

Social Care Law Developments: A Sideways Look at Personalisation and Tightening Eligibility Criteria

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Major changes are afoot for social care. In April 2011 the Law Commission will publish its proposals for codifying all the disparate adult care statutes enacted since the Second World War. In July 2011 we expect publication of the report from the Commission on 'Long Term Funding of Adult Care'. The government's stated intention is to introduce a Bill addressing these two reports in 2011. Even if all goes to plan, we are unlikely to see the impact of such legislative changes for 3 or more years.

In the meantime, a reform (some might call it 'a revolution') in the way social services does its business is taking place. It is generally referred to as 'personalisation' – which (like the previous great idea 'community care') has a soft, non-threatening feel to it. How could 'personalisation' be anything other than amiable? At the local level older people will encounter this new scheme, when they are told that instead of being provided with a 'traditional community care service' they will receive a 'personal budget'. This conversation may fail to mention that, in contrast to the many statutory duties and the fanfare of regulations that underpin community care law, personalisation is based on no law whatsoever.

What is 'Personalisation'?

Like 'community care', it is difficult to say with any precision what the government means by personalisation, apart from at the rhetorical level. In this rarefied atmosphere we have a reasonably clear vision: of care arrangements that take into account what the disabled, elderly or ill person wants; of what they want to achieve (referred to as 'outcomes' by those in the know). Instead of parking the person in a service that might be arranged for the convenience of the service provider (for example, being put into a dull unchallenging Day Centre or

having inedible/inappropriate meals delivered by a meals-on-wheels service) the disabled or older person (or perhaps more commonly his or her family carer) takes control and commissions more interesting, more relevant, more inclusive services. Instead of the Day Centre, a series of mainstream activities could be arranged, such as painting classes, going to the Mecca for Bingo, watching the local football team, and of course paragliding. Instead of the meals on wheels service – a meal in the local pub or at the neighbourhood café – and so on. This is what is known as ‘self directed support’ (‘SDS’ to those in the know).

No sensible person could argue against the idea of giving such choices to disabled or elderly people, and no one who has any knowledge of the grim nature of many of their current service options could dispute the need for radical change: so why the hesitancy? This derives from three factors. First, there is little hard evidence that this new scheme addresses the needs of most older people, as opposed to younger physically disabled people (see for example, C Glendinning, et al, *Evaluation of the Individual Budgets Pilot Programme* (Social Policy Research Unit, University of York, 2008), at para 15.3.4 and M Lymbery, ‘A New Vision for Adult Social Care? Continuities and Change in the Care of Older People’ (2010) 30(1) *Critical Social Policy* 1 5–26). Secondly, for such a vision to succeed there would almost certainly need to be very significant new investment in this sector. Finally, it seems that the government’s real ‘personalisation’ agenda is something else.

It is at this stage, considering the sheer incongruity of the situation that a Leonid Brezhnev anecdote comes to mind. The USSR hard-line president had a new and not dissimilar plan: that within 5 years every Russian would be provided with a personal aeroplane. When asked ‘why’ he replied, ‘so they can fly around the USSR and find the shortest sausage queues’. The case of Elaine McDonald (see below) illustrates this point. She is being told that instead of being given help getting to the toilet, her authority (Kensington and Chelsea one of the richest in Europe) proposes to save money by putting her in incontinence pads. Against this backdrop of cutbacks, to be talking of funding aerobics classes, paragliding and season tickets to Stockport United (all given as examples of SDS) sounds not so much absurd as offensive.

The Mechanics of Personalisation

In England local authority key performance indicator NI 130 (see the Audit Commission website www.audit-commission.gov.uk/localgov/audit/nis/) requires that by April 2011 30% of all community based services should be delivered either as a direct payment or as a personal budget. Give a public body

a target, and it will generally hit it. It may well have to slash the practical, burn the valuable and distort much of reality – but it will hit it. The target requires that there is evidence, in each case, that the disabled or older person (or their ‘representative’) exercised some element of choice in the way their support plan is constructed. It does not require that the person be given any choice about having such a personal budget in the first place.

Distinguishing direct payments and personal budgets?

A direct payment is a sum of money actually paid to someone entitled to community care services (or to a third party on their behalf – this option is now available in England as a consequence of s 146 of the Health and Social Care Act 2008). The amount of the direct payment must be ‘sufficient to enable the recipient lawfully to secure a service of a standard that the council considers is reasonable to fulfil the needs for the service to which the payments relate’ (Department of Health Guidance on direct payments for community care, services for carers and children’s services England 2009, at para 111). Both the previous and current governments are keen on direct payments since they transfer responsibility for arranging care back to families (‘the third way’; ‘big society’, etc). This transference of risk applies not only to the responsibility for the actual care arrangements but also the risk of overspending, since there is the potential (albeit unlawful at present) to cap any increase in the direct payment if the local authority has to make cutbacks. The state’s commitment then becomes not one of ‘meeting a need’ but simply one of providing an ‘entitlement’ (ie a sum of money, which may or may not be sufficient to pay for the person’s care needs). Whilst this may be the ultimate aim of the policy makers – it has not yet become a reality, because the law is still based on the welfare state model – the National Assistance Act 1948 – and with it an obligation to meet need.

Although direct payments have been permitted by statute for over 13 years, only a small proportion (less than 4%) of older people who receive community care services, receive them by way of a direct payment (as compared to 24% of adults with physical disabilities – see *The state of social care in England* (CQC, 2010), at p 28 and *The state of social care in England 2007–08* (CSCI, 2009), at p 17). There are many reasons for this lack of enthusiasm including: the fact that older people are often in crisis when they make contact with social services; that local authorities have the contracting muscle to get lower fees from care providers – self funders almost always have to pay more than those who have local authority assistance, even if using the same agency; that many older people simply don’t want (or are unable to manage) the hassle of arranging their own care, employing care assistants, contracting with care agencies and so on.

The government sees personal budgets as a halfway house to the ideal of having everyone on a direct payment. In order to streamline the process, local authorities are being encouraged to avoid face-to-face community care assessment, and to get disabled and older people to complete a 'self assessment' form. This practice continues despite a decision by the court that such assessments are of very questionable legality – in *R (B) v Cornwall CC* [2009] EWHC 491 (Admin), at para [68] Hickinbottom J observed that a council could not 'avoid its obligation to assess needs etc by failing to make an appropriate assessment themselves, in favour of simply requiring the service user himself to provide evidence of his needs'.

These self-assessment forms have a series of tick boxes, which (when returned to the council) are assigned a score by a computerised process (known as a 'Resource Allocation System' – or RAS) that analyses the answers. So, for example, in response to a question about the amount of personal care a person needs during the day, there may be five possible boxes to tick – ranging from 'none' (which would score zero) to 'constant care' (which might, say, score 12). The next question asks about how much help the person receives from family and friends, with yet more boxes to tick – ranging from 'I get all the help I need' (which would wipe out the previous score) to 'I get no help' (which would leave the previous score intact).

The form produces a total score for the person – which might, for example, be 16 (which it was in the case of Savva – see below). The local authority then has to decide what a point is actually worth. There is guidance on this, but essentially it is determined by the cost of care in that locality, so the value of a point would need to be greater in Kensington and Chelsea than in (say) Sunderland (no offence to colleagues in Sunderland). The point score is then, multiplied by the value assigned to a point. It is at this stage that any science in the process is jettisoned in favour of witchcraft. The resultant sum is then reduced. The reason for this has variously been explained as providing 'headroom ... to avoid overspending' or to avoid inducing 'dependency' (see L Clements, 'Individual Budgets and irrational exuberance' (2008) 11 CCLR 413–430). The resultant figure is known as an 'indicative amount'.

The trouble is that this figure is generally very different from the amount actually being spent purchasing care for the individual. This of course surprises no-one, other than the government, computer geeks and those charged with ironing the Emperor's new clothes. For them this is yet further evidence of the unreliability of reality, and their response is two-fold. First, they tweak (at not inconsiderable expense) their computer programmes, on the basis that one more

tweak and all will be perfect. Secondly, and with the aid of the 'dark arts', they adjust the indicative amount. The recent case of *R (Savva) v Kensington & Chelsea Royal London Borough Council* [2010] EWHC 414 (Admin) (see case reports at page 28 above) illustrates the point. The 70-year-old applicant completed a Self-Assessment Questionnaire (SAQ) and as a consequence the council decided that this equated to a 'points score' of 16 under their RAS. This translated into a monetary value of £82.91 per week. The funding was then adjusted by the council to £132.56, and was then increased to £170.45. A few months later she was admitted to hospital and on discharge, she completed another SAQ and was awarded 28 points which translated into a value of £112.21. The sum was then adjusted to £142.02 per week and then increased to £170.45. This figure was challenged successfully on the basis that although her needs had increased substantially, her allowance remained unchanged: the judge, like the applicant could make neither head nor tail of it. The problem, of course is that many older people in this situation lack the networks and/or resources to make such challenges, and so the rollout of personal budgets continues unabated.

The danger of generating 'indicative amounts' is that they quickly become rebuttable presumptions; figures that can only be varied for good reasons; figures that can only be varied in exceptional circumstances; figures that can only be varied temporarily (ie in transition as the services reduce). This is exactly what Black J found them to be in *R (JL) v Islington* [2009] EWHC 458 (Admin), [2009] 2 FLR 515 despite the council's contra-assertion. She found that the indicative amount in question was stated as being 'the maximum amount' that 'could be allocated'; a figure for which the assessor was 'not able to make special exceptions'; a 'fait accompli'; a figure upon which the assessor had no 'discretion to depart from'; it was 'rigid', a 'threshold and limit'. It was also unlawful.

Where exactly is the Dignity Threshold?

Set against the surreal backdrop of older people paragliding, visiting Mecca and watching football at public expense, *R (McDonald) v Kensington and Chelsea* [2010] EWCA Civ 1109 (see case reports at page 30 above) is a chilling judgment that brings reality in with the most dreadful shock.

The applicant is 67 and a former principal ballerina with the Scottish Ballet. She has suffered a stroke and in consequence has reduced mobility. She was assessed by Kensington and Chelsea as needing assistance at night to use the commode. Once a community care need of this nature has been 'assessed' as 'eligible', then the law obliges the local authority to meet that need. Although the council provided this support, it later decided that it could save money by putting Elaine

McDonald in incontinence pads at night and sorting these out the next day. There are two problems with this approach: one, a narrow legal one and the other, that it is an indictment of any society that lays claim to be civilised.

As to the cold legal question, the service that was proposed would not and could not meet the applicant's assessed need for 'assistance at night to use the commode'. What the council was proposing was to make a continent person incontinent: and incontinence brings with it innumerable and well documented problems – not merely risks of infection and compromised skin viability but also issues of profound depression deriving from a sense of despair and shame. If you should need evidence of this, see for example BAS, Broome, 'The impact of urinary incontinence on self-efficacy and quality of life' (2003) 1 *Health and Quality of Life Outcomes* 35 – who cites (amongst others) P Meade-D'Alisera, T Merriweather, M Wentland, M Fantl, M Ghafar, 'Depressive symptoms in women with urinary incontinence: A prospective study' (2001) 21 *Urologic Nursing* 397–400; AJ Watson, L Currie, S Curran, GJ Jarvis, (2000) 88 'A perspective study examining the association between the symptoms of anxiety and depression and severity of urinary incontinence' *European Journal of Obstetrics and Gynecology and Reproductive Biology* 7–9; and BH Zorn, H Montgomery, K Poeper, M Gray, WD Steers, 'Urinary incontinence and depression' (1999) 162 *Journal of Urology* 82–84.

After a High Court hearing the council decided to reassess the applicant's needs. Since her personal circumstances had not changed, it is not unreasonable to suggest that the reassessment was merely a procedural device to judicial review 'proof' the council's position. The reassessment served this purpose by changing her 'assessed needs' to that of a 'need for support at night'. If ever there was a case that established the futility of judicial review', it is this one. Halliday and others have long argued that when faced with an adverse judicial review judgment, public bodies do not, as a general rule, modify the substance of their corporate culture, choosing instead to change their processes to 'proof' that culture against similar criticism – see for example S Halliday, 'The Influence of Judicial Review on Bureaucratic Decision-Making' (2000) *Public Law* 110–122, at p 117. In this case, to sustain its resource decision, the council shamelessly modified 'process' to avoid an administrative challenge – and the Court of Appeal found the nothing untoward with this state of affairs. Had the court thought that the case engaged fundamental human rights it could have subjected the process to 'anxious scrutiny': see *R (Daly) v Secretary of State for the Home Department* [2001] UKHL 26, at paras [27]–[28]. Had the court wanted to, it could so easily have disposed of this case by reference to the irrationality of the council's reassessment process: had the court wanted to.

So much for the narrow legal issue: the wider question of course is that of the applicant's dignity.

Elaine McDonald was unequivocal as to her horror at having to use the pads, which she considered to be 'an affront to her dignity'. The council, however, took the view that she did not understand her own dignity – since the use of 'such products provided greater privacy and dignity' and more importantly they would enable her to be 'kept safe from falling and injuring herself'.

Baroness Hale in her 2004 Paul Sieghart Memorial Lecture referred to research concerning (amongst others) residents with dementia. This gave an instance of them being fed whilst they were sitting on the toilet, so that staff could get their work done within an allotted timeframe. Baroness Hale wondered 'whether we can recognise a real human rights abuse when we see one' and whether this obvious rights abuse would 'seem obvious to the law?' It is difficult to see any fundamental difference with Elaine McDonald's situation: indeed the residents in the research study may not have been 'horrified' since they were unaware of the indignity being perpetrated and in any event, what was being done in both cases was being done for resource reasons.

The Court of Appeal saw nothing obviously wrong with the council's approach. Elaine McDonald's horror could be justified on the basis of costs and her own safety. The suggestion that considerations of physical safety trump dignity; trump despair; and trump a sense of self shame has been eloquently challenged by Lord Justice Munby. Speaking extra judicially (see page 32 above) he stressed that a person's welfare 'extends beyond safety and physical health': that to understand the European Convention on Human Rights' conception of dignity 'we have to strive to safeguard not just P's safety but also, and most importantly, her happiness'.

Although the Court of Appeal accepted that Article 8 (the right to respect for one's private life) might be engaged by the facts of the case it had little difficulty in dismissing this aspect of the claim. It did so by first expressing its 'sympathy for the misfortunes of Ms McDonald' and then expressing its sympathy for council's 'difficult task' of balancing its responsibilities within its limited resources. It then came down firmly on the side of the council. The Court placed considerable reliance on *Sentges v Netherlands* (2003) Application No 27677/02. *Sentges* was, however determined primarily on the 'margin of appreciation' doctrine – namely that issues of this nature are to be decided by domestic courts and not in Strasbourg (see O De Schutter, (2005) 'Reasonable Accommodations and Positive Obligations', in L Lawson and C Gooding (eds), *European Convention on Human Rights in Disability Rights in Europe: From Theory to Practice* (Hart

Publishing, 2005); and see also L Clements and J Read, (2005) 'The Dog that didn't bark' also in *Disability Rights in Europe: From Theory to Practice*).

Whilst restrictions on the rights of alleged terrorists bring forth from the courts (rightly) ringing affirmations as to the sanctity of human rights (even in times of international peril) there is a perceptible silence when the frail, the vulnerable and the elderly are subjected to the most distressing of indignities – and if there is any squeamishness on the part of the judiciary, it is quickly disposed of by reference, not to international perils, but to the tolling bell of tight resources. The declaration (rightly) in *Napier v Scottish Minister* ([2002] UKHRR 308) that slopping out was degrading treatment contrary to Art 3, was a decision that had very considerable cost implications – but the fact that this activity diminished the applicant prisoner's 'human dignity' and aroused in him 'feelings of anxiety, anguish, inferiority and humiliation' meant that the resource argument was dismissed. Whilst there are clearly differences between *Napier* and *McDonald* one has to ask whether they are really fundamental – or is it that our courts are having difficulty recognising real human rights abuses?

McDonald suggests that this difficulty is real: the difficulty of conceptualising human rights when considering the claims of vulnerable or elderly people. By way of example, in *R (Pretty) v DPP* [2001] UKHL 61, [2002] 1 FLR 268, the House of Lords did not consider that Dianne Pretty's suffering engaged Art 8 at all (but in *Pretty v UK* (2002) 35 EHRR 1 the European Court of Human Rights found that Art 8 was engaged). Similarly, in the Bournemouth litigation (*R v Bournemouth Community and Mental Health NHS Trust ex parte L* [1999] 1 AC 458), the Court did not see any deprivation of liberty (and indeed studiously avoided any human rights analysis), whereas in *HL v UK* (2004) Application No 00045508/99; judgment 5 October 2004, the Strasbourg Court found, unanimously, that Art 5 was violated.

In the leading case of *R v Gloucestershire County Council ex p Barry* ([1997] 2 WLR 459, (1997) 1 CCLR 40) the applicant's barrister, Richard Gordon, argued that the criteria which determined whether a person should receive community care services should be based on the 'values of a civilised society'. The majority of the House of Lords rejected this approach as insufficiently precise. What these cases concerning the care needs of older people suggest, is that (with honourable exceptions – not least Lord Justice Munby and Baroness Hale) we are very unlikely to learn from the courts what the values are, of a civilised society.