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. 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.

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.

‘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.’

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.
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 care
- services are more responsive to the needs of users
- individuals and communities build up a sense of ownership of services
- users gain knowledge and self-confidence
- policy and service quality improves.

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), which focuses on how to promote the quality of life of this group. The second is the South East Regional Initiative, 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 assertiveness
- no access to service information and support
- lack of transport and financial help to attend meetings
- 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’
- older people in rural areas face particular challenges – including finding it difficult to organise as a group and individuals may experience difficulty finding peer support
- 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 poverty
- lack of consultation with black and minority ethnic communities mean that BME older people are doubly disadvantaged
- failure of organisations to devolve professional power to individuals and communities and to support co-production.

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

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


16. South East Regional Initiative (SERI), NDTi and Centre for Policy on Ageing


18. NDTi and Helen Sanderson Associates (2009) Personalisation – don’t just do it – co-produce it and live it!, Dorset: NDTi

SCIE’s At a glance briefings have been developed to help you understand as quickly and easily as possible the important messages on a particular topic. You can also use them as training resources in teams or with individuals. We want to ensure that our resources meet your needs and we would welcome your feedback on this summary. Please send comments to info@scie.org.uk, or write to Publications at the address below.