

Achieving Human Rights for People who Lack Capacity

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In November 1999 a conference entitled “Mental Incapacity. New Millennium - New Law” was organised by the Law Society, Royal College of Psychiatrists and the Mental Health Act Commission. It concluded with the Lydia Sinclair Memorial Lecture delivered by William Bingley.

Introduction

Being invited to give this lecture is probably the greatest honour of my 16 years in mental health. It is also a daunting one - not only because it is almost impossible to do justice to Lydia Sinclair’s contribution but also because - being the last speaker after such a galaxie - I strongly suspect there is not much more to be said.

One of my major achievements in mental health was to recruit Lydia Sinclair to MIND in 1983 as its Legal Officer, and even that is a gross exaggeration - essentially she recruited herself. Her subsequent and distinguished career, which came to a grievously premature end with her death in May 1998, included the Legal Directorship of Mencap, private practice with Birnbergs and latterly Scott-Moncrief Harbour and Sinclair, membership of the Mental Health Act Commission and membership of the Law Society’s Mental Health and Disability Committee. All provided vehicles for her unique and invaluable contribution to, amongst other things, the field that is the focus of our attention today - and I think it is important not to forget that back in 1983 when she joined MIND - *today* and what it represents would have been unimaginable. What Lydia Sinclair was about was rights and especially the rights of particular groups too often denied them. My presentation today is about “Achieving Human Rights for People Who Lack Capacity” and I would like to intertwine what I saw as some of the characteristics I observed in Lydia Sinclair with the challenge ahead, as I see it, in implementing, consolidating and taking forward the rights of those described as lacking capacity.

In particular, what I would like to do is:-

3 *Law Commission. Mentally Incapacitated Adults and Decision Making: An Overview. Consultation Paper No 119 (1991, HMSO: London)*

- a. Identify three characteristics of Lydia Sinclair's work which I think are instructive for today;
- b. Briefly address the challenge of ensuring that those who lack capacity do not become the new excluded;
- c. Restate some of the fundamental political values which I think we should not forget especially as we review where we are today;
- d. Briefly set out what the law can do and also look at the principles and values that should underlie not only legislation but maybe also our dealings with each other (including those whom we describe as lacking capacity); and
- e. Make a plea for early action in relation to two areas.

What I will vigorously avoid is any studious philosophical examination of the strengths and weaknesses of the so-called "rights approach" to those who lack capacity. Some may take a rather narrow rights and responsibilities approach and, whilst not arguing that those who lack capacity do not have human rights, may suggest that in these particular circumstances such an approach is of limited value. I take a rather more imprecise view that human rights (as Chris Heginbotham and Tom Campbell said in *Mental Illness, Prejudice, Discrimination and the Law*)¹ are those rights which are the inalienable possession of every human being. This means that no distinction between individuals or groups is tolerable with respect to the enjoyment of human rights. I guess there is a difficulty - in a general sense - in that customarily the focus of the human rights approach and discourse is about increasing autonomy and some may argue that in relation to people who lack capacity, the room for this is much more limited. Whilst this is so, let us not forget that crucial part of the Law Commission's report² (3.5) when it talks about the "functional" approach to capacity - "most people, unless in a coma, are able to make at least some decisions for themselves and may have levels of capacity that vary from week to week or even from hour to hour."

a. Lydia Sinclair

Any attempt to describe Lydia's contribution will not do her justice. She somehow combined tenacious casework, recognition of the importance of policy and its development, a true understanding of the law, an appreciation of the significance of research and a principled and yet realistic and pragmatic ability to contribute to the management of organisations. She managed to pursue these alongside an energetic, enriching and at times demanding family life a keen sense of humour and an energy that was truly and justifiably enviable. Above all else, what she managed to do in her years in the field of mental health and learning disability (and I suspect this was a characteristic of her whole life) was to keep intact her ability to be outraged when it was right to be so. All her professional life her activities focused on individuals and the infinite care which she took with individual cases as well as the way in which they influenced her activities in other areas sums up for me what Lydia Sinclair stood for.

Pursuing this a little further there were three things about Lydia which it is appropriate to mention, especially today:-

- Firstly, I think it is fair to say that she was amongst the first to recognise the potential significance of the concept of capacity - I think at MIND and more centrally at Mencap, she worked out the

importance of capacity and incapacity as ideas, especially in relation to decision making.

- Second, Lydia did recognise very early, the potential (and the limitations) of the law as a vehicle for pursuing rights. What she was involved in, it seems to me, logically preceded and ties in with the approach that is implicit within the Human Rights Act and all that may give us. If she was still here today it is not difficult to envisage the creative use she would have made of it.
- Thirdly, what Lydia Sinclair did was to go the extra mile. All her colleagues over the years have seen how that ability and willingness enabled her to engage with the most jaded, most damaged and most disengaged service users or carers in a way that was almost magical. At her best that extra mile could win cases and secure justice for people who never anticipated it.

b. People who lack capacity - the new excluded

That ability to engage even the most excluded, to me, highlights a fundamental challenge that we face today if we turn to look at the group of people who we describe as lacking capacity. In many ways a heterogeneous group described by the Law Commission³ back in 1991 as including some people with learning disability, some elderly people with mental infirmity, some people with mental illness and some people with brain damage, physical illness or physical handicap. This is a large group of people and taking them as a group for many purposes will not be terribly helpful. On the other hand they, or at least some of them, are not immune from society's well documented need from time to time to create demon groups on to whom we pour out, at times, our most irrational fears and terrors. At the moment I guess it is those with serious mental health problems whose needs, care and treatment have (for a number of reasons which I do not think are too difficult to identify) got tied up with, amongst other things, the debate about community safety. In terms however of getting a raw deal they are clearly not alone. For example, Age Concern tells us that older people are getting a particularly raw and discriminatory deal in relation to medical treatment. If their perceptions are true, then imagine what is happening if you are elderly, lack capacity and do not have somebody to fight for you.

Many of the people who fall within the group described as lacking capacity are still effectively excluded and it is that fact which gives particular importance to the Government's commitment to reduce social exclusion and, it seems to me, the potential value of the Human Rights Act in - without over-investing it with unrealistic expectations - securing for excluded people some basic rights and entitlements that too often they are deprived of.

c. Incapacity and Fundamental Political Values

In pausing for a moment and attempting to see where we are it may not be unhelpful to return to some first principles in looking at the strength of our foundations especially in relation to where we want to go from here in pursuit of the human rights of people who lack capacity.

Chris Hegginbotham and Tom Campbell posited a set of principles and fundamental political values which they hoped might lead to a substantial consensus as to the most important values upon which to judge the morality of society's response to mental illness and in particular to provide a framework in which debate about discrimination can take place. Given and take a little, it struck me that the same

4 N Eastman and J Peay. *Law Without Enforcement: Integrating Mental Health and Justice*. (1999, Hart: Oxford)

principles could provide a framework for us to determine the morality or at least a consensus as to how we should respond to those who lack capacity. They suggested the following values:-

Basic Equality

A prior assumption of all acceptable systems is a belief in the inherent equality of all human beings. Not a matter of descriptive identity - what we are talking about is an assertion of the equal significance of each human being, in that one person's life and experience is, in itself and for its own sake, as important as anyone else's. This is a principle, as the authors state, which has general support, even if it is hard to reconcile with how we actually treat those who are unable to sustain a satisfactory existence - as a visit (and remember they were talking about the late 1980s) to many long-stay "back" wards in many a psychiatric hospital would bring home to us.

Well Being

The most evident and uncontroversial human value which follows naturally from our minimal definition of what it is to be human is happiness or utility defined as the experience of pleasure and the absence of pain. In an extremely complicated argument - the details of which I will not bother you with - Hegginsbotham and Campbell suggest that the value of wellbeing implies there should be in any acceptable polity, a practical concern for the welfare or wellbeing of all members of the community with priority being given to the relief of distress or unhappiness over the opportunity for pleasure or enjoyment.

Autonomy

The authors identify that the basic utilitarian value of well being requires supplementation by other important moral and political values principal amongst which is the value of autonomy. In an important discussion they distinguish between **instrumental autonomy** (the freedom of individuals as to *how* they should pursue their objectives) **goal autonomy** (the capacity of an individual to make up their own minds as to the *ultimate objectives* of their daily lives) and **control autonomy** (best identified, they suggest, as the capacity of an individual to control his or her life).

Autonomy they argue is not a unified and all or nothing matter which contains an obvious threshold of reduced capacity beyond which individual choice has no value. Failure they argue to take account of this fact leads to much unnecessary curtailment of liberties for persons with mental disabilities and illness. This basis for discrimination is reinforced by giving excessive weight to instrumental autonomy over goal autonomy, thereby depriving the instrumentally less competent of the real opportunity to set their own goals in life.

Justice

A fourth value that it is worth identifying in this context is justice. As Eastman and Peay in *Law Without Enforcement*⁴ state, justice might be broadly conceived in terms of "being dealt with equitable and/or in

accordance with the law". It can relate to the substantive law as well as its procedural application and can be distinguished between the individual taken alone and the individual in relation to others. On a broader front we have wider and possibly more collective notions of justice - for example social justice. Campbell and Hegginsbotham argue that "there is ample evidence that rules as they are applied to persons with mental illness are so open-ended and so loosely interpreted as a result of the extensive de facto discretion enjoyed by those who have authority in this sphere, that there is much less formal justice in mental health matters than in other areas." They go on to say "The general idea that we should do what is best for those with mental illness tends to push to one side the thought that they have a right to be treated according to established rules." Maybe part of what we are talking about today is beginning to address that. Clearly justice is about the interaction of many other things - criminal behaviour and mental disorder, incapacity and criminal behaviour and the debate, almost as old as time, about the so-called mad, bad and the sad.

This list of values is not exhaustive - and of course they compete and conflict and have to be traded off against each other. Talking in a slightly different context about the relationship between justice and mental health, Eastman and Peay note that attempting to integrate or at least finesse these two objectives sets up different sets of harmonies and conflicts which both the law and services have to be able to respond to. The same I would suggest is true in relation to the concept of incapacity.

d. The role of law in securing rights for people who lack capacity

If the law is one way in which to give effect to the results of the trade off in fundamental values we make when determining objectives for those who lack capacity, what role can it actually play in the pursuit of human rights? I guess that the law is essentially a social instrument or mechanism which balances the often competing rights and responsibilities of individuals, groups, organisations and of society as an entity and its purpose is to strike an appropriate balance between those competing considerations.

In his consideration of the possible role of the law, Larry Gostin constructed his so called Ideology of Entitlement in which he suggested that in relation to mental health you could ask the law to be involved in three principal areas:

i. Entitlement to a service

Clearly state services are provided with a statutory basis but the extent to which the law has provided potential beneficiaries with an enforceable entitlement has been less apparent. The implications of the Human Rights Act are going to be particularly important in this regard.

- ii. Second, the law could be asked to provide the authority to compel in certain circumstances and also set out the safeguards which should accompany that authority. That is the principle objective of the 1983 Mental Health Act.
- iii. To protect and/or enhance the civil and social status of those with mental health problems. It seems to me that, for example, the proposals set out in Making Decisions⁵ could be said to fall under this general category.

Not a bad breakdown of what you can ask the law to do and it may be that under those headings and in

⁶ *R v Bournewood Community and Mental Health NHS Trust, ex parte L (Secretary of State and others intervening)* [1998] 3 All ER 289.

light of all that we have heard today - its contribution is going to be more considerable than before and more focussed. But as Eastman and Peay say "Changing the law is a laborious and time consuming process albeit it is much easier than changing people's practices". But the law, or the possibility of changing it, can set an agenda and it can facilitate good practice by "for example specifying for decision makers factors which they should take into account, the sequence in which they should be done and the weight to be attached to them". It seems to me that the Law Commission report *Mental Incapacity* to a considerable degree has had a profound effect on many professionals and service providers (may-be it was the consultation process that led up to its publication) and is a good indicator of how the law making process - even in its early stages can impact on real life.

I guess that the ultimate test for any legal change is, does it result in real changes - the better observation of what we describe as the human rights of people who lack capacity in everyday life - and in that context, law makes an important but not exclusive contribution. Societal attitudes, professional attitudes and the principles and values we attach to our relationships to each other (not lest those with incapacity) are equally important and as we peer into the future it may not be unhelpful to remind ourselves of the key principles that the Law Commission³ identifies in its first discussion document eight years ago. It seems to me that they have stood the test of time and provide us with a clear set of future guidelines - even if the first is expressed slightly differently today:

- a. Normalisation** - valuing everybody as having a contribution to make to society - attempting to integrate them into mainstream life, maximising potential and promoting the highest degree of independence.
- b. The presumption of competence** Our dealings with everybody should be based on the premise that every individual is capable of looking after his or her own affairs until the contrary is proved. It follows that although people may have to be categorised for certain purposes their general type of disability should not be used as a criterion, otherwise, once the existence of that disability is proved, a finding of incapacity tends to follow almost automatically.
- c. Least restrictive alternative** This means that not only should treatment or care be provided in the least restrictive circumstances but that we should give preference to the means of accomplishing an end that is least restrictive of individual rights.
- d. Safeguards** Safeguards should be provided in the least stigmatic way possible - an argument perhaps in light of *Making Decisions* and the shortly to be published Scoping Committee report on future mental health legislation for a Health Bill and not a mental health bill.
- e. Best Interest** We should arrive at a definition of best interests that gives priority to the previously expressed wishes (where that is possible) of the person who lacks capacity;
- f. Balance** We should aim to provide a mechanism that maximises the chances of coming to a decision that defensibly balances the inevitable overlaps and conflicts between these values when they actually have to be traded off.

It seems to me that today we have a set of legislative proposals in relation to incapacity - a set of possible proposals in relation to future mental health legislation (and here I would especially underline the significance attached to incapacity in the Scoping Committee Draft Outline Proposals) and a Human Rights Act that in relation to the limitation periods is in effective already in force - that provides us with