cases from the date of the test case judgment.³⁹

The contentious argument in all retrospective challenges would be that the DWP now accepts that, where applicable, points should be awarded for psychological distress from the date of the decision in MH or, if later, the date of claim. The backdating of arrears could be argued on the failure to award points under one of these descriptors because the cause of their impairment was mental health disability rather than physical which was a presumption that now should be regarded as wrong.⁴⁰

IV. UNDERSTANDING MENTAL ELEMENT IN MOBILITY CLAIMS

There have been several claims in which a number of Upper Tribunal decisions resulted in differing approaches to the interpretation of the Activity 1 descriptors for people whose problems with planning and following journeys stem from psychological problems such as anxiety and depression. The issue has been explored in the context of the Daily Living Activity 3 that covers "Managing therapy or monitoring a health condition" and is one of

Trends and Figures. London: Joseph Rowntree Foundation. Last accessed 19 December 2018 at https://www.jrf.org.uk/report/uk-poverty-2018

³⁷ Office of the High Commissioner on Human Rights (2018) Statement on Visit to the United Kingdom, by Professor Philip Alston, United Nations Special Rapporteur on extreme poverty and human rights. London, 16 November 2018. Last accessed 3 December 2018 at https://www.ohchr.org/Documents/Issues/Poverty/ EOM_GB_16Nov2018.pd

³⁸ Changes to the Personal Independence Payment eligibility criteria, House of Commons library, Steven Kennedy. 17/4/18. commonslibrary.parliament.uk/research-briefings/cbp-7911

³⁹ Social Security Act 1998, section 27

⁴⁰ The aftermath of the decision was that On 19 January 2018 the Secretary of State for Work and Pensions announced that the government did not intend to appeal this decision to the Court of Appeal and that the Department for Work and Pensions will now undertake an exercise to go through all PIP cases affected by this judgement, with payments to affected individuals to be backdated to the effective date in each individual claim. Every person receiving PIP will have their claim reviewed, the DWP and a total of 1.6 million of the main disability benefit claims will be reviewed, with around 220,000 people expected to receive more money. The review could cost £3.7bn by 2023. Changes to the PIP eligibility criteria, House of Commons Briefing Paper, no 7911, 13 April 18 by Steven Kennedy. *researchbriefings.files.parliament.uk/documents/CBP-7911/CBP-7911.pdf*

10 activities in the PIP assessment which, taken together, are intended to assess the extent of an individual's daily living needs. $^{\rm 41}$

In *Secretary of State for Work and Pensions v LB (PIP)*⁴² the claimant had been entitled to the lower rate of the mobility component of disability living allowance and the middle rate of the care component for the period from 6 July 2013 to 16 June 2015. Prior to expiry of that award she was invited to make a claim for PIP, which she did by she and her partner completing a PIP2 questionnaire that was apparently received on 7 April 2015. This stated the diabetes 1, dyslexia and depression and anxiety among her conditions. The partner mentioned that he was constantly monitoring her blood sugar levels and encouraging her to eat as she could get tired and low due to the diabetes, depression and anxiety. ⁴³ He helped her with food and sugar intake as her dyslexia meant she could not judge how much insulin to take.⁴⁴

The assessor who visited her at home scored on descriptors needing prompting to be able to read or understand complex written information (activity 8: 2 points) and for needing prompting or assistance to be able to make complex budgeting decisions (activity 10: 2 points), in both cases because of her dyslexia. The claimant was not in difficulty with reading except for budgeting decisions but otherwise could self manage on treating herself for dyslexia. The total score did not achieve the threshold for payment of the PIP. The DWP 's decision was that the claimant was not entitled to PIP because she only scored four points on daily living activities (below the necessary eight for the standard rate) and none on mobility activities. However, she was deemed to have no cognitive impairment, it was accepted that she struggled to understand bills due to her dyslexia and would require help with prompting and assistance to make a complex budgeting decision.

The First tier Tribunal allowed the claimant's appeal on papers and decided that she was entitled to the daily living component of PIP at the enhanced rate for the period from 17 June 2015 to 16 June 2018 and to the mobility component at the standard rate for the same period. The tribunal adopted the four points accepted by the Secretary of State for daily living activities and in addition awarded four points for needing prompting to be able to take nutrition (activity 2(d)), four points for needing supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week (activity 3(d)), and two points for needing prompting to be able to engage with other people (activity 9(b)). This made a total of 14, in excess of the 12 needed for qualification for the enhanced rate.

The Secretary of State appealed to the Upper Tribunal and in his ruling, Judge Mesher stated that the appeal raised "difficult questions" about the proper interpretation if the descriptors under two of the Daily living activities in the context of the conditions affecting the claimant. He stated that it "illustrates once again the gaps left in the drafting of that Schedule, requiring a large expenditure of effort to render its provisions coherent and thus making it ineffective as a simple day- to-day test of disability that needs to be applied by

⁴¹ As set out in Schedule 1 of The Social Security (Personal Independence Payment) Regulations 2013 ; SI 2013/377 as amended.

⁴² [2016] UKUT 0530 (AAC)

⁴³ Page 18

⁴⁴ Page 20

non-lawyers". ⁴⁵ He considered this to be an "anomaly" and that he was " acutely aware that other cases will throw up circumstances and difficulties that I have not thought of and which may not be catered for in a ruling made in the context of the circumstances of the present case. But that is so whatever interpretation I adopt.⁴⁶ On balance I have concluded that what I have labelled alternative interpretation A (paragraphs 25 – 30 above) does the least damage to the intended structure of the descriptors under activity 3. It maintains some practical operation for the whole of descriptor 3(b)(ii) and substantially reduces the anomaly of claimants with more needs qualifying for fewer points than claimants with fewer needs".⁴⁷

After exploring various alternative ways of interpreting the descriptors to address the anomaly, Judge Mesher concluded that, even if a claimant needs extensive and timeconsuming assistance with managing medication and monitoring a health condition, s/he can never score more than one point under descriptor 3(b), in contrast to those who need help with managing therapy who can score between two and 10 points under descriptors 3(c)(d)(e). He held that:

... descriptor 3(b)(ii) does not apply if supervision, prompting or assistance is needed for both managing medication and monitoring a health condition and only applies if it is needed for one only of those alternatives. It also does not apply if the supervision etc is needed for elements of what would ordinarily be regarded as therapy that go beyond either managing medication or monitoring a health condition within the meaning of descriptor 3(b)(ii). In both those circumstances in which descriptor 3(b)(ii) does not apply, the case would potentially fall within the therapy provisions in descriptors 3(c)–(f), depending on how far the supervision etc relates to something that can properly be called undertaking therapy and with the scale of points depending on the time for which the supervision etc is needed. All elements of therapy in its ordinary meaning could then be considered, including any taking of medication or monitoring of a health condition. If the need for supervision etc is limited to one or other of those alternatives in descriptor 3(b)(ii), then in order to allow the descriptor to have any practical application the application of descriptors 3(c) – (f) would be excluded.⁴⁸

The First-tier Tribunal decision was deemed to contain an error of law and was set aside. ⁴⁹ The claimant's appeal was allowed and that she is entitled to the daily living component of PIP at the enhanced rate for the period from 17 June 2015 to 16 June 2018, but not entitled to the mobility component from and including 17 June 2015.

The DWP issued an Explanatory Memorandum in the aftermath of this ruling and viewed the decision to be contrary to the objectives of the legislation. It summarised the effect of the decision as follows:

... the Upper Tribunal held that supervision, prompting or assistance to manage medication or monitor a health condition (which scores 1 point) may amount to supervision, prompting or assistance to manage therapy (which scores 2 to 8 points, depending on the number of hours support required), and in particular will do so where a claimant needs supervision, prompting or assistance both to manage medication and to monitor a health condition. 50

⁴⁵ Para 1

⁴⁶ Para 24

⁴⁷ Para 33

⁴⁸ Para 34

⁴⁹ Para 51

⁵⁰ DWP, Explanatory Memorandum to The Social Security (Personal Independence Payment) (Amendment) Regulations 2017, no 194, para 7.5. www.legislation.gov.uk/uksi/2017/194/pdf/uksiem_20170194_en.pdf

It states further that "Regulations 2(2) and (3) 'clarify the drafting of Schedule 1 to the PIP Regulations to reverse these aspects of the ruling and more clearly reinstate the Government's originally intended meaning'. They do so by separating out the definitions of 'manage medication' and 'monitor therapy' and making it clear that 'monitor therapy' does not include receiving or administering medication (by any means), or any action which (in the case of the particular claimant being assessed) falls within the definition of 'manage medication' or 'monitor a health condition'. They also make it clear that the 1 point score applies even if two or more elements of the descriptor are met".⁵¹

As a consequence of this ruling and *Secretary of State v MH* the government made changes to the legislation. On 23 February 2017, DWP initiated before Parliament the process to amend the PIP eligibility criteria from 16 March to "clarify the drafting and reverse the effect" of two recent Upper Tribunal judgments, which had interpreted the Schedule setting out the assessment criteria "in ways which the Government did not intend." The LB judgment relates to the PIP daily living activity 3 ("managing therapy or monitoring a health condition"); and MH considered Mobility in Activity 1, 'planning and following journeys'.

The DWP in passage the regulations, in particular the exclusion of 'psychological distress' from consideration in descriptors 1(c), (d) and (f), and there is much debate that there should have been prior consultation and debate in Parliament. The House of Lords has considered two motions relating to the PIP regulations following a report from the Lords Secondary Legislation Scrutiny Committee that drew special attention to the regulations "on the ground that they give rise to issues of public policy likely to be of interest to the House". ⁵² The Committee received submissions from a number of organisations pointing out the likely negative effect of the changes on claimants, particularly those with mental health conditions.

The Lords Committee has raised the issue against the claim by the DWP that no changes need be made to the guidance for Healthcare Professionals undertaking PIP assessments, following the regulations (original emphasis). The implications of the "two significant Upper Tribunal decisions because the interpretation of the current descriptors was inconsistent or misunderstood. The wording of the descriptors has been changed, which suggests that, as a minimum, those making the assessments should be provided with revised guidance to ensure that they take proper account of the distinctions made" .⁵³ The Committee points to the response from DWP at paragraph 28 above which indicates that the assessors do not have either the ability or the capacity to implement the Upper Tribunal decisions "in a safe and consistent manner"⁵⁴ also indicates a need for review. ⁵⁵

The House of Lords have in their deliberations considered this to be a matter of public policy. They have shown concern with the manner in which mental health problems are being interpreted and their evaluation by the DWP. It has also brought to the fore the issue of the lack of training of the assessors who come into contact at the earliest stage with the claimants that have these debilitating conditions.

⁵¹ Ibid, para 7.6.

⁵² Lords Secondary Legislation Scrutiny Committee Twenty Seventh Report, HL 126 2016-17, 9 March 2017

⁵³ HL Deb 27 March 2017 cc431-2

⁵⁴ Lords Secondary Legislation Scrutiny Committee Twenty Seventh Report Para 28

⁵⁵ Ibid para 33

V. CONCLUSION

The government took a huge step in transferring from the DLA to the PIP as a welfare benefit that covered the social security claimants.

It achieved a major transformation when it enacted the Welfare Reform Act 2012 which made the DLA obsolete and put in place the Personal Independence Payment. This is an individualised benefit that takes into the personal circumstances of the applicant and has its own criteria for payment which is separate from any other benefit paid. This was inaugurated after a consultation that included stakeholders from different disability organisations and charitable organisations.

This benefit can be divided into 2 components which are Living allowance and the Mobility allowance. These are paid at a basic and at an enhanced rate and there is an intricate criteria that needs to be satisfied in order to fall into the bracket which will trigger the payments. They both have a nexus which is based on the mental health factor and the impact on the psychological effect that is responsible for the stress on those who may have the mobility in carrying out their tasks.

The seeming urgency with which the DWP has implemented this benefit shows that they did not take into consideration the possible impact from the overwhelming stress that those who do not have problem with their mobility. It is this factor that falls within the descriptors that has raised the issue in the courts and which has been heard by means of litigation. The outcome has been that it has shown that there was incomplete consultation at its outset and not enough preparation went into devising its provisions The government had proceeded to sidestep the legislation by the statutory instrument that led to its interpretation that narrowed the terms under the Act. This meant that it applied in a discriminatory manner and not only it breached the purpose of the legislation but also the Human Rights Act Article 14.

The courts have now expunged that part of the Welfare Reform Act which neglected psychological stress and that has helped place the regulations back on track. The need is for the greater willingness of the Tribunals and the courts to give the claimants a greater benefit of the doubt in order to redress the perceived shortcomings that arise from inconsistent evaluation in the assessment process. This is particularly in circumstances where mental health is a common denominator in both the benefits under the provision.