

Individual Budgets and Carers

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Abstract

This paper considers progress in implementing the Department of Health's proposals for the development of Individual Budgets (IBs) with particular reference to their relevance for carers. It follows an earlier paper 'Individual Budgets and irrational exuberance'⁴ which provides an overview and general analysis of the initiative including the legislative framework within which the pilot programmes operated.

The "Personalisation" and "Self Directed Support" agenda are moving forward rapidly throughout England and the evidence suggests that personalised services have both the potential to improve support for carers and, if misapplied, to undermine it. This paper reviews the evidence concerning the programme's impact on carers, considers some of the pitfalls that have arisen and suggests how the implementation process can, not only comply with the law concerning carers rights, but also maximize the personalisation agenda's potential to liberate both carer and the disabled person being cared for, alike.

Background

In June 2009, the Department of Health held three well attended national events about "carers and personalisation". In the invitation for these, the Department of Health commented that:

"Ensuring that personalisation works well for carers is vital to effective transformation and achieving the outcomes of Putting People First".

It is understood that the Department of Health is now working with a range of stakeholders to follow this through including disseminating the learning from these events. It may therefore be useful to explore the background to these developments, to be clear about what carers' rights are and consider potential barriers to success.

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⁴ Clements, L. (2008) *Individual Budgets and irrational exuberance* 11 C.C.L.R. 413-430A pre-publication Draft copy of which is accessible at www.lukeclements.co.uk/page1/page1.html

In 2005 the English Government announced its intention to develop a programme of 'individual budgets' for those people who currently access social care support services.⁵ Such arrangements have been proposed by a number of agencies⁶ and essentially pool funds from various sources such as social services, community equipment, Access to Work, independent living funds, disabled facilities grants and the Supporting People programme – but not NHS resources.⁷ In a 2006 White Paper⁸ the Government outlined its programme, stating:

Individuals who are eligible for these funds will then have a single transparent sum allocated to them in their name and held on their behalf, rather like a bank account. They can choose to take this money out either in the form of a direct payment in cash, as provision of services, or as a mixture of both cash and services, up to the value of their total budget. This will offer the individual much more flexibility to choose services which are more tailored to their specific needs.

In 2006 the Department of Health announced⁹ the piloting of Individual Budgets in 13 local authority areas (Manchester, Barnsley, Coventry, Gateshead, Oldham, Kensington and Chelsea, Barking and Dagenham, Essex, Lincolnshire, Norfolk, West Sussex, Bath and North East Somerset, and Leicester). The pilots were to be evaluated in 2008¹⁰ and the final report published in February 2009¹¹ - which in this paper is referred to as the IBSEN 2009 Report. In December 2007 a Department of Health led concordat *Putting People First*¹² was signed by a range of Governmental and non-governmental bodies, committing councils, by April 2011 to the goal of ensuring that 'everyone eligible for publicly funded adult social care support has personal budgets other than in circumstances where people require emergency access to provision'.

The term Personal Budget is also often used to describe Individual budgets made up solely from local authority funding but in some areas the terms have been used interchangeably. In this paper, we have simply used the term individual budget to refer to any such agreed budget allocation for people who use services or their carers.

⁵ Department of Health, *Independence, Well-being and Choice*, 2005.

⁶ See *A Mature Policy on Choice* at http://www.ippr.org/ecomm/files/A_mature_policy.pdf.

⁷ Department of Health, *Our health, our care, our say: a new direction for community services*, Cm 6737, 2006, para 4.39. Separate arrangements for NHS Personal Budgets are however proposed in the Health Bill (2009) Chapter 3 – see Department of Health (2009) *Personal health budgets: first steps*.

⁸ *Ibid*, paras 4.32 et seq.

⁹ LAC (2006)8 *Adults' Personal Social Services (PSS) Allocation 2006-07: Individual Budget Pilot Projects*.

¹⁰ Department of Health, *Our health, our care, our say: a new direction for community services*, Cm 6737, 2006, para 4.33.

¹¹ Glendinning, C. Arksey, H, Jones, K. Moran, N. Netten, A and Rabiee, P (2009) *The Individual Budgets Pilot Projects: Impact and Outcomes for Carers: Working Paper No 2298* Social Policy Research Unit, York and Personal Social Services Research Unit, University of Kent.

¹² HM Government (2007) *Putting People First. A shared vision and commitment to the transformation of Adult Social Care* at www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf

Concern has been expressed by people working with carers that this decision was taken before the impact of the pilot programmes on carers had been adequately assessed. This concern, essentially that carers were not seen as central to the implementation of the new programme, is also born out in the IBSEN 2009 Report which notes that in a number of Individual Budget pilot areas, the officers with lead responsibility for supporting carers had not been involved in developing the pilot. As the Report notes, this was justified in one case on the grounds that ‘the IB team had spent so much time and effort developing and implementing IBs for service users that there was no time to consider carers’ issues and in any case it was expected that IBs would have no impact on carers’ (p.28). As the Report goes on to explain, this view must be mistaken, since the programme has a direct impact on carers.

Carers: the legal and policy context

The struggle by disabled people for political and legal recognition has been mirrored by that waged by carers. The two campaigns are linked¹³ albeit that disabled people have, in the last 20 years, achieved many of their legal goals. Disabled people are now seen as ‘rights holders’ and it is generally accepted that their marginalisation and social exclusion is the product of social and political factors and not the inevitable consequence of their physical or mental impairments. Carers are still some way from achieving a similar recognition, even though they experience similar levels of social exclusion.¹⁴ The support carers receive is still viewed as evidence of the state’s beneficence rather than as compensation for the discrimination they experience from the non-carer majority, and in consequence they are still not seen as ‘rights holders’.

Carers have, however, achieved a great deal in the last 15 years, and it is essential that these gains are not lost – or traded away in any new legal or policy initiative.

One way of charting these achievements is to plot them against the evolutionary scale propounded by Twigg and Atkin in 1994.¹⁵ In their opinion carers could be conceptualised in four distinct ways, namely:

1. where the carer is viewed as a resource valued only in terms of their ability to provide support for the disabled / older person;

¹³ Carers cannot however attain full freedom – to have access to life chances and opportunities on an equal footing to those who do not have caring responsibilities – until disabled people have the unconditional right to high quality support.

¹⁴ Carers represent one of the most socially excluded groups of people – for whom the Government’s inclusion policy appears (to date) to have failed - *Breaking the Cycle: Taking stock of progress and priorities for the future. A report by the Social Exclusion Unit* Sept 2004, Office of the Deputy Prime Minister, London: para 6.17.

¹⁵ Twigg, J and Atkin, K (1994) *Carers Perceived: Policy and Practice in Informal Care*. Open University Press, Buckingham

2. where the carer is viewed as a co-worker whose well-being is addressed solely to ensure that the caring role remains sustainable;
3. where the carer is viewed as a co-client entitled to support in their own right;
4. the superseded carer model – where the care planning process for the disabled person aims to dispense with the need for informal care.

It is arguable that the NHS and Community Care 1990 treated carers as a resource valued only in terms of their ability to provide support (level 1 on the above scale). The Act made no reference to the rights for carers, relying instead on the rhetoric of the guidance to deliver the message that they were valued. It was the lack of recognition that promoted Carers National Association (now known as Carers UK) and Malcolm Wicks MP to engineer the passage of the Bill that became the Carers (Recognition and Services) Act 1995. The Act provides recognition by entitling carers to an assessment of their needs – albeit that this assessment is directed at sustaining their caring role – and so placing this at stage 2 of the scale. Accompanying the Act was important guidance that stressed (amongst other things) that the voluntary basis of the caring role¹⁶ and that carers assessments should in general take place in private – ie in the absence of the looked after person.¹⁷

The 1995 Act, by its single focus on sustaining the caring role, was seen as problematic as was its requirement that the carer's assessment could only arise when the disabled person was 'being' assessed: not least that the disabled person had the power to negate the right by refusing to be assessed. The Carers and Disabled Children Act 2000, again a Private Members Bill supported by Carers UK, addressed these shortcomings by providing for a freestanding right of carers to an assessment of their needs and for services in their own right – and thereby conceptualising the carer as a co-client entitled to support in their own right. This was further strengthened by the Carers (Equal Opportunities) Act 2004 (the third Private Members Bill, engineered by Carers UK and Dr Hywel Francis MP). This provided for carers to have support in accessing (or retaining) employment, education training and leisure opportunities. .

Incremental as the above gains may have been, they have each been contested and have proved to be highly valued by individual carers. The right to a freestanding, separate and private assessment; the recognition that caring is not a legal obligation but only to be done by those 'willing and able'; the recognition that carers have a right to work, to participate in education, training and leisure activities on an equal footing to non-carers and that the promotion of these aims is a public responsibility are - in their way – no less important than the rights

¹⁶ Para 9.8 LAC (96)7 Carers (Recognition and Services) Act 1995 Practice Guidance to the 1995 Act WOC 16/96 and WHC (96)21 in Wales.

¹⁷ See Para 9 - 11 LAC (96)7 Carers (Recognition and Services) Act 1995 Practice Guidance to the 1995 Act and WOC 16/96 and WHC (96)21 in Wales – advice amplified in the Carers and Disabled Children Act 2000: Carers and people with parental responsibility for disabled children: Practice Guidance para 59 (and the Welsh Assembly publication 'Guidance 2000 Act' 3.11)

gained by disabled people during the same period, notwithstanding that carers have yet to achieve the broad based entitlement delivered by the Disability Discrimination Act 1995.

These gains are of core importance and any new development – legal (ie the enactment of the Equality Bill) or policy (ie the personalisation agenda) must secure and then build on these gains and must in no way, be seen as compromising them.

Personalisation: the legal context

A number of commentators have referred to the lack of any statutory reference to Individual Budgets¹⁸ and the point emphasised that, insofar as an Individual Budget contains community care monies (which, almost invariably, it will) then its processing/payment must comply with the community care legislative regime. In relation to adults, community care funding is only available¹⁹ once an individual has had a community care assessment or a carer's assessment (for carers' services under the Carers and Disabled Children Act 2000) and his or her needs have been deemed 'eligible needs' by reference to the assessing authority's eligibility criteria. It would be inequitable and almost certainly unlawful discrimination for individuals receiving Individual Budgets to have any preferential entitlement to local authority community care support resources over those individuals who are entitled to support through some other arrangement. Binding policy guidance²⁰ and Directions²¹ issued by the secretary of state create a strong presumption that carers are involved in the community care assessment of the person for whom they care. Carers have a statutory right to a separate assessment of their ability to sustain their caring relationship and councils a corresponding duty to take account of the conclusions when deciding what community care services it is necessary to provide. This should either result in informing the delivery of services to the disabled person, enhancing the package, outcomes or method of delivery, or by providing services to the carer.

Much of the early (and some recent) material published concerning Individual Budgets overlooks these legal requirements²² – suggesting that a “self assessment” can substitute for an assessment that complies with the legislation and policy guidance. In March 2009 the High Court²³ felt it necessary to reiterate in trenchant terms that the notion of self assessment was entirely at odds with the statutory duties on local authorities: the court asserting that a council ‘cannot

¹⁸ See for example, Clements, L. (2008) see footnote 4 above, Ferguson I (2007) *Increasing User Choice or Privatizing Risk? The Antinomies of Personalization*, British Journal of Social Work; vol 37: 387 – 403 and Lymbery, M (forthcoming) *A New Vision for Adult Social Care? Critical Social Policy*.

¹⁹ Save in emergencies – section 47(5) NHS & Community Care Act 1990.

²⁰ *Community Care in the Next Decade and Beyond: Policy Guidance*, HMSO, 1990, and *Fair Access to Care Services Policy Guidance*, Department of Health, 2002.

²¹ *Community Care Assessment Directions 2004*.

²² See additionally, Clements, L. (2008) see footnote 4 above at page 417.

²³ *Hickinbottom J in R (B) Cornwall CC [2009] EWHC 491 (Admin) 16th March 2009 para 68.*

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’.

The de-linking of the Personalisation programme from the underpinning statutory regime may have benefits for certain service users but it is by no means clear that this is the case for carers. For carers, as we have noted above, the statutory regime imposes a number of important obligations on those undertaking community care assessments: obligations that have been hard fought for, involving no less than three private members bills. The Government have repeatedly stated that self directed support should be delivered within the framework for community care which includes carers legislation. However, there is a raft of publications and articles that have suggested that new flexibilities will somehow trump the existing law. While this is clearly not the case, further advice needs to be given to local authorities by the Government, as otherwise carers rights to an assessment and access to services could be bypassed by these (officially sanctioned) emerging ‘self assessment and the Resource Allocation Systems’.

Evidence of the potential for this problem emerges from the IBSEN 2009 Report (para 3.4.1) which noted that at only a ‘handful of sites’ had the self-assessment forms enabled carers to state what support they provided and whether or not they were willing and able to continue providing that level of support – or indeed whether the carers themselves were in need of support – and that even fewer had sought to establish the carers’ wishes in relation to employment, training/education and leisure activities, as required under the Carers (Equal Opportunities) Act 2004. The evidence suggests that these problems remain and in consequence there is a need for a clear Department of Health statement that personalisation procedures must address these vital (and legally obligatory) questions, not least:

- For carers to be asked directly whether or not they are willing to provide care (or the same level of care) regardless of the whether the current level of caring is onerous;
- For carers to be told that the expectation is that they will have a carers assessment in private – ie that the information they provide may be given in confidence;
- For carers to be asked about their wishes in relation to employment, training, education and leisure opportunities and signposting (at the very least) provided to support them in this respect;
- To identify whether there are children or young people in the household and if so do they have caring responsibilities
- For carers to be asked about what might happen in an emergency or if they are no longer able to care for whatever reason.

Other issues that should be addressed stem from non-binding Guidance and the Care Quality Commission’s Performance Framework include:

- For carers to set the outcomes that they want to achieve in relation to themselves and their family (this is not legally obligatory, I know but I'm trying to find out how to frame this in relation to the Human Rights Act 1998).
- How their health is faring and whether they think that caring will impact on their health.

Although these are not directly legally binding, the evidence shows that caring can impact on health and undermine carers ability to have a "family life". Ignorance of these aspects can lead to a contravention of the carer's human rights. Failure to address these issues will also leave local authorities vulnerable to criticism by the Care Quality Commission.

Carer invisibility in the personalisation initiative

A Social Care Institute for Excellence 2007 review²⁴ of the Individual Budget initiative referred to the risk of carers being sidelined by the pilots noting, that carers had also been 'poorly represented among recipients of direct payments' and that carers also faced 'many of the barriers' that handicapped disabled people.²⁵ In similar vein Arksey and Glendinning have referred to their relative 'invisibility' in the official policy documents concerning the personalisation programme.²⁶

In their 2007-08 report on "The State of Social Care in England" January 2009, the Commission for Social Care Inspection (CSCI) commented that as Self Directed Support was rolled out, particular care needed to be taken to avoid discrimination against older people and carers. The Executive Summary to the report highlighted a need for Councils

addressing equality and human rights issues so the focus is on the barriers that disabled people face rather than their impairment; and on ensuring services do not discriminate against older people and carers

As we have noted above, the lack of an evidence base on the programme's impact on carers did not restrain the Government in December 2007 from proceeding with the full scale implementation of the programme: the IBSEN 2009 Report was not with the Government until the second half of 2008 and not published until February 2009.

Although the 2009 Report suggests that there is evidence that the pilots had had an overall positive impact on carers, it is at pains to highlight its limitations –

²⁴ Social Care Institute for Excellence, *Research Briefing 20: Choice, control and individual budgets: emerging themes*, 2007, accessible at <http://www.scie.org.uk/publications/briefings/files/scare20.pdf>.

²⁵ Citing Fletcher M., in Leece J., Bornat J. (eds), (2006). *Development in direct payments*, Bristol, The Policy Press, Ch. 13

²⁶ Arksey, H. and Glendinning, C (2007) *Choice in the context of informal care-giving* Health and Social Care in the Community (2007) 15 (2), 165–175 at 165.

making repeated reference to the small size of the sample (129 carers) and the lack of statistical significance of many of its findings (a point it mentions on no less than 25 occasions). Whilst clearly a scholarly report from an unquestionably prestigious research team – some of the published interpretations of the raw data, could be expressed equally precisely in alternative terms – for example, it is stated (p62) quite correctly that ‘64 per cent of the carers reported that the IB process changed their view on what could be achieved in their life either a lot or a little’ although the data also reveals that ‘82% of the carers reported that the IB process had not changed their views at all – or only a little.’ The Report, however, is guarded and balanced in its tentative findings – for example, although it states (p71) that ‘there were high levels of satisfaction among carers with the value of the IB and how it was paid’ it also states (p77) that the carers in the non-IB group were also ‘extremely or very satisfied’ and there was no statistically significant differences in satisfaction between the two groups and that (p 62) ‘a substantial proportion of carers expressed some dissatisfaction and these views were noticeably stronger in the IB group’.

A more limited study of carer’s experiences of direct payments included around 360 carers. This found that 68% said that they had made a positive improvement to their lives, but it also highlighted significant risks that were also highlighted by the IBSEN report.

The still limited availability of carers’ specific research material is of concern, given that many of the published accounts make the assumption that carers are a substantial resource to be tapped, in promoting the independent living aspirations of disabled people. The Individual Budgets Evaluation Network (IBSEN) June 2007 report²⁷ acknowledged the potentially negative consequences for carers, noting that ‘the management of [the Individual Budget] support arrangements required even greater input from families and friends, and this was a particular problem when the Individual Budget was less than the value of existing support services’. The report further observed that without external support from independent brokers or professional advocates certain disabled people with complex support needs would have great difficulty managing their Individual Budgets – the group being those ‘who have little family support, or who do not want to rely on their families for help with managing their IB’. Implicit in this statement is the assumption that many family and carers will have to take on the potentially daunting role of managing such schemes. This view is born out by one of the few large scale international studies of an analogous arrangement (in Canada – referred to at pp 7 – 8 of the IBSEN 2009 Report), which found that the managerial role undertaken by such carers in administering Individual Budgets was not only daunting but had the potential to create ‘increased stress’.²⁸

²⁷ The Individual Budgets Evaluation Network (IBSEN) (2007) *Individual Budgets Evaluation: A Summary of Early Findings June 2007* p8 at p4 at www.ibsen.org.uk/metadot/index.pl?id=2191&isa=Category&op=show

²⁸ Rosenthal, C., Martin-Matthews, A. and Keefe, J. (2007) Care management and care provision for older relatives among employed informal care-givers, *Ageing and Society*, 27, 5, 755-78 cited at pp 7 – 8 of the IBSEN 2009 Report

Many of the examples given at presentations that highlight the success of the Individual Budget pilots concern cases where family or friends have taken on not inconsiderable management, financial accounting and other responsibilities: this is also reflected in the case histories used to illustrate some of the publications concerning the programme. The IBSEN 2009 Report (p6) also picks up on this point when referring to the fact that 'well-publicised cases of successful IBs involve carers playing a key role in managing both the IB resources themselves and the on-going support purchased with an IB'.

By way of example, Duffy²⁹ details three case histories, and in each one the disabled person's family took on a significant management role. His first example concerns a disabled person who had 'a reputation as one of the most challenging individuals within the hospital system' and 'whose autism, his partial-sightedness and his severe learning disability plus twenty years of institutionalisation had left him deeply isolated and with highly dangerous and unpredictable defensive behaviours'. Whilst the outcome of the Individual Budget arrangement appeared to be transformative for the disabled person, it involved his family creating at a specific Trust and securing the disabled person a house 'near his sister who then acted as his appointee and could oversee the service offered to her brother'. Consideration of the case examples 'stories' on the Care Services Improvement Partnership Individual Budget site also suggest that carers and family input into Individual Budget arrangements may be substantial.³⁰ Whilst many family and carers will willingly take on such roles and responsibilities, it is of concern that so little attention has been paid to this question³¹ – given that in many of the examples advanced by the proponents of the scheme this is proving to be a crucial – and unpaid – function. The experience of some carers managing direct payments and a number of care assistants providing care is that this is a full-time job that they receive no recompense for. Indeed, the irony is that some of these families exist on Income Support, whilst providing this highly complex management function, are unable to work because of the complexity of care and yet are at poverty levels.

In this regard the practice guidance for each of the three Carers Acts stresses that local authorities must not assume that carers are willing to provide or continue to provide care – and by extension authorities must not make any assumptions that carers are prepared to manage an Individual Budget. The guidance for the Carers Equal Opportunities Act 2004 has re-emphasised this important advice, particularly in relation to carers' employment: that authorities must not assume a willingness to give up work in order to care.

²⁹ Duffy, S *Individual Budgets: Transforming the allocation of resources for care* Journal of Integrated Care February 2005 Volume 13 Issue 1.

³⁰ As of 01/11/07 the site [<http://individualbudgets.csip.org.uk/dynamic/dohpage8.jsp>] gave 9 case examples – presumably illustrative of the potential range persons who could benefit from an Individual Budget arrangement. Of the 9 'stories' 2 appear to require considerable family/carer input and a further 3 (at least) suggest that family/carer input may also be occurring.

³¹ See however footnote 2 above.

The management of Individual Budgets

The perceived benefits of the Individual Budget initiative will require, in individual cases, a considerable degree of financial and other management control, and the Government suggests that this will be provided by a 'broker or advocate, family or friends, as the individual desires'.³² The phrasing here is interesting – suggesting that the choice will be made by the service user – in effect that the 'the family or friends' may not have a choice. This difficulty cannot be rejected as semantic, since the Government envisages that the national implementation of the scheme will be delivered within local authorities 'existing financial envelope'³³ – ie that there will be no extra cash. The Government argue that additional funding is not required because 'people can get support that works better for them, using no more resources, if the person *and those around can be more involved* in designing something that suits them'³⁴ [emphasis added]. Logically this suggests that if the service user is not able (or does not choose) to use his family / carers to develop and manage the arrangement, s/he may be worse off: it would seem to follow that family / carers may be put under considerable pressure by the service user and / or the local authority to take on this role. The assumption that carers will fulfil this role is so widespread that it is, troublingly, presented by Hatton *et al* 2008³⁵ as a problem for those without carers, when they suggest that under the proposed RAS funding arrangements (see below) that recipients who have no family or friends to rely on would in consequence be 'treated less equitably than others'.

It should be noted that the guidance for all three Carers Acts stress that local authorities must not assume the willingness of the carer to care and so, at law, a local authority can not require that a carer take on responsibility for managing an individual budget or place carers in a position where they have little choice but to agree.

Burns (2007)³⁶, writing as a family carer with experience of Individual Budgets, refers to several of her colleague carers who provide intensive ongoing supervision and support of this kind, but comments that in every case these comprise 'at least one relative who is not in employment and who is able and willing to spend a great deal of time in their son or daughter's house talking with staff about their work and dealing with numerous issues which arise – ie providing on-site management and supervision'. She, however, is not in a position to undertake this role and expresses her concern that the available funding makes no distinction 'between people who have the ability to manage agency staff directly and those who require a fully managed service'.

³² Ibid; access to free brokerage, professional advocates and/or mentoring was seen as crucial, especially if users did not want to rely on families for support in managing their individual budget. *Individual Budgets Evaluation. A Summary of early findings*, Ibsen, June 2007.

³³ Care Services Improvement Partnership Individual Budget web site at <http://individualbudgets.csip.org.uk/dynamic/dohpage6.jsp>

³⁴ Ibid.

³⁵ Hatton et al, footnote 6 above, p70.

³⁶ Burns, L (2007) *In Control? : making sure we're not out of control! Some issues for people considering a direct payment or an individualised budget* (unpublished)

Such a fear – arising out of a fear of a funding shortfall – is by no means irrational, as a Social Care Institute for Excellence research paper³⁷ has observed that '[v]irtually every analogous scheme in the EU has been based on an underestimate of costs, at least partly due to unpredicted demand and previously undetected unmet need'.

Resource Allocation Systems

A factor in the pilot Individual Budget programmes that has attracted considerable attention, concerns the process for determining the funds that should be made available to individuals who seek to have their community care support arrangements in the form of an Individual Budget. This paper considers the proposed new funding process as it may impact on carers: for an analysis of the general nature of the proposed new funding process, however, see the companion paper.³⁸

The process by which the financial value of an Individual Budget is quantified has come to be termed the 'Resource Allocation System' (RAS). Despite frequent references to RASs, with the exception of a 2005 paper by Simon Duffy³⁹, very little in concrete terms has been published concerning the detail of the criteria *vis-à-vis* carers.

The 2005 paper describes a funding approach that has been (broadly) applied by 7 of the 13 local authority pilots. The RAS described has three key determinants, namely:

- Level of need: expressed as low, medium or high
- Family situation: expressed as whether living in the family home or not
- Complexity: expressed as either yes or no

The RAS deals with these three criteria by constructing two tables, one for disabled people living within their 'family home' and the other where they are not. The funding for a disabled person living within the family home is typically half or less than half that of a disabled person living 'outside' their family home. For example, a person living in the 'family home' with 'high level need' which includes a need for 'support for 24 hours a day' would receive £15,000 under the RAS – whereas a person living 'outside family home' with lesser needs (ie only a 'medium level need' which did not require such 24 hour support⁴⁰) would be entitled to £30,000 under the system.

³⁷ Social Care Institute for Excellence, *Research Briefing 20: Choice, control and individual budgets: emerging themes*, 2007, accessible at <http://www.scie.org.uk/publications/briefings/files/scare20.pdf>.

³⁸ (2008) 11 C.C.L.R. 413-430.

³⁹ Duffy, S *Individual Budgets: Transforming the allocation of resources for care* Journal of Integrated Care February 2005 Volume 13 Issue 1.

⁴⁰ Who could dress and carry out his or her personal care needs but required guidance and direction and help with cooking.

Welcome as Duffy's paper is, as an early example of RAS configurations, it is troubling that there is no theoretical analysis or explanation as to why people living with their families / carers should only be entitled to half (or less than half) of the financial support that they would receive if not living in such an environment. Even if there is no underpinning assumption that it is the role / burden of families to subsidise disabled relatives (a form of Poor Law Liable Family Rule) the approach is highly suspect – in that it risks entrenching into a funding formula existing financial hardships born by carers / families with disabled members.

It might be argued that in modern Resource Allocation Systems are significantly more sophisticated. However, even if this is the case, there is still little or no evidence that they have incorporated 'carer' specific (or at the minimum, carer neutral) mechanisms and the recent judgment of *R (JL) v. Islington LBC (2009)*⁴¹ would suggest that some local authority systems remain, from a carer perspective, highly problematic

The case concerned a new system developed by Islington for the allocation of support services. It claimed that the new system allotted support according to 'need rather than diagnosis' and did so in a way that was 'transparent' and 'equitable' – all descriptors regularly used to justify RASs. In relation to respite care, the authority's system comprised three bands with the top band providing for 12 hours a week. Although at the hearing the authority claimed that there was discretion in the application of these bands, the judge concluded that this in practice was not the case.

The new system had the effect of reducing the applicant's son's care package by 50% - a decrease in respite care from 1248 to 624 hours a year. The court considered that for community care law purposes, such a drastic reduction in provision required explicit justification (eg a 'really marked improvement in the child's condition or in family circumstances') and considered that this was lacking (para 36 and para 42). In her judgment (para 39) Black J states:

I find it hard to see how a system such as this one, where points are attributed to a standard list of factors, leading to banded relief with a fixed upper limit, can be sufficiently sophisticated to amount to a genuine assessment of an individual child's needs. There will be times when, fortuitously, the needs assessed by such a system will coincide with the real needs of the family but it is difficult to have any confidence in that occurring sufficiently frequently to justify the use of eligibility criteria on their own.

Not only did Black J appear to cast doubt on the *raison d'être* of RAS allocations for community care law purposes, she also held that, since such a system must, inevitably, have a disparate impact on different categories of disabled people⁴², it followed that before implementation the local authority should have subjected it

⁴¹ [2009] EWHC 458 (Admin)

⁴² Research suggests that under such systems people with higher and more complex needs tend to be overall losers – see Henwood, M. & Hudson, B (2007) *Here to Stay? Self-directed support: Aspiration and Implementation A review for the Department of Health*. Towcester: Melanie Henwood Associates, para 3.37.

to a full disability impact assessment in accordance with s49A DDA 1995. In the judge's opinion Islington had not so complied and for this reason too, the system was unlawful.

Given the practical and legal problems associated with such allocation systems local authorities should (in relation to their obligations towards carers) ensure that these:

- Prior to their introduction, have been subjected to, not only a full disability impact assessment in accordance with s49A DDA 1995, but also a similar process in relation to the associative discrimination experienced by carers – as highlighted by the European Court of Justice in *Coleman v Attridge Law* (2008)⁴³ and to be formalised in the Equality Bill (currently clause 13). As the IBSEN 2009 Report make clear (pp 28 – 29), RASs have a clear impact on carers and this appears to have been overlooked by a number of people charged with implementing the personalisation agenda.
- explicitly recognise the right of carers' to choose whether or not to care;
- (where carers do chose to continue in their caring roles) make provision ('allocations') for breaks, support for working carers, leisure and education and training needs⁴⁴;
- (in the case of disabled parents) ensure that unreasonable responsibilities are not placed on young carers.
- Are sufficiently flexible to meet eligible needs for both people who use services and carers.
- Protect and enhance both civil and human rights rather than undermine them and create unwanted dependencies between carer and disabled person.

Implementation

The 2007 *Putting People First* Concordat provides the framework for the development of the personalisation programme. In doing so, it stresses that the resultant systems must be 'on the side of the people needing services and their carers'; must be developed 'through the participation of users and carers at every stage' and be 'fair, accessible and responsive to the individual needs of those who use services and their carers'. Carers must, therefore be central to the new agenda -

In similar vein in 2008 the Care Services and Carers Minister Phil Hope has spoken of the need for a 'renewed emphasis on the role of carers and that care services can only be delivered effectively when family, friends, neighbours and Communities feel that they are able to enhance the quality of care without feeling that unreasonable burdens are being placed on them' [Government

⁴³ *Coleman v Attridge* ECJ C-303/06 Judgment 17 July 2008 accessible at <http://curia.europa.eu/jurisp/cgi-bin/form.pl?lang=EN&Submit=rechercher&numaff=C-303/06>

⁴⁴ As required by the Carers (Equal Opportunities) Act 2004.

Response to Cutting the Cake Fairly, Phil Hope Care Services Minister 22 October 2008]. Other recent expressions of concern about the need to re-emphasise the rights of carers have been made by the Commission for Social Care Inspection⁴⁵ (now the Care Quality Commission), whose inspections revealed that 'inappropriate assumptions are made about the willingness of carers to provide support leading to too low an assessment of their level of need and risk' and that 'too few Carers receive an assessment, and follow-up analysis on the family's support needs as a whole is not taking place. The CSCI report "Cutting the Cake Fairly" also said that it is essential that local authority eligibility policies towards carers should ensure adherence to legislation and guidance on supporting carers and assessing their needs, and in particular that this review re-emphasise the continued need for

- Carers' needs assessments;
- The rights for carers to be consulted during the user's assessment;
- Carers to be provided with an appropriate range of information;
- That the risks to carers of sustaining their caring role by addressed when making eligibility decisions.

These key issues have also been taken up by the Social Care Institute for Excellence and Carers UK, which in their 2009 briefing⁴⁶ stressed that 'personalisation for carers means:

- tailoring support to people's individual needs and being part of the discussion about support for yourself and support for the person you are looking after
- not having to take on all the responsibility and all the managing of care and support – the local authority should ensure that you are sufficiently supported
- recognising and supporting carers in their role, while enabling them to maintain a life beyond their caring responsibilities – you should have your own needs assessed and have choices about your own support
- ensuring that people have access to information and advice to make good decisions about their care and support
- ensuring all citizens have access to universal community services and resources such as health, transport and leisure
- making services more flexible so you can agree outcomes and find solutions that are right for your situation
- if needs change over time, personalisation should enable you and the person you are looking after to change the way you are supported. "

There appears to be considerable variability of approach by Councils in addressing carers needs. Analysis by Carers UK has highlighted examples of

⁴⁵ CSCI (2008) *Cutting the Cake Fairly* CSCI, London – pp 38 and 67.

⁴⁶ SCIE (2009) *Personalisation briefing: Implications for carers* at www.scie.org.uk/publications/atagance/atagance10.asp

Local Authority Self Assessment and Supported Self Assessment Forms with significant apparent defects:

- One form describes what the social worker / disabled person consider to be the amount of “informal care” that is provided - but does not have a column for the carer to give his or her view of this
- although carers have a right to a separate 'private' assessment, this is in some cases negated by the fact that his or her views have to be set out on the same form as for the service user;
- One form left no scope for saying that the carer simply does not choose to care
- Several councils' forms fail to identify whether there are children or young people under the age of 18 (which is required by FACS and guidance for the Carers Acts). It will be difficult to identify young carers if this question is not asked.
- Some councils appear to be asking carers to self assess the level of carers needs in isolation from a carers assessment.
- Many Councils are developing a Carers RAS but in some cases this appears to be in lieu of the carers assessment influencing the main RAS (which is a requirement arising from the Carers Recognition and Services Act 1995)

Each of these failings is at best poor practice and could potentially leave a local authority open to a charge of maladministration or risk of legal proceedings. However, there are also examples of where councils are endeavouring to embed carers rights within new processes and this has included:

- Eligibility decisions (to access SDS) address risk to carers as well as people who use services
- Carers Assessments being embedded so that carers needs taken into account as part of the main assessment and not seen as an optional addition.
- No automatic reduction being made to the resource allocation for the service user as a result of the carer being present.
- Carers are specifically asked if they are able and willing to continue to provide the level of care they currently deliver.
- The resource allocation is broken down and, among other things indicates how much should be deployed to reduce the carers input if this was indicated as a need in the assessment.
- Carers needs that are over and above those to directly support their caring role can be met through resources outside the service users RAS and a carers RAS designed to assist here.
- The needs of young carers identified as part of the core process

Carers will expect that there is a more consistent approach that avoids a “post code lottery” and respects their rights at law. These are issues that may well be

considered by the Care Quality Commission through its regulatory role with local authorities.

Where a Carers RAS is developed with simple banded responses (ie low up to £200, medium £400 and high £600) this may work well for provision of preventative services . However such an approach risks censor if used as a sole mechanism to address assessed needs for the carer, because it might constitute a fettering of the authority's discretion to exceed these figures.

Some councils have developed larger Carers RAS that allow for allocations over £2000 and for such payments to be made in addition to a service user's RAS and/or for a response to a stand alone carers assessment.

Involving Carers in the Process

Whatever the approach taken by a local authority, what seems essential is for local authorities involve carers in the development and evaluation of new systems for allocating individual budgets for people who use services and their carers. Such evaluations should explore whether the legal requirements described above are being effectively delivered and experienced as positive outcomes by carers. It is likely that the Care Quality Commission will expect councils to give evidence of this in the annual Self Assessment Survey which they provide to the regulator. CQC will particularly focus on outcomes and the evaluation criteria used by the inspectorate "Outcomes and Performance Characteristics" have a strong focus on carers throughout.

Councils are required to have developed arrangements for a more personalised approach to assessment and service provision by 31 March 2011. As part of this process, there needs to be an Equality Impact Assessment. Once the Equality Bill is enacted and comes into force this will include consideration of the impact on carers as well as those of different groups of disabled people. This process will require the involvement of carers. As it is likely that this provision is likely to come into force before March 2011, it would seem wise for Councils to anticipate this and include carers in the EIA.

Conclusions

Local authorities should be mindful that they are obliged, not merely to provide all disabled people who are subject to the scheme with a community care assessment (and their qualifying carers with carers assessments) but they are also required to ensure a package of support is made available to meet the assessed need. Carers UK has long argued that a lack of proper accounting for unmet need has driven a continual under-funding of the sector. Analysis of the impact of the lack of care on carers' lives, for example, finds significant direct and opportunity costs in terms of loss of employment, reduced pension entitlements, loss of health, social contact, etc. Where an independent third party such as a Carers Centre or broker undertakes part of a carers assessment, the Council

itself must complete this and make a service provision decision based on its own investigation as well as that of the third party.

RASs (like the Individual Budget initiative itself) are at best merely creatures of 'policy' and have no foundation in law. Where authorities are operating Individual Budgets as an additional option for people entitled to community care support services, the law requires that users and carers must be have genuine choice in deciding whether or not to opt for an Individual Budget. Where the option of an Individual Budget is chosen, the law requires that carers have the same right to decide whether to care and if they chose so to do, the right to decide the extent of their caring role. Where a RAS is used by an authority, it must ensure that the system is sensitive to the needs of carers and is sufficiently flexible to respond to the need for:

- different levels of support - ie. cases with special needs are more expensive;
- short (and indeed 'longer') breaks;
- carers to undertake or to continue with education, training, leisure and employment activities / responsibilities;
- carers services under the Carers and Disabled Children Act 2000;
- support for disabled parents so that children and young people are not left with unreasonable levels of caring responsibilities
- support in relation to unexpected or exceptional circumstances
- the promotion of carers' health and well-being and
- the safeguarding of the principles of the Human Rights Act 1998

There also needs to be an Equality Impact Assessment which includes consideration of the impact on carers as well as those of different groups of disabled people. Carers organisations have suggested that an equalities impact assessment of local authorities processes in relation to the treatment of carers for the purposes of Individual Budgets would leave many wanting.

Local Authorities should involve carers in the development and evaluation of new systems for allocating individual budgets and explore whether the legal requirements described above are being effectively delivered and experienced by carers as positive outcomes. Evidence of this should be included in each Council's annual submission to the Care Quality Commission which is known as the Self Assessment Survey