



Co-production and participation: Older people with high support needs

Key messages

- In 2007, 1.3 million of the population were aged over 85 and around 40 per cent had some form of severe disability. This group is projected to grow to 3.3 million by 2033.
- The group of older people with high support needs is changing in nature and becoming increasingly diverse.
- Service user and carer participation is high on the agenda in social care but the practice around older people with high support needs remains limited.
- While there are examples of co-production and good practice, the voice of those with high support needs remains largely unheard.
- The benefits of involving users in decisions about their care and service improvement are well documented. It is fundamental to a sense of wellbeing for the individual and results in better quality in both policy and service development.
- Organisational barriers are powerful obstacles to the development of participation and co-production.

Introduction

The number of people aged over 85 is rapidly increasing. The proportion of this group who have high support needs and the average years spent with a disability are also likely to increase as a result.² There are wide variations in older people's social and financial circumstances, and there are also small but significant numbers of black and minority ethnic (BME) and lesbian, gay, bisexual and transgender (LGBT) older people.¹

This At a glance briefing summarises a review of literature and a small-scale survey of good practice on the participation and co-production of older people with high support needs. The evidence base for the review was limited as relevant material was either about participation as it relates generally to older people or was about older people with high support needs but contained very little reference to participation.

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Benefits of participation

Genuine participation means having a voice – and being heard – in key decisions that affect your life chances. Older people can take part either as individuals or as members of whole communities. The opportunity to get involved in care decisions and service improvement issues is fundamental to an individual's sense of wellbeing and enhanced self-confidence.²

‘Barriers to participation are primarily to do with negative and ageist attitudes to older people.’

Benefits to service providers include:

- better outcomes of treatment and care³
- services are more responsive to the needs of users
- individuals and communities build up a sense of ownership of services⁴
- users gain knowledge and self-confidence¹¹
- policy and service quality improves.⁵

Barriers to participation

Barriers to participation are primarily to do with negative and ageist attitudes towards older people and a lack of funding to support real involvement (see box opposite).

Examples of participation and co-production

Two recent, major research programmes involve older people with high support needs. The first is the Joseph Rowntree Foundation’s (JRF) *The Better Life Programme (2009–2013)*,¹⁵ which focuses on how to promote the quality of life of this group. The second is the South East Regional Initiative,¹⁶ which had two strands. These were:

1. change management support to three local authority areas aimed at increasing the voice, choice and control of older people with high support needs
2. a qualitative research study to follow the experiences of older people.

Key findings showed that older people with high support needs wanted:

- to live a normal life
- to maintain an individual identity

Barriers to participation

- lack of support for older people to develop personal skills such as confidence building and assertiveness⁵
- no access to service information and support⁸
- lack of transport and financial help to attend meetings⁵
- inaccessible venues
- organisational culture – a lack of effective leadership to develop a systematic approach to age equality
- not enough training for staff in communicating with older people – particularly those with sensory impairments or dementia, who run the risk of being ‘written off’^{6,7,8,9,10}
- older people in rural areas face particular challenges – including finding it difficult to organise as a group and individuals may experience difficulty finding peer support¹¹
- some methods for engaging with older people – newsletters, meetings and surveys for example – are inappropriate and do not allow for poor mobility, sensory impairment and poverty⁶
- lack of consultation with black and minority ethnic communities mean that BME older people are doubly disadvantaged^{12,13}
- failure of organisations to devolve professional power to individuals and communities and to support co-production.¹⁴

- to pursue meaningful personal networks
- to have hopes and aspirations for the future
- to retain a balance of power in personal relationships
- to have choice and control over finances.

These findings are closely linked to the six ‘keys to a good life’ identified by older people in the JRF study.¹⁷

There are examples of older people being asked their opinion to produce better services. These include improving both sheltered and residential

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care environments, developing communication tools with people with dementia, promoting self-assessment processes and being involved in the evaluation of assistive technology.

There are also campaigning groups of older lesbian, gay, bisexual and transgender (LGBT) people and older people from BME communities.

Co-production¹⁸ – where older people are working with local authorities and voluntary organisations to plan, develop and evaluate services – is taking place in some areas. There are also examples of county- and city-wide partnership groups, where older people are taking on a significant role.

The Dorset Age Partnership

This is a network of representatives from various older people’s forums and groups, and strategic leads and lead officers from Dorset County Council, the primary care trust, the district councils, police, fire and rescue services and voluntary organisations. It is the theme group for the Dorset Strategic Partnership but has been designed as a partnership body where older people are in the majority, and is always chaired by an older person. It has district/locality groups – also with majority older people involvement – which influence its strategy.

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While these good examples exist, it is not always clear from references that older people with high support needs have been included.

Recommendations

Recommendations for improved practice include workforce issues, co-production, better partnership working between all key agencies, improving communication, diverse consultation methods and filling some of the research gaps. Organisations and government need to recognise the resource implications of these recommendations. Greater detail is found in the main report.

References

1. Centre for Population Change (2010) *Demographic issues, projections and trends: Older people with high support needs in the UK*, York: Joseph Rowntree Foundation (JRF)
2. Evans, S. and Vallely, S. (2007) *Social well-being in extra care housing*, York: JRF
3. Barnes, M. and Bennett-Emslie, G. (1997) *If they would listen... An evaluation of the Fife User Panels Project*, Edinburgh: Age Concern Scotland
4. Ridley, J. and Jones, L. (2002) *User and public involvement in health services: a literature review*, Edinburgh: SHS Trust
5. Carter, T. and Beresford, P. (2000) *Age and change: Models of involvement for older people*, York: JRF
6. Branfield, F. and Beresford, P. (2010) *A better life: Alternative approaches from a service user perspective*, York: JRF
7. National Audit Office (2010) *Progress in improving stroke care*, London: The Stationery Office
8. Granville, G., Dorothy Runnicles, D., Barker, S., Lee, M., Wilkins, A. and Bowers, H. (2011) *Increasing the voice, choice and control of older people with high support needs: A research findings paper from the South East Regional Initiative (SERI)* National Development Team for Inclusion (NDTi) and

- Centre for Policy on Ageing (available at www.cpa.org.uk/odi-seri/finalreport/south-east-regional-initiative-research-findings.pdf, accessed 14 May 2012)
9. Older People's steering group (2004) *Older people shaping policy and practice*, York: JRF
 10. Law, J., van der Gaag, A., Hardcastle, B., Beck, J., MacGregor, A. and Plunkett, C. (2007) *Communication support needs: A review of the literature*, Edinburgh: Scottish Centre for Social Research
 11. Thornton, P. (2000) *Older people speaking out: Developing opportunities for influence*, York: JRF
 12. Bousetta, H. (2001) *Extending democracy, participation, consultation and representation of ethnic minority people in public life*, Bristol: Centre for the Study of Citizenship and Ethnicity, University of Bristol
 13. Policy Research Institute on Ageing and Ethnicity (2005) *Black and minority ethnic elders in the UK: Health and social care research findings*, Leeds: PRIAE
 14. Doel, M., Carroll, C., Chambers, E., Cooke, J., Hollows, A., Laurie, L. and Nancarrow, S. (2007) *Developing measures for effective service user and carer participation*, London: SCIE
 15. JRF (2009) *The Better Life Programme (2009–2013)*: www.jrf.org.uk/work/workarea/better-life
 16. South East Regional Initiative (SERI), NDTi and Centre for Policy on Ageing
 17. Bowers, H. et al (2009) *Keys to a better life*, York: JRF
 18. NDTi and Helen Sanderson Associates (2009) *Personalisation – don't just do it – co-produce it and live it!*, Dorset: NDTi

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