



Who cares: who pays?

This briefing summarises the main findings of an independent report – Who cares: who pays? Personalisation in social care – by Professor Hilary Land of Bristol University and Professor Sue Himmelweit of the Open University.

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*The full report can be downloaded from:
unison.org.uk/localgov/personalisation.asp*

Section A:

Policy recommendations

The report highlights a number of important issues that have to be resolved in rolling out cash for care schemes under the personalisation agenda. The authors' wide-ranging recommendations are aimed at governments (central and local), policy makers and trade unions.

The issue of choice

1. The introduction of personal budgets needs to be handled sensitively so that those who prefer to be provided with an established package of well-run services can continue to have that option.
2. Some services must continue to be provided and improved even as they become more expensive as a result of loss of economies of scale and lower levels of usage. Such collective provision brings benefits including social contact that it can be difficult to produce through spending individual budgets on their own.
3. Direct payments cannot meet systemic needs such as the need for public amenities to be made accessible. Separate funding must still be provided for this.

Assessment and the level of payments

4. There should be a national framework which determines which needs are to be covered in order to avoid the postcode lottery. The process should not include a means-test and be either social insurance-based or funded through general taxation.
5. Staff need to have adequate support, training and pay levels and the skills and experience to facilitate assessment of needs and help people find the services that suit them best. This should be borne in mind before assuming that brokerage needs to be provided separately from assessment.
6. Assessments should be carer blind ie

not take account of whether there is an existing family carer – the interests of family carers may not always coincide with those of the person needing care and could open the door to future restriction of publicly funded care to those who do not have any family support.

7. Better support is needed for carers to combine caring with employment, including better leave in line with that for parents, and an end to the UK 48-hour working time opt-out. No-one should have to become a paid personal assistant (PA) to the person they care for because they are not able to access alternative employment.
8. Funding levels need to be adequate to cover all the costs of employment including replacement care during sickness absence or leave, training costs and tax and NI, as well as pay rates necessary for appropriate qualifications and experience.
9. Levels of support should be continually reviewed since needs change. Older people in particular tend to have increasing need. All personal budget holders should have the right to a review of the level of their budget and interim support provided in the meantime.

The relationship between direct payment holders and their personal assistants

10. Some of the benefits claimed for being a direct payment employer sound like those of a 19th century factory owner, able to hire and fire at will, secure complete working time flexibility and avoid health and safety risk assessments which other employers have to adopt. Direct payment holders need guidance about the responsibilities and reasonable demands of employers. A range of

standard contracts could be produced which local authorities endorse as the basis of the employment packages they are willing to fund.

11. While not wishing to lose the benefits of informal working arrangements, it is not acceptable to create a large class of employment effectively exempt from good employment practices. It is reasonable to require some regulation of the way in which taxpayers' money is spent which gives both sides some protection when things go wrong. This has been accepted in respect of childcare where tax credits can only be used on registered forms of provision.
12. Alternative models need to be developed, including where the local authority remains the employer, as is the case in other countries with longer experience of personalisation. This might also make direct payments more attractive to those who do not wish to take on employer responsibilities.
13. An induction course for PAs could be provided by local authorities outlining their legal rights and responsibilities, health and safety issues, training and development options, and ways of negotiating work practices with their employer.

Isolation and learning from mutual experience

14. Local authorities should encourage and support financially, local associations involving both PAs and their employers, building on their shared interest in providing good quality care and working conditions. These could allow sharing of costs in respect of training and absence cover and overcome isolation and lack of experience for direct payment holders and their PAs.
15. PAs should be enabled to mentor and support each other. User groups being set up with government

assistance should provide for inclusion of representatives of PAs. UNISON's partnership working with the Scottish Personal Assistants Employers Network provides a model.

Sustaining the care workforce

16. There should be more effective regulation of homecare agencies and general employment agencies to prevent exploitation of vulnerable workers.
17. Efforts need to be made to widen the pool entering social care including attracting more men, and career changers.

Training and career structure

18. Career structures need to be developed which will offer a reason to stay in social care for those workers coming in through apprenticeships. Care is too important to be treated as a job of last resort.
19. This must include PAs – good employers look after the development as well as training needs of their staff. This should be funded by the government as part of a national concern with creating a sustainable workforce.
20. Pay systems must reward greater training and responsibility.
21. There should be structures which allow older and more experienced care workers to help develop the skills and confidence of the next generation of workers, as happens in Finland.
22. The skills involved in care work must be fully recognised and valued. With the boundaries between their respective tasks blurring, health and social care workers should have opportunities to work and train more closely together.

Trade unions

23. Unions need to find ways of organising migrant workers, PAs, apprentices

and others who may be at risk of marginalisation by:

- setting up programmes to recruit and organise PAs and address their concerns
- seeking involvement in the new traineeships and apprenticeships aimed at the long term unemployed making clear the benefits of union membership
- setting up a comprehensive advice and support service for PAs
- finding ways of supporting PAs through collective bargaining on contracts, terms and conditions
- setting up new institutions which bring together direct payment holders and PAs, learning from the SEIU experience in LA
- providing access to training facilities for PAs
- challenging restrictions on migrant workers' mobility in the UK
- supporting effective regulation of agencies which recruit care workers from overseas, including extending the

remit of the Gangmasters Licensing Authority

Funding

24. Higher taxes will be needed to pay for a social care system that reaches all. It is worrying that personalisation can be used as a way to push that inconvenient truth on to care recipients themselves, since it will be easier to fail to increase personal budgets in line with wages and prices than to cut services.
25. To ensure that payments keep up with costs, an independent auditing body should be set up to monitor payment levels and to publicise the implications of political decisions on whether to uprate them, and by how much.
26. To succeed in providing good quality social care to all who need it, care provision will have to change from being the poor relation of the NHS and care will have to be more highly valued.

Section B: Summary of findings

Introduction

1. The pressures on the social care system are set to increase in coming years as the demographic time-bomb combines with growing public dissatisfaction with social care provision in terms of its cost, quality, accessibility, and co-ordination with other services.
2. Government drives to contain the costs of social care are likely to accelerate as a result of the recession – with more responsibility likely to fall on individuals and their families.
3. Care work continues to be undervalued reflecting perceptions of it as something women used to do unpaid and the fact that formal care and informal care continue to co-exist.
4. Good care is all about the quality of the relationship. There is an irreducible time component to good care which means traditional models of increasing productivity by speeding up activities do not apply. Nor does investment in training translate into a reduction in the number of staff needed.
5. The issue of public spending on social care is a key political issue which needs to be properly debated. To say good care is no longer affordable is absurd.

Learning from history

6. Domiciliary care services were developed because women were conscripted during World War II. These services were targeted on those who were unmarried and childless with the state stepping in when people had no family or the family failed to care for them.
7. In the 1970s social services became statutory for the first time. Residential care became more expensive as the traditional workforce – unmarried women who lived in – came up to retirement.
8. Personal care was not in the job description of home help workers. This was the preserve of district nurses. By 1980 district nurses were visiting over a million households, three times as many as were visited by home helps. Subsequently, homecarers began to do on a means-tested basis what district nurses used to do for free, and domestic work dropped off their agenda.
9. A market in residential care market developed because there was an incentive for local authorities to place people in residential care as the Department of Health and Social Security paid ‘board’ costs. Residential care became an affordable choice for many people for the first time. Between 1980 and 1989 the number of residential care places rose from 39,000 to 93,000 and the cost to the DHSS rose from £10m to £1bn. A quarter to two-thirds of older patients were discharged from hospital straight to residential care.
10. During the same period, the home help service became ‘homecare’. Services were expanded but fewer people were eligible to use them. As a result the service was less influential. Today’s focus on maximising independence is not new – this was a key component of the old nationally agreed job description in the local government manual workers agreement. However, it proved difficult to achieve due to lack of resources and organisational barriers, and little room for participative planning.
11. The Exceptional Circumstances Allowance, introduced in the mid 1960s for supplementary benefit claimants, was a kind of forerunner to direct payments, although paid out of social security. It was not much publicised, at its peak only around 16,000 people claimed, and from 1980 it was limited to private arrangements. The existence of this subsidy was not enough to stimulate a market in the way that had happened in residential care – and there is a lesson here for cash for care schemes.
12. The ‘care in the community’ reforms from the mid 90s onwards arose out of pressure to cut hospital and residential care home stays. Residential care was transferred from the social security budget to become entirely a local authority responsibility. A needs test was introduced to create further rationing. People were directed to cheaper domiciliary care in the first instance.
13. The rule that 80% of care budgets had to be spent in the private and voluntary sector was based on the market ideology that purchasers would naturally choose the best quality for the money. The theory was therefore that the most efficient providers would expand and the least efficient would have to improve or die.
14. This approach was taken to the next stage in the direct payments model which came on the scene in the mid 1990s because here the local authority as purchaser/care manager was replaced with the individual.
15. A market for homecare began to develop consisting of small hand to mouth agencies and we continue to have an unstable provider market and an unstable labour market.

16. The history of transferring resources from social security budgets to social care budgets may be repeated if some disability benefits are moved across into personal budgets and local authorities get the responsibility for distributing them, as has been mooted during the 2009/10 debate on future funding of care and support in England.

Economic theory and market (il)logic

17. The logic of privatisation is that competing providers give the purchaser choice and improve quality and value for money. Purchasing directly by the service users take this logic one step further. **However the market conditions which would be needed to support this logic don't hold true for care:**

- the quality of care is hard to assess and monitor – because the quality of relationships can not be measured through tasks;
- there is a considerable cost to acquiring information about quality – providers lower costs in ways that don't show up in monitoring;
- even where you have information that another supplier offers better quality there is a considerable cost to acting on the information because of the importance of continuity of care and because new carers still need time to learn how to care for and support someone
- choice is constrained by funding policy

Labour market conditions and quality

18. The usual measure of high productivity ie a high client to staff ratio is actually a measure of low quality in sectors such as care and education.

19. Unit wage costs rise faster in care than in other areas because staffing can't

be so easily reduced.

20. There is little financial gain for staff acquiring additional training, no career structure and employers are in any case reluctant to train because of high staff turnover.

21. There is evidence to show that motivation and the public service ethos are diluted following privatisation. For example, research from the Netherlands has shown decreased staff motivation after privatisation. It concluded that the pursuit of cost savings destroys job satisfaction leading to increased staff turnover which actually undermines those cost savings.

Government responses

22. Personalisation policies have partly been about recognising the limitations of market theory.

23. Personalisation in the form of cash for care seeks to overcome the problem that the purchaser and end user may have divergent views and interests. Direct payments came into being as a result of disabled people's campaigns for independent living and the right to self determination.

24. But cash for care is still based on the flawed assumption that the market needs to be extended and that the actions of individual purchasers will "stimulate the market to provide what people want".

25. The Individual Budget pilots found that older people were less likely to get other sources of funding packaged in with their social care entitlement and that managing multiple streams was complex. Personal budgets are now being rolled out consisting solely of social care money.

Can cash for care schemes restrain public expenditure?

26. UK governments have been attracted by anecdotal evidence that with

cash for care arrangements, people spend more frugally and imaginatively. The Audit Commission found that where savings were generated, this was through paying lower rates to individuals than the hourly cost of services, on the grounds that they buy from a different market ie friends and families. There was also a big variation in spending on support services, although there was no consideration of the training and support needs of personal assistants (PAs).

27. This differential between the rates paid out in direct payments and for care services often translates into lower rates of pay for PAs than for homecare staff. One study found that taking account of unpaid overtime a PA was being paid less than £3 an hour.
28. The extent to which direct payments are 'cost-effective' depends on what basis the comparisons with publicly provided services are made. If the basis is too narrow, the extent to which direct payments contain the costs of social care will be exaggerated; and the transaction costs, which fall on the direct payment holder themselves and their carers, will be minimised or ignored.

Problems with cost containment

29. Savings on wage costs may result in poorer quality care. Once the existing pool of labour is absorbed, the same pressures on cost will re-emerge.
30. Direct payments may add to costs because:
 - a) transaction costs from a myriad of small contracts will be higher than for big block contracts. Providers may raise charges or drop out of the market due to loss of economies of scale.
 - b) there are greater costs associated with providing training and back-up cover for emergencies because this is not done on a collective basis.

c) some forms of provision such as daycare will be lost due to lack of viability. For example daycare centre closures in Northumberland were blamed on under-use as a result of personal budgets.

31. It is politically easier for governments to get away with holding cash payments down than to the costs of services. Stopping cash payments from rising in line with costs can be done on the quiet when those in receipt of them are isolated care recipients, many of whom employ previously informal carers. In Germany in 2001 three quarters of domiciliary care users took the option of a cash payment which was worth half the value of services in kind – many to pay an informal carer. There is now evidence that more are opting back into services, not least because the cash amount has not increased since it was introduced.

Cost containment through informal carers

32. The extension of direct payments to allow the employment of relatives was done because it was recognised that the pressure on budgets would become intolerable if the government did not find ways to sustain informal care.
33. The important role of informal carers has long been recognised even in countries which have a much bigger formal care sector. In the 1970s in Norway family carers were employed alongside municipal home helps and had the same employment rights. Family carers can still be employed by municipalities in Norway.
34. However relying on informal carers won't be sustainable without adequate support for them and their needs. The adverse impact on carers' health of insufficient support is well-documented.
35. And it must be recognised that

the availability of informal carers in the future will be reduced with the rise in economic activity rates for older women, coupled with raising the retirement age and greater involvement in caring for grandchildren.

Personalisation on the ground: Direct payment holders and their personal assistants

36. Many PAs operate at the boundary between the formal and informal care sectors, and at contrasting ends of the working time spectrum. Some are friends and relatives. Some work short hours as a PA alongside a job in the formal social care sector. Others (often migrant workers) are employed on a 'live-in' basis and may find themselves on call 24 hours a day.
37. Some employers seek to limit their employer responsibilities by employing one or more people for fewer than eight hours – sometimes several PAs. This impacts on their benefits and pension entitlement. Bogus 'self-employed' status is another risk area entered into by both parties without a clear knowledge of the tests that the HMRC and employment tribunals will apply.
38. Evidence from the Commission on Vulnerable Employment, UNISON branches, Citizens Advice Bureaux, the Low Pay Commission and various research studies show that PAs may be vulnerable due to:
 - Unclear employment status as a result of short hours, live-in hours or dubious self-employment. All have a knock-on effect on entitlement to benefits and employment rights
 - Lack of written contract or job description
 - Job insecurity eg uncertain work when an employer is hospitalised or in respite care
 - Level of payment insufficient to meet the needs of the service user
 - Lack of clarity about whether the

direct payment includes tax, NICs, cover for holidays, sickness and maternity/paternity/adoption

- Lack of clarity on working time and minimum wage rights in the case of overnight or live-in support
- Mutual employer and employee lack of knowledge and awareness of employment rights and responsibilities
- Lack of access to advice and support if the relationship gets difficult
- Lack of training opportunities including on health and safety
- Agency workers being vulnerable to exploitation

Working relationships

39. Lack of a contract or job description and blurring between formal and informal care can be an issue in terms of the potential for conflict when working alongside other carers or family members who have different views from the service user about what tasks need to be done. This highlights the need for access to professional support, advice and guidance in handling tricky situations.
40. Most studies of working relationships with PAs have featured early adopters of the personalisation system, so they over-represent those who were dissatisfied with their care arrangements and had well-formed ideas about what they wanted to do with a budget. These studies find high satisfaction levels with users reporting more time and more continuity of care. Many reported that being able to start paying an informal carer reduced their sense of dependency.
41. These studies reveal that boundaries are an issue particularly where service users view the PA as a friend. It often means the worker doing more than they got paid for.
42. The job can be very satisfying but also emotionally draining especially as you do not have colleagues or a manager to talk to for support.

Problems for direct payment holders employing PAs

43. A Skills for Care study found concerns among two in five employers about recruitment and retention; establishing the relationship; dealing with paperwork; handling disputes and relationship breakdown; cover in emergencies, and pay and benefit levels.
44. On the other hand, the option of using a direct payment to pay an agency means paying them a 10-15% administration fee which reduces the amount left to pay the worker.

The boundaries of employer responsibility: policy and practice across the UK

45. The introduction of direct payments and other forms of cash for care has been more cautious in other parts of the UK than in England.
46. Practice with respect to which costs are covered by a direct payment

varies across the UK, as well as within England. As does how comprehensive the support services which go round the direct payment.

47. In Northern Ireland a payroll service is provided to all direct payment holders and this includes the drawing up of a contract. Trusts also pay for and arrange employer's indemnity insurance. Every new direct payment holder is introduced to an existing direct payment holder and/or appropriate user group.

Experience and lessons from Europe and elsewhere

48. Demographic, social and political trends and rising unit costs for care mean that cost containment is a key driver for social care policies across many industrialised countries. A study of 19 OECD countries found spending will need to double by 2050 just to maintain current service standards, yet in many countries there is widespread dissatisfaction with current standards of care and levels of rationing.

International alternatives for the employment of personal assistants

Secure...

In some European countries some of the problems in the direct payment employment relationship are avoided or reduced because the holder is not the legal employer. Instead the chosen PA can become an employee of the municipality as happens in Finland, Norway and Sweden. They enjoy the same benefits as other municipality employees and can join the pension scheme. Alternatively a service user can choose a user-led voluntary organisation to become their PA's employer.

In the Netherlands direct payments were introduced in the 1990s and from the beginning the National Insurance Board was the PAs' employer. This is still in operation although now there are alternative options such as securing a worker through a homecare agency, or arranging for a worker the service user has found themselves to be taken on as an employee of the agency.

In some countries there are organisations which assist mainly with recruitment, although some provide training to care workers seeking to migrate as well. The largest of these is the charity Caritas which operates in Germany, Italy, Austria and a number of Eastern European countries. In Austria Caritas may also act as an employer of PAs.

...and insecure

In other countries, notably those of Southern Europe, there is evidence that many PAs and migrant domestic workers are operating in a grey labour market with little visibility or protection of employment rights.

Experience in the US and elsewhere shows that lack of regulation may fuel state-funded expansion of the grey economy.

For example the 'companion payment' in Italy has been around for 20 years, but there is little state oversight. It is not means tested and is available to people who need constant care. In 2003 well over a million people were receiving it. Migrants are often employed as live-in carers. Even if they are documented, they can be paid below the minimum wage and can be instantly dismissed. It is estimated that half of home carers and domestic workers are migrants.

49. In some countries particularly in Southern Europe, formal care services remain under-developed and state provision is only there as a last resort. In these instances cash payments have developed as a way of sustaining family responsibility for delivering care, instead of developing services.

50. In other countries existing publicly funded care provision is being scaled back and cash payments have developed as a replacement for services. In both models cash payments are part of a policy of curbing growth in care costs.

Spotlight on France

In France policy has been focused on expanding the boundaries of the formal labour market in relation to care work, rather than extending the role of informal or grey forms of care. In 1990 tax incentives were introduced in the form of covering the employer's pension contribution for those who start paying their informal carer the minimum wage and paid holidays.

An earlier version of direct payments for older people fell into disrepute because it was rationed to the highest need, costs were recovered from the older person's estate, and it created unskilled, casual and insecure jobs.

In 2002 it was replaced by a scheme which was more universal, open to all with support needs at whatever level. Cost recovery from estates was abolished and access to the same level of service across the country was guaranteed, with a specified amount of money per level of dependency. This was underpinned by a state guarantee to make good any shortfall in resources of individual local authorities. A co-payment element was introduced above a certain income threshold.

There was a rapid increase in claimants and cuts were made in spring 2003 reducing the proportion who paid nothing from 67% to 36%. The 2003 heatwave, which resulted in 15,000 older people dying, prompted a rethink. A new fund was established based on employer contributions of 0.3% of payroll and a 0.1% increase in employee social insurance contribution.

Alongside this, the training and development of care workers was also addressed. In 2002 a national qualification was introduced to raise the quality and status of care work. This requires 500 hours of theoretical learning, 560 hours of practical training and 17 hours of personal tuition. Large numbers of agency-employed workers now hold the qualification, as well as health and safety training. Agency workers have regulated and scheduled hours – on-call hours must be paid at a rate not less than 2/3 of the standard wage. However the familiar concerns about being rushed and obliged to limit their work to a fixed set of tasks mean that many workers feel they cannot practice in the holistic way in which they have been taught.

A collective voice in Los Angeles

We can also learn from attempts to create organisations which involve both the PAs and those using cash for care schemes to employ them. The SEIU trade union in Los Angeles County created a long-term alliance between care workers and service users in order to give security and a voice to both parties.

The union first attempted to gain union recognition by arguing that LA county was the employer because it was the source of 90% of the money which paid wages so effectively it also determined the number of hours and pay rates. This argument was rejected by the courts.

The union began to enrol members on a voluntary basis from which they developed a registry of care workers to assist service users looking to recruit, and raise the public profile of the workforce. The union then won the right to become a 'public authority' able to act as an 'employer of record' for the care workers while the service users retained the right to hire, fire and supervise. The new organisation can bargain on behalf of both care workers and service users. It now campaigns for more public funding to raise wage rates and to have all the costs of employing a care worker covered.

Issues critical to the roll-out of cash for care

51. The levels of family support which have enabled many early adopters to manage their cash for care will not necessarily be available to those who come on stream once the schemes are rolled out more widely.
 52. Local markets do not necessarily meet the needs of cash for care recipients and there is often no easy way to go about finding a PA if you are not able to employ a relative.
 53. Although personalisation builds in 'self-assessment', older people are more likely than other groups to require considerable input from social workers and care co-ordinators. And
- research from the UK, Europe, USA and Canada shows that older people are more reluctant to take on cash for care especially if it involves becoming an employer.
54. The new UK points-based immigration system excludes low-skilled occupations, so now only senior care workers will be allowed in to work. There is real concern that the government has under-estimated the impact on the care sector of the recruitment and retention difficulties which will arise. It is far from certain that recruitment subsidies for recruiting long-term unemployed as care workers and apprenticeships will be able to plug the gap.



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