



The impact of Personal Budgets and Direct Payments
on older people.
What are the arguments, what's the evidence and
do we need a different approach?
Lessons from England.

Dr John Woolham, Senior Research Fellow,
Dr Nicole Steils, Research Associate,
Social Care Workforce Research Unit, King's College London

Sotemuutos ja henkilökohtainen budjetointi –seminaari

Helsinki, Finland, 21.09.2017.

Structure of presentation



1. Definition of key terms
2. The emergence of personal budgets and Direct Payments in England.
3. The arguments: claims, counter-claims and underlying values
4. Policy issues for older people
5. Evidence of impact for older people
6. If not Direct Payments, what?



"There is no alternative."

Definitions



1. Personal budgets
2. Direct Payments
3. Managed personal budget

1. An arrangement in which a sum of money, calculated following an assessment of need by a social worker, is given to people eligible for social care services to pay for their care and support.
2. Payments made directly into a dedicated bank account controlled by the person with care needs (or their legal proxy) and can choose the kind of care and support they require.
3. Personal budgets spent on care or support on behalf of the eligible service user by a nominated third party.

1. The emergence of Personal Budgets and Direct Payments in England



- Direct Payments & personal budgets: the sole means of achieving personalised care in England.
- How did this happen?
 - Independent Living Fund; Cash for Care
 - Younger disabled people have campaigned for more control over care
 - Direct Payments Act 1997
 - 'In Control' & campaign for Self-Directed Support
 - Department of Health (DH) endorsement of In Control
 - DH commissioned IBSEN study
 - £500m DH Transformation Grant announced *before* IBSEN findings were published
 - IBSEN findings (more later!) & response
- After 2008 the focus became not 'do personal budgets work?' but 'how can we make them work?'

'... older people did not find the individual budget system used in the pilot as easy to use as the other groups, and they did not appear to like the idea of managing their own support.'

(Extract of IBSEN team summary)

'Since this research was undertaken more support has been put in place for older people and early indicators have shown that this has transformed their experiences of using individual budgets. We will conduct further research to investigate the impacts further.'

(Phil Hope M.P., Minister of State for Care Services)

2. The arguments: claim and counter-claim

Advocates

- Response to failures of care management
- Better outcomes
- Empowerment
- More dignity
- More choice
- A chance to exercise personal responsibility
- Fuller citizenship & greater inclusion
- Marketization improves choice, drives up quality
- Better 'targeting' /personalisation of care (people know about their own needs better than anyone else)
- Reduced Social Services Care Management input

Dissenters

- Public services should *not* be about delivering 'choice'
- Downsides to choice
- Transfer of responsibility from state to individuals & privatisation of risk
- Wider concerns re. public sector reform:
 - shrinking the state,
 - replacement of universal social rights with (increasingly rationed) consumer choice,
 - the dominance of managerial not professional cultural values in social care services
 - potential fragmentation of care provision following marketization.

2. Claim and counter-claim: underlying values

Has the term 'personalised' replaced 'person-centred?'

- 'Person-centred' - easy to describe but hard to achieve
 - Case/care management for older people
 - Individual Programme Plans & Shared Action Plans for people with learning disabilities
 - 'Personhood' for people with dementia
- 'Personalised' & 'person-centred' seen as the same by many practitioners, in England, but are the values the same?
 - More emphasis on 'self direction', 'user empowerment', 'personal choice'
 - 'Support' is now used alongside or instead of 'care'
 - Service user rather than professional definitions of need
 - 'Customers' not 'service users'

'Personalisation means thinking about care and support services in an entirely different way. This means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives'.

(Carr 2011 p. 3)

'Individuals not institutions take control of their care. Personal budgets, preferably as direct payments are provided to all eligible people. Information about care and support is available for all local people, regardless of whether or not they fund their own care'

(Department of Health Vision for Social Care. Nov. 2011 p. 8)

3. Policy issues for older people

- Older people are the largest consumers of social care services in the UK. The proportion of older people in the general population will continue to increase for many years
- Values underpinning key English Government policy documents: [e.g. 'Putting People First' 2007; 'Shaping the Future of Care' 2009] are problematic for older people
- Older people, personal budgets/Direct Payments and citizenship
- Are older people being squeezed into a one-size-fits-all model of personalisation?

- People who can exercise independence and self-determination & those who can't: 'choice-and-control' vs. 'care-and-protection'
(Barnes 2011)
- Re-defining of care as a way to restore people to play a role as active citizens – reshaping a fundamental human need to something instrumental and narrowly defined.
(Lloyd 2010)

'For many older people, achieving full citizenship is not an 'aim' in the same way as...for many younger disabled people. Most older people have already experienced citizenship in the form of an active role in family, work and community life: it is not an unrealised aspiration. However, many do complain of their growing 'invisibility' as they age, of the discrimination and exclusion they suffer and the ways in which their citizenship is progressively eroded.'

(Orellana 2012)

4. Evidence of impact of personal budgets and direct payments upon older people



- Evidence in 2008
- IBSEN
- The two graphs compare outcomes for older people on the Adult Social Care Outcome Toolkit (ASCOT)(top) and the General Health Questionnaire (GHQ) (bottom).
- Bootstrapping analysis shows no cost effectiveness for older people compared to younger adults
- IBSEN did find that the same measures offered cost-effective outcomes for younger disabled people.

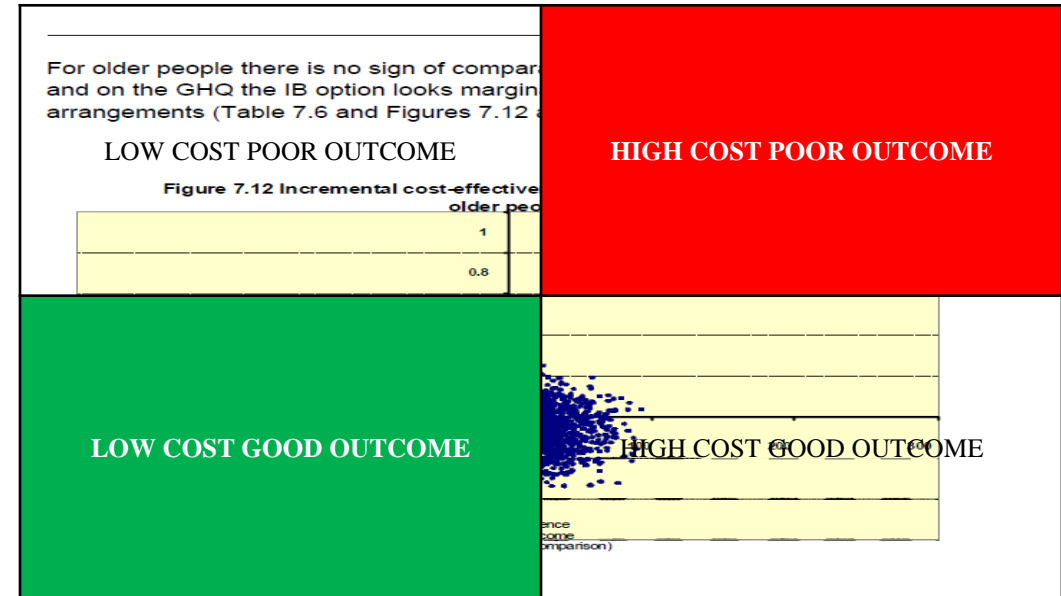
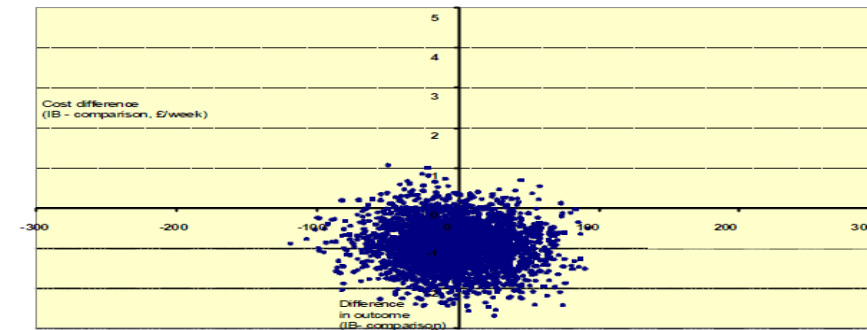


Figure 7.13 Incremental cost-effectiveness ratio for observed GHQ-01: older people



4. Evidence: comparing evidence from the most influential studies



In Control

- Model based on successful work with younger adults with learning disabilities.
- Evangelists for Self-Directed Support (a kind of Direct Payment) and personal budgets.
- Early studies: small numbers, biased samples, no specific focus of impact on older people.
- Later POET survey: analysis of findings for older people found no benefits from Self-Directed Support/personal budgets.

IBSEN

- Very robust design
- Large(ish) samples
- Probably some sample bias
- Analysis of costs and benefits by care group suggested positive impact for younger adults but negative impact on older people
- Speculated that this was because managing a budget caused stress

4. Own evidence of impact of personal budgets and Direct Payments upon older people

Own study 2012

- Single site study comparing budget holders with people receiving traditional care packages. 558 participants.
 - No evidence of benefit to older people compared to younger adults
 - Much larger budget size did not translate into much better outcomes for older Direct Payment users compared to 'traditional' users
- (Woolham & Benton 2012)

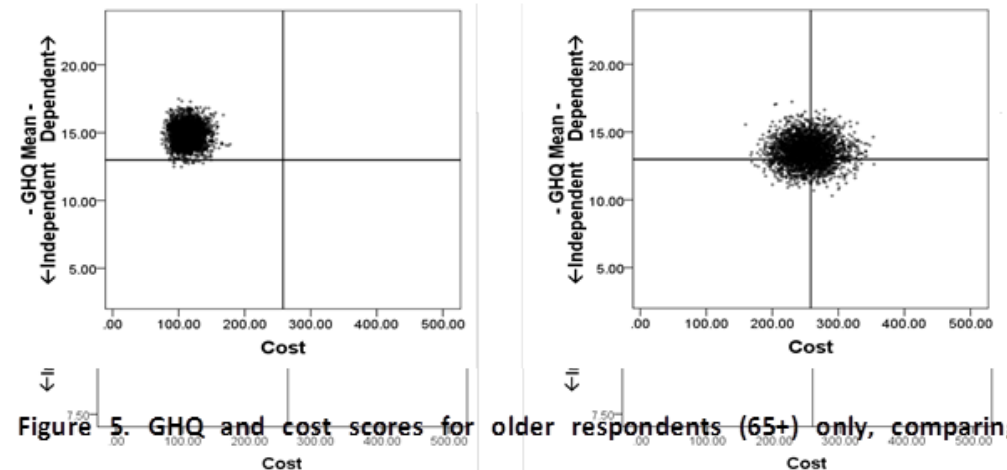


Figure 4. ADL and cost scores for older respondents 65+ comparing bootstrapped data for 'traditional' package users (left) and budget holders (right).

4. Evidence of impact of Personal Budgets and Direct Payments upon older people



Own study 2012-13

Further research on impact and effectiveness of personal budgets and Direct Payments.

Purpose was to find out, 5 years after IBSEN, and 3 years after the 2012 study, if outcomes for older Direct Payment users were better (IBSEN researchers suggested that impact of Personal Budgets may happen over longer timescales)

Mixed method, 2 stage design, 3 local government social services sites.

- Postal survey of 1341 older (75+) Direct Payment and managed personal budget users in three Adult Social Care Departments in England.
339 older people replied.
- Follow-up interviews, both face-to-face and by telephone, with 14 budget users.

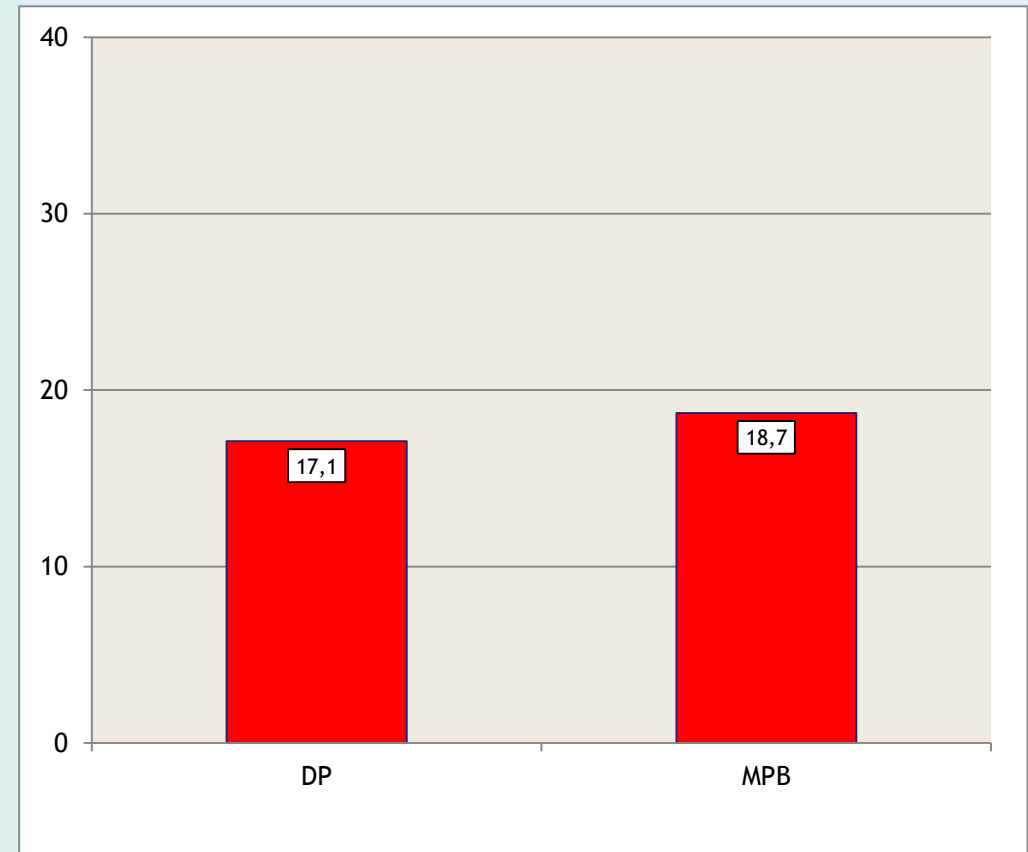
4. Evidence of impact of Personal Budgets and Direct Payments upon older people



- No statistically significant differences in outcome for older Direct Payment and managed personal budget users on 3 dimensions

1. *Health* (EQ5 D)

2. *Perceived stress* (Sheldon & Cohen PS scale)



4. Evidence of impact of Personal Budgets and Direct Payments upon older people

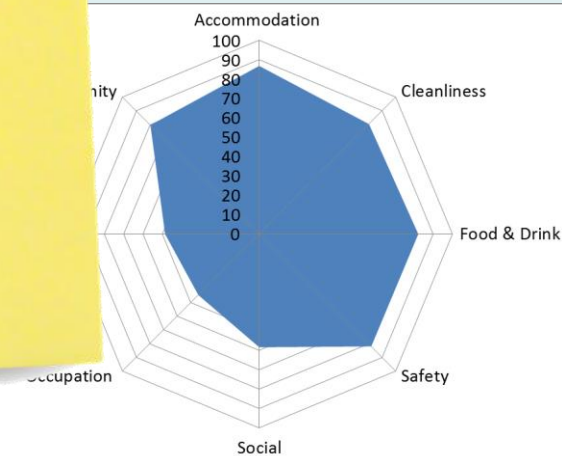
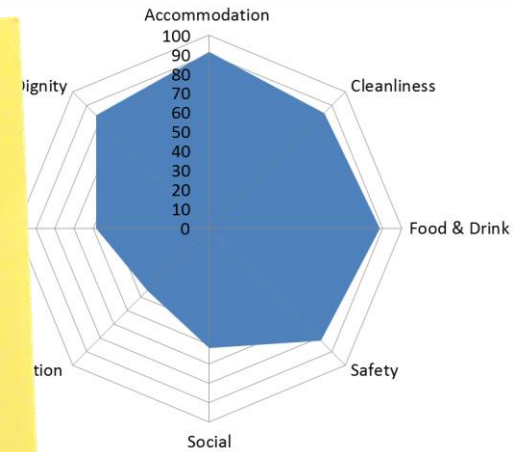


3. ASCOT overall scores = 0.75 for DP users and 0.70 for MPB users.

Little difference between Direct Payments and managed personal budget

ASCOT score profiles suggested that needs relating to accommodation, cleanliness, and food & drink were met for the overwhelming majority in both groups.

However, large proportions of respondents in both groups had unmet needs relating to opportunities for social contact, occupation, and control.



4. Evidence of impact of Personal Budgets and Direct Payments upon older people



- Evidence suggests Direct Payments can work for younger disabled adults if
 - Budgets are large enough
 - People have enough information and can understand it
 - There's sufficient diversity and capacity amongst local care providers
 - There's adequate support available
- There's no robust evidence that Direct Payments work well for most older people.



5. If not Direct Payments then what?

Do Direct Payments and personal budgets work for older people?

- Older people do not achieve such good outcomes as younger adults when given a Direct Payment.
- The size of the personal budget doesn't enable people to have much more than their basic care needs met.
- Direct Payments and personal budgets reinforce a view of care-as-commodity in which the customer is king: but is care a commodity?(Is it about relationships or about transactions?)
- Are consumer rights replacing citizenship rights? Does it matter?
- The 'model' of personalisation and use of Direct Payments as the means of achieving personalised support may not suit many older people.

5. If not Direct Payments then what?



- Older people may want choice and control, but want to exercise it in a different way.
- Restoration of lost abilities to enable full community participation isn't always realistic.
- Independence isn't always what older people want.
- Empowerment may mean the ability to ask others to do things for or with them rather than them having to do it themselves.
- Control may be more effectively exercised through opportunities for older people to develop relationships of trust and friendship.

5. If not Direct Payments then what? Conclusions

We may need to think less about choice and following processes & much more about what good care looks like:

Good care depends on the quality of the care relationship:

'Commissioning on the basis of 'time and task' has excluded the costs of the emotional labour needed to build a relationship with the user'

(Lewis & West 2014:5).

Person-centred care may offer a better approach than 'personalised' support to the kinds of issues facing older people – but would require:

- Recognising the importance of the care relationship
- Genuine co-production of solutions to care & support needs
- Adequate remuneration

Selected references



- Barnes, M. (2011) 'Abandoning Care? A Critical Perspective on Personalisation from an Ethic of Care'. *Ethics and Social Welfare* 5 (2) 153-167.
- Clarke, J., Newman, J., and Westmarland, L. (2008) 'The Antagonisms of Choice: New Labour and the reform of public services'. *Social Policy and Society* 7 (2) 245-253.
- Clarke, J., Smith, N., and Vidler, E. (2006) 'The Indeterminacy of Choice: Political, Policy and Organisational Implications'. *Social Policy and Society* 5 (3) 327-336.
- Daly, G. (2012) Citizenship, choice and care: an examination of the promotion of choice in the provision of adult social care. *Research Policy and Planning* 29 (3) 179-190
- Ferguson, I. (2007) 'Increasing User Choice or Privatizing Risk? The Antinomies of Personalization'. *British Journal of Social Work* 37 (3) 387-403.
- Glendinning, C., Challis, D., Fernandez, J. L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M. (2008) *IBSEN: Evaluation of the Individual Budgets Pilot Programme, Final Report*. Social Policy Research Unit, University of York).
- Hatton, C, Waters, J, Duffy, S, Senker, J, Crosby, N, Poll, C, Tyson, A, O'Brien, J, and Towell, D. (2008) *A report on In Control's Second Phase Evaluation and Learning 2005-2007*. London, In Control Publications
- Lewis, J. and West, A. (2014) Re-shaping social care services for older people in England: policy development and the problem of achieving 'good care'. *Journal of Social Policy* 43 (1) 1-18.
- Lloyd, L. (2010) The Individual in Social Care: The ethics of care and the 'Personalisation Agenda' in services for older people in England. *Ethics and Social Welfare* 4 (2) 188-200.
- Woolham, J. and Benton, C. (2012) 'The Costs and Benefits of Personal Budgets for Older People: Evidence from a Single Local Authority'. *British Journal of Social Work* 43 (8) 1472-1491.
- Woolham, J., Daly, G., Sparks, T., Ritters, K. and Steils, N. (2017) 'Do Direct Payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment'. *Ageing and Society* 37 (5) 961-984.
- Woolham, J., Daly, G., Steils, N. and Ritters, K. (2015) 'The evolution of person centred care to personalised care, personal budgets and direct payments in England: some implications for older users of social care services'. *Sociologia e politiche Sociali* 18 (1) 145-162.

Acknowledgement and disclaimer



The authors are grateful for the funding from the National Institute for Health Research School for Social Care Research (NIHR SSCR) for the most recent research by the authors cited in this presentation, and very grateful to all participants in this and earlier studies.

The views expressed in this presentation are those of the authors, not necessarily those of the Department of Health, NIHR SSCR or NHS.

The authors also gratefully acknowledge the contribution to the most recent study: Dr Malcolm Fisk, De Montfort University, Leicester; Mr Jeremy Porteus (Director, Telecare Local Improvement Network); and Professor Kirsty Forsyth, Queen Margaret University Edinburgh.