DoLS or QUALITY CARE?

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I. INTRODUCTION

A comprehensive mental capacity jurisdiction was established for England and Wales on 1st October 2007 when the Mental Capacity Act 2005 was implemented. Shortly prior to this the 'Bournewood Gap' was identified when the European Court of Human Rights held that there was a breach of the human rights of adults who lacked capacity and were deprived of their liberty by the state.¹ A legal procedure was required to authorise this and in consequence our legislation was amended to introduce Deprivation of Liberty Safeguards (commonly referred to as DoLS) with effect from 1st April 2009.² These applied only to adults resident in hospitals and care homes and were found to be insufficient when the Supreme Court held that some adults in community settings were also being unlawfully deprived of their liberty.³ A further procedure was urgently required and Sir James Munby as President of the Court of Protection set up the *Re X* streamlined, paper-based judicial authorisation procedure to cope with the thousands of anticipated applications.⁴ It is to these two different procedures that I refer in this article.

II. A PARENT'S PERSPECTIVE

I first encountered the 'Bournewood Gap' before it was even identified. Our son Paul was a strapping lad over 6 feet tall with no physical impairments, but he had grown up with severe learning disabilities and challenging behaviour that made him increasingly difficult to manage. We were determined to achieve a life for him that was not dependent on our household which he was likely to outlive. We made strenuous attempts to settle him in various care homes and communities (I became a founder of one and a trustee of several) but they could not cope with his behaviour and ultimately he was sectioned under the Mental Health Act for the purpose of moving him to a health authority unit shared with two other young adults (although the section was then discharged!). We had never resorted to the use of drugs but he was soon drugged so heavily that he could barely stand or converse with us on our visits. Ultimately he died there in 2004 at the age of 28 years due to inadequate supervision – there should have been at least two carers but on that morning for some reason there was only one and he choked to death on his breakfast.

^{*} Retired district judge and nominated judge of the Court of Protection. Gordon Ashton draws on his experience as a parent and a judge to consider the relevance of deprivation of liberty safeguards in the context of the care of adults who lack capacity to make their own decisions but need constant supervision, and then outlines his perspective as a potential consumer of the mental capacity jurisdiction.

¹ *HL v UK* (2004) 40 EHRR 761, overturning the decision of the House of Lords in *R v Bournewood Community and Mental Health NHS Trust ex parte L* [1999] AC 458, [1998] 2 FLR 550.

² Mental Health Act 2007 which inserted clause 4A and B and Schedules A1 and 1A in the Mental Capacity Act 2005.

³ P v Cheshire West and Cheshire Council and another; P and Q v Surrey County Council [2014] UKSC 19, concerning the living arrangements of P, MIG and MEG.

⁴ Re X and others (Deprivation of Liberty) [2014] EWCOP 25.

How does this relate to Deprivation of Liberty Safeguards?

As parents we were not concerned that our son's liberty was being restricted – we would have been appalled if this had not been so. What concerned us was whether the care arrangements were the best that could reasonably be achieved for our son. We learnt that this depended on the dedication of carers and the implementation rather than wording of the care plan. This justifiably stated that he should not leave the flat unless accompanied by two responsible adults, but there were seldom two adults available and when my wife wished to take him for a walk there was no-one to accompany them. So the reality was that he was confined to a small flat with two others needing continuous supervision.

Would the DoLS or *Re X* procedure have given our son more freedom or saved his life? No, because the former only addresses the justification for deprivation of liberty⁵ whereas the latter would have found the care plan acceptable on the face of it. This might have created an opportunity not otherwise available for us to ventilate our concerns about the quality of his lifestyle, but the reality was that no other options were then available and the courts could not oblige the authorities to fund something better.

There is now uncertainty as to whether safeguards should apply to care at home where there is some involvement of the local authority. During the years that we looked after our son we would have found it laughable if anyone had suggested that we were depriving him of his liberty in view of his irrational behaviour and lack of awareness, and would have felt threatened and undervalued if intrusive reports had to be prepared and reviewed at intervals. Of more importance was the extent to which we were providing him with opportunities that would not otherwise have been available to him, and as parents we looked to the authorities for support not policing. I found myself in sympathy with the initial attempt of Sir James Munby to head off the looming disaster by adopting the 'relative normality' approach whereby arrangements that were normal or perhaps inevitable for such an individual did not amount to a deprivation of liberty.⁶

III. A DISTRICT JUDGE'S PERSPECTIVE

I never aspired to be a judge, but after 28 years in general legal practice my activities outside the office motivated by the struggle with our son displeased my partners so much that I applied to be a District Judge. I had been a deputy for some years and also a part-time chair of the Social Security Appeals Tribunal, but was also a member of the Law Society's Mental Health & Disability Committee, lecturing to lawyers and charities on disability issues and writing my first book, *Mental Handicap & the Law* the publication of which in 1992 coincided with my appointment. Not only did life on the Bench give me more time for these activities but I also found that the judiciary lacked awareness of the need to make reasonable adjustments for people with physical, sensory and mental impairments. Thus began my long association with the Judicial Studies Board (now the Judicial College) and their Equal Treatment Advisory Committee through which I provided information and training to judges on disability issues.

⁵ See Hillingdon London Borough Council v Neary [2011] EWHC 1377 (COP).

⁶ Cheshire West and Cheshire Council v P [2011] EWHC Civ 1257, overturned by the Supreme Court. It is the existence of a deprivation that is relevant, not the reason for it.

When human rights 'came home' with the passing of the Human Rights Act 1998 I complained that the Court of Protection as then constituted under the Mental Health Act was not compliant because apart from the Master it was run by nominated officers with the courtesy title of 'Assistant Master' who lacked the independence of a judge. Also a court that sat only in London was not accessible to elderly and disabled people in the north of the country. Shortly thereafter I was appointed a Deputy Master to hear cases at my court in Preston, Lancashire and subsequently I was involved in setting up the new Court of Protection under the Mental Capacity Act 2005.

How does this relate to Deprivation of Liberty Safeguards?

As a nominated Judge of the Court of Protection I inevitably became involved in deprivation of liberty situations although challenges under the DoLS procedure were initially reserved to High Court Judges. It seemed to me that if a care plan was in the best interests of an incapacitated person, any deprivation of liberty would be justified so I concentrated on the former and treated DoLS as a parallel path that would only concern the Court if there was a specific challenge. The problem then became that one was restricted to that which the relevant authority was prepared to fund. In many cases the Court seemed impotent to achieve its view of best interests especially when only one care option was available. In one of my final cases where I had expressed unresolved concerns I threatened to invite the press to the next hearing on the basis that the court of public opinion may be more powerful than my own role.

Yet despite my extra-judicial experience I did not feel best placed to decide what care provision would be in the best interests of the incapacitated person, and had to remind myself that my judicial role was not to dictate that such provision be provided but merely to ensure that decisions made for the individual were in his or her best interests. In that respect the incapacitated person was in the same position, no better and no worse, than any other person in seeking adequate care provision. One can only choose from that which is, or might be, available. However, the DoLS amendment extended the judicial role to determining whether any deprivation of liberty was in the best interests of the individual and that widened the powers of the Court considerably because a refusal to accept the extent of the deprivation obliges the provider to reconsider the care arrangements.

IV. A RETIRED LAWYER'S PERSPECTIVE

I am now retired and living with my wife of almost 45 years who has Parkinson's disease. We are apprehensive about the future together and then perhaps for one of us alone. If we cannot cope due to physical or mental infirmity we shall become dependent on others, a situation we have not faced since childhood and do not relish. We do not wish to be a burden to our daughters or to be kept alive by medical care if the quality of our lives cannot be preserved. We may even become consumers of the mental capacity jurisdiction! I became responsible for my mother who spent her last years in a nursing home and died there in 2013 at the age of 97 years. I knew that she was receiving the best care available because I had arranged it for her. These experiences made me painfully aware that it is for the benefit of such persons, and not the lawyers, that the jurisdiction exists. I find myself reflecting on what has been

achieved, less defensive of the Court of Protection and more willing to identify its failings.

How does this relate to Deprivation of Liberty Safeguards?

Should I have been concerned about deprivation of liberty when I visited my mother and found her sitting in her room alone or 'confined to bed'? My thoughts related more to the quality of her care and whether the staff were being kind to her because she needed guidance and support rather than freedom. I would have been angry at the intrusion and waste of resources if people unknown to me had wished to carry out a fruitless annual enquiry as to whether she was unlawfully being deprived of her liberty. I do not worry about being deprived of my own liberty in the event that I become infirm and lack capacity just as long as good quality care is provided by people who treat me with respect and create opportunities for me to enjoy some activity. Being cared for by uncaring persons but with more freedom than one could cope with would be a worse fate than being excessively restricted by persons providing loving even though misplaced care.

V. CONCLUSION

Entrenched human rights are necessary to preserve a free society but the framers of the European Convention could hardly have anticipated that they would be applied with such intensity in these situations. The Human Rights Act 1998 made the Mental Capacity Act 2005 necessary but has it now become a threat to this jurisdiction? Of course the incapacitated individual is vulnerable to inappropriate confinement, and we need judicial procedures to prevent people from being wrongly declared as incapable and then deprived of their liberty. Enforceability of human rights then becomes important, but the obsession of lawyers with the prospect of deprivations of liberty in every case results in a clash of objectives with too much emphasis being placed on personal freedom and too little on the need for support or supervision. The cost of this in terms of financial and professional resources is enormous and in times of austerity inevitably depletes the budget for the delivery of care. How much of our limited resources are we to devote to that issue when the real question is whether the care plan and the way it is being implemented is in the best interests of the individual?

The underlying problem with a rights based approach is that it focuses solely on rights and life is not like this. With rights come responsibilities to oneself, one's family, one's carers and society. None of us have total freedom to exercise our rights as we need to be heedful of the needs of others. Those who lack decision-making capacity are unlikely to be mindful of these natural constraints. Why should they be treated as released from them in the decision-making process and thereby become entitled to have everything their own way? The person who constantly says 'I know my rights' provokes other people to keep their distance which is not in the best interests of that person. This brings us back to the delicate balance between empowerment and protection. There are times when we need to be protected from ourselves and the constraints of our normal personal relationships often have this outcome. If we lack the capacity to recognise and respond to those constraints we would surely expect that they would be applied externally in any decision-making process. The notion that I should have a supporter who ascertains what I want so that this can be demanded on my behalf is not one to which I would wish to subscribe. If as a result of a lack of awareness or judgment I wished to give all my money away I would not expect this to be the decision made on my behalf even though if I did not lack capacity I would have the legal right to do so. A supporter may recognise this but in seeking to exert influence would perhaps be going beyond the true role of a supporter and would be moving towards a 'best interests' approach to decision-making without the safeguards of the statutory criteria.

I have no wish to condemn the procedures that we have without offering a viable alternative. I would sooner concentrate on the enforceability of human rights where appropriate than universal enforcement. Otherwise the emphasis in care provision for those lacking capacity becomes minimum restriction rather than maximum support. I favour a whistle-blowing procedure to protect those who may be deprived of more liberty than is necessary, but with someone in authority capable of responding by making a reference to the Court of Protection for judicial scrutiny. There should be widespread public knowledge of this procedure as part of the culture of care so that relatives and concerned persons may blow the whistle, and a designated local official to monitor the care of those who have no such contacts. Resources would then be reserved for those who needed protection.

During the past 25 years I have campaigned for this jurisdiction, participated with the Law Commission to achieve it and then worked in the judicial system to implement it. Has my dream become a nightmare? I respect the impeccable logic of the Appeal Courts in applying the broad principles of international Conventions but wonder whether in days of austerity our society can afford to deliver such an idealistic approach. It seems out of touch with the reality of life as an involuntary carer faced with expectations but insufficient support from the authorities, whose right to personal freedom must not be overborne by the similar right of the one cared for. I conclude this contribution with the words that I have used in many of my lectures over these years: "The structure is there but it all depends on how we, the lawyers and other professionals, implement the legislation – *pragmatic or legalistic?*"