

Submission to the Joint Committee on Human Rights of the House of Lords and House of Commons on behalf of the Centre for Participation (C4P), Cambridge.

The Centre for Participation (www.C4P.org.uk) was established in Cambridge by four organisations all directly involved in either research or the support of people with learning disabilities. These include Speaking Up (an advocacy organisation), the Cambridgeshire Learning Disability Partnership (the lead commissioner of services); the Faculty of Education and the Learning Disabilities Research Group in the Academic Department of Psychiatry both at the University of Cambridge, and the Eastern Region representative of the Valuing People support team. The Centre was established with the prime aim of promoting and undertaking research together with users of learning disability services to inform policy and practice.

We recognise that the policy of successive UK Governments since the 1971 'Better Services for the Mentally Handicapped' has very positively promoted community living and that more recent White Papers, 'Valuing People' and 'Our Health, Our Care, Our Say' have established basic principles of rights, independence, choice and inclusion that should guide service development. We are strongly supportive of this. We recognise that achieving these goals requires appropriate levels of resources from national and local government to Local Authorities and Primary Care Trusts so that the necessary services and adequate and appropriate health and social care support can be provided. We are aware that there are many areas of actual or potential concern with respect to the human rights of people with learning disabilities (for example, health inequalities, parenting, victimisation as a result of being a person with a learning disability, and access to services for minority ethnic groups). However, in this paper we raise four broad areas of concern that we are aware of as a result of a recent C4P conference, and from the work of those of us who are clinicians in the local learning disability services, and as a result of specific research projects. These are considered in turn.

1. Concerns raised at the C4P conference

The C4P Conference held on 2nd March 2007 had as one of its aims the involvement of people with LD in the setting of the research agenda. Through small workshops people with LD were asked to state what was important to them, the purpose being to identify themes that research by the C4P might subsequently address. The workshops then consider whether what they wished

for was achievable. From the list we have selected the following as in each case concerns were expressed: employment, adult educational opportunities, housing, quality of life and family life, and leisure activities. For this section we have no specific data. However, the concerns expressed at the conference had been raised at other local meetings (e.g., Cambridge Parliament for People with Learning Disabilities) or were recognised from other sources. Broadly they included: the increasing fragility and inconsistency in the provision of further, adult and continuing education, the lack of full or supported employment opportunities, limited support for community living (in part possibly due to increasingly strict eligibility criteria with respect to additional entitlements for social care support), and attitudes and support structures that were seen as restrictive resulting in limited choice and opportunities. These issues and the concerns expressed illustrate how the level and nature of support offered can help to compensate for any individual limitations and thereby can enable the person with a LD to contribute to society in line with what is expected from the Convention on the Rights of Persons with Disabilities (e.g. Articles 4, 19). If opportunities to learn and appropriate empowering environments and opportunities are not available then people with LD will be further disadvantaged and socially excluded. We ask that the Committee considers whether services provided to people with LD are adequately meeting such educational, social care and personal needs such that people with LD can be supported to be full citizens in their community and contribute to society.

2. Research findings on voting by people with LD following the recent general election

With funding from a Health Foundation grant, the C4P undertook a study of voting by adults with LD at the last general election. We compared the names and addresses on the electoral registers for constituencies in Cambridgeshire with the names and addresses of those known to be receiving services from the Cambridgeshire Learning Disabilities Partnership. These findings are reported in full in two papers presently in submission. These are available on request. In essence the key findings were: a) only 66% of people known to LD services were registered to vote compared to 95% for the rest of the population; and b) only 22% of those with a LD registered actually voted compared to 61% of the rest of the population. In looking at what personal or environmental factors predicted the likelihood of registration and of voting, it was the presence of one other person in the household who voted that was crucial. The statutory duty to register adults with LD to vote is being neglected. Furthermore, it is very likely that insufficient attention is being paid to supporting adults with LD to make political choices and to vote. To date attempts to address the political disadvantages experienced by adults with LD have treated their needs as analogous to those of adults with physical and/or sensory impairments or those with low literacy skills. The need to improve the capacity of people with LD to be involved in the political process would appear to have been systematically neglected. This is contrary to the Convention on the Rights of Person with Disabilities (for example Articles 5 and 29). We ask that the Committee enquire as to what provisions are being made to ensure that people with LD are on the electoral register and how they are being

supported to gain the knowledge and understanding necessary for them to form a view, if they are able and wish to do so, and to then vote.

3. Concerns relating to recent or proposed Government legislation

These concerns arise from research undertaken by the Learning Disabilities Research Group before and since the establishment of the C4P that informed the then Mental Incapacity Bill and also proposals for revision of the Mental Health Act 1983. These have been the subject of discussion at subsequent C4P meetings. Our concerns also relate to the issues raised by the case of *Mr L vs Bournemouth NHS Trust* and the Government's subsequent response to the ruling from the European Court. In essence our concerns are broadly as follows: a) whilst the *Mental Capacity Act 2005* is an enlightened piece of legislation, there is the worry that not all is or will be done to optimise the decision-making capacity of people with LD or to involve them as part of 'best interests' decisions if they lack the capacity to make the decision in question. Thus, the *MCA* will be used to as a restricting rather than enabling legislation; b) with respect to civil sections under proposals for amendment of the *Mental Health Act 1983* no recognition is given to the right of people with a mental disorder to make those decisions about treatment for their mental disorder that they have the capacity to do so. Such a right exists for those with capacity to make decisions about their physical health and not to grant that to those with capacity who are asked to make decisions about their mental health is discriminatory. We recognise that different conditions should apply if the person concerned is charged or convicted of an offence. Research undertaken comparing the present *MHA* and a capacity-based *MHA*, which was created by us, has shown that such legislation would enable those with severe mental illness and/or other mental disorders to be detained, where it was clearly required, as this group of people invariably lacked the capacity to make admission or treatment decisions for themselves (papers available on request); and c) whilst Government proposals address the very narrow concerns raised by the European Court of Human Rights in the *Bournemouth* case (i.e., deprivation of liberty) it does little to address the extreme vulnerability of people like Mr L whose mental disability was such that, in the absence of carers who argued on his behalf, he would not have been able to challenge what was being done to him. Families also may be reluctant to challenge authorities for fear of upsetting those that are providing care or concern that they will then be asked to provide the care. For example, whilst we recognise that restraint can be necessary, such restraint can be used excessively, inappropriately, and without a proper understanding of why the person has had to be restrained and what might be done to prevent the need for it in the future. Whilst the *MCA* requires that such restraint is proportionate those people who lack capacity to understand what is happening will not be in a position to challenge the actions of others. The common thread to all these issues are the fact that staff, whilst in no way acting malevolently, rarely take a human rights perspective. With respect to the *MCA* there is a need to recognise the importance of providing the educational opportunities and care strategies that optimises understanding and therefore a person's capacity to be party to decision making (paper illustrating this with respect to financial decision-making available

on request), the need for advocacy (such as Independent Mental Capacity Advocates in the *MCA* – see review undertaken by us of the pilot IMCA sites on the Department of Health web-site), and the education of staff about how to address the tension between individual rights and a duty of care. Our concern is that old practices continue to exist and insufficient attention is paid to the importance of care that is both empowering and protecting and which also respects individual rights but provides for individual needs. We ask that the Committee specifically considers the impact of proposals for mental health reform on the human rights of people with LD (see also the report of the Parliamentary Human Rights Committee on the proposals for mental health reform) and whether further training, monitoring or advocacy arrangements are advisable particularly with the implementation of the *MCA 2005*.

4. People with LD in trouble with the law and/or placed out of county

We have concerns about people with LD placed some distance from their homes as a result of the failure of local services to meet the needs that have arisen as a result of problem behaviours or offending, often in childhood. This was identified as an issue over 10 years ago in the report on ‘Services for people with learning disabilities and challenging behaviour and/or mental health needs’ prepared by a committee chaired by Professor J. Mansell in 1992/1993. Locally, our experience is that children placed out of county by education authorities because of their problem behaviour are not readily returned to county in adult life for reasons that are unclear. Furthermore, a recently completed three centre study (research undertaken in Tayside, Northumberland, and Cambridgeshire and Norfolk) of the care pathways of people with LD who have had contact with the criminal justice system has shown that where they are placed, especially in private secure hospital care, they are invariably a long way from their home. The mean distance away from home for those placed in statutory district in-patient services was 9 miles, for those in statutory medium secure services: 117 miles, those in non-statutory medium secure services: 137 miles, and those in statutory high secure services: 100 miles. This leads to several concerns. First, it restricts the opportunity for continuing family contact particularly as many are from families who are socially and financially disadvantaged. Secondly, there may be little monitoring by the funding authorities given the distance thus the possibility of undetected abuse, exploitation, or neglect. Whilst inspection processes are improved it is of note that the majority of those who were subject to severe abuse as highlighted by the *Longcare* inquiry in Buckinghamshire (in this case in social care provision) were placed from other counties. Thirdly, for those who are detained under a Hospital Order (*MHA*) following a conviction and placed in an out of county secure setting may be placed there under circumstances that impedes their rehabilitation. For example, if clinicians and managers from local services are not involved when the court is advised by a forensic psychiatrist that a person requires secure hospital care, no local care pathway may be available for subsequent discharge. Delays to being discharged due to lack of engagement of local services at the time of admission and also heightened concerns about risk, given the Government agenda on public protection, both can result in prolonged restriction or possibly deprivation of liberty and prolonged dislocation

from family and other contacts. Thus the right of individuals to freedom of movement and to a family life are unnecessarily curtailed. We ask that the Committee seeks information on out of county and secure hospital placements and the impact of such placements on the individuals with LD.

Conclusions

In our submission to the Committee we have highlighted four broad areas of concern. It is likely that the Committee will receive related evidence on such matters and may therefore be able to form a comprehensive view as to all areas of concern. We wish to re-emphasise the crucial importance of the Government agenda that has set the ideals that we should aspire to. However, there are serious concerns about the human rights of people with LD. These concerns have their routes in legislation, historical and present day attitudes, and in established policy and practice. We are willing to provide further material and/or to attend to give evidence if requested.

Submitted on behalf of the Centre for Participation in Cambridge.

Members of the Centre include:

Craig Deardon-Phillips, Amy Forgacs, Wendy Lansdown, and John Woodhouse from Speaking Up. Richard Byers (Faculty of Education) and Isabel Clare, Tony Holland and Marcus Redley, (Learning Disability Research Group) from the University of Cambridge, Simon Whitehead from the Eastern Region Valuing People support team, and Mike Hay from the Cambridgeshire Learning Disability Partnership.

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