

Research Report

Diversity in older people and access to services – an evidence review

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A report of research carried out by the Social Care Workforce Research Unit at King's College London

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Introduction

Background

Age UK commissioned the Social Care Workforce Research Unit at King's College London to complete a literature review that would provide information on equality and diversity issues relevant to older people living in the United Kingdom (UK) in relation to the following areas:

- Falls prevention
- Home from hospital services
- Practical support at home (e.g. handyman services)
- Befriending
- Day opportunities

The review was structured around the experiences of older people in terms of their protected characteristics, as defined in the Equality Act 2010.⁽¹⁾ To the best of our knowledge, this is one of the first times that this legislation has been used as a framework for summarising the current evidence base.

Equality Act 2010

The Equality Act 2010 replaced previous anti-discrimination laws with a single piece of legislation to make the law simpler and to remove inconsistencies. The Act covers nine protected characteristics which cannot be used as a reason to treat people unfairly. We all share some of the protected characteristics, so we are all protected against unfair treatment. The protected characteristics are:

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race
- religion or belief
- sex
- sexual orientation

Most provisions of the Act came into force in October 2010. The age discrimination ban was implemented on 1 October 2012. The Act outlaws the following types of treatment:

Discrimination

There are two types of discrimination which are outlawed by the Equality Act 2010: direct and indirect discrimination. *Direct* discrimination is where a person is treated less favourably because of a protected characteristic. For example, two care

workers are helping a person get dressed. One of the care workers uses racist language to describe the service user.

Indirect discrimination occurs when rules are put in place that apply to everyone but put some people at an unfair disadvantage because of their protected characteristic. For example, the manager of a large home from hospital scheme tells a group of volunteers who include Muslim men and women that volunteers cannot request to visit people of the same gender as themselves.

Harassment

Harassment refers to unwanted behaviour that makes people feel intimidated, humiliated, or degraded or that creates a hostile environment on the grounds of their protected characteristics. For example, day service staff repeatedly make negative comments about gay people in the hearing of one of the workers whom they know to be a lesbian.

Victimisation

Victimisation is about treating people unfairly as a result of making a complaint about discrimination or giving evidence when someone else makes a complaint. For example, a transgender service user complains to a home care agency that some of its care workers have made transphobic comments about him. A worker who has witnessed these comments corroborates his complaints. She then finds that she is always given the most inconvenient shifts. Her requests for holidays are always refused, although other workers who submitted similar requests at a later date have had them agreed.

The Public Sector Equality Duty

The public sector equality duty requires public bodies to consider all individuals when carrying out their day to day work – in shaping policy, in delivering services and in relation to their own employees. It requires public bodies to have due regard to the need to eliminate discrimination, advance equality of opportunity, and foster good relations between different people when carrying out their activities. Based on the information that they have collected, an organisation might decide that special steps are needed to help groups who are disadvantaged on the basis of their protected characteristics. For example, a falls clinic finds that Urdu-speaking Muslim women make up a very high proportion of people coming to the clinic, in excess of what they would expect given their numbers in the local population. The health and wellbeing board funds a local community organisation to run strength and balance exercise classes for women. The classes are held in Urdu.

As part of the government's aim of reducing bureaucracy, it has announced a review of the Equality Duty⁽²⁾ to see if it is operating as intended. The review is due to be completed by April 2013.

The government's Equality Strategy

The government has issued an Equality Strategy⁽³⁾ which outlines the steps it will take to achieve improvements. Its five priorities are:

- Early years, education and social mobility
- Creating a fair and flexible labour market
- Opening up public services and empowering individuals and communities
- Changing culture and attitudes
- Making it happen

The Strategy stresses the importance of achieving outcomes in terms of equalities so that we move away from processes and procedures towards demonstrating impact. This involves not just monitoring whether people with a protected characteristic are using a particular service but looking deeper into the barriers preventing them from using a service, examining whether different groups of people have different experiences to others, and considering whether any differences that are identified contribute to other outcomes such as satisfaction with the service and whether they think it contributes to their quality of life.

Framework for describing and analysing research

We developed a framework for looking at research into each particular topic based on some of the factors that might lead to different outcomes for people with differing protected characteristics. This looked for evidence of differences in:

1. **Need** – Do some groups have a greater need for a particular service than others?
2. **Access** – Is there any information about whether uptake of services varies by different groups?
3. **Outcomes** – Does a particular service or intervention seem to work better for some groups than others?
4. **User experiences** – Are some groups more satisfied with a service than others?
5. **User engagement** – To what extent have users with different protected characteristics been involved in developing the service? Are some groups more likely to have been excluded from this process?

Which protected characteristics did we consider?

We looked at all the protected characteristics, with the exception of pregnancy and maternity and marriage and civil partnership which concern people's treatment as a paid employee. We have considered each characteristic separately. In reality, interactions between two or more protected characteristics may lead to greater differences than for each factor separately. However, deficiencies in the way that data are collected and reported mean that a multi-strand, or intersectional, approach has not been possible.⁽⁴⁾ We have used the terms 'race', 'sex' and 'gender

reassignment' because these are the terms used in the legislation, although it is more usual to talk about ethnicity, gender and transgender or trans people. We have not discussed socio-economic differences, even though these contribute to inequalities,⁽⁵⁾ because the government has made the decision not to enforce the socio-economic duty created by the Equality Act 2010.

Inclusion of research undertaken outside the United Kingdom (UK)

Equalities legislation differs across different countries. In addition, older people's rights to care and support vary. Age UK, the funder, asked us to consider research on falls prevention, home from hospital, handyperson, befriending and day services. They suggested research undertaken outside the UK was excluded to maximise the relevance to a UK context. Some contextual information based on selected non-UK research has been included where there is no equivalent evidence from the UK but this is clearly identified.

Challenges for the review

Introduction

Literature reviews have many different purposes. Where there is an established evidence base, they can summarise findings, consider where the balance of evidence lies if findings from different studies are conflicting, and provide the basis for recommendations for policymakers, researchers and practitioners.⁽⁶⁾ Where a topic is under researched or where the evidence is patchy, an increasingly popular approach is to undertake a scoping review. This helps to:

- identify extent, range, and nature of research activity in a particular area
- identify gaps in the existing literature
- make suggestions for future research priorities.⁽⁷⁻¹⁰⁾

We knew from the start that there was very little published research on inequalities *within* groups of older people in terms of their protected characteristics so we undertook a scoping review of equalities in terms of older people's experiences of falls prevention, home from hospital, handyperson, befriending and day services because we knew from the start that there was very little published research on inequalities *within* groups of older people in terms of their protected characteristics. Before going on to discuss our findings, we thought it would be useful to explain why this is the case.

Types of knowledge

Pawson and colleagues make a distinction between different types of knowledge. They refer to:

- organisational knowledge
- practitioner knowledge
- user knowledge
- research knowledge
- policy community knowledge⁽¹¹⁾

This approach does not assume that one type of knowledge is better than another and recognises that each makes a different contribution. However, depending on the topic, the evidence base varies between these different constituents. Delays and difficulties in translating important messages from research into daily practice are often described as a 'research-practice gap' but it is also possible to find examples of a 'reverse practice theory gap' where research knowledge lags behind other types of knowledge. For instance, guides on providing appropriate services for older lesbian, gay, bisexual and transgender people draw on policy, practitioner, user, and organisational knowledge because comparatively little research specifically looks at their experiences.⁽¹²⁻¹⁴⁾ Some individual services have good records in

supporting a diverse range of people in terms of their protected characteristics.^(15, 16) However, developments such as these are rarely evaluated and written up as published research. Even when this has taken place, it can be difficult to access this research knowledge. This is because the findings may not have been formally published and deposited in one of the copyright libraries where they are publicly available. Reports may have been printed in limited numbers or, as is more common nowadays, hosted on websites that are no longer maintained or contain out of date links. This type of material is called 'grey literature' and it can be particularly challenging for researchers to access, especially when the time and resources for searching are limited. However, they often contain information which is different to that included in journal articles or book.

Few studies specifically focus on equalities

Very few of the studies into falls prevention, home from hospital, handyperson, befriending, and day services identified for the review were specifically aimed at exploring equalities in terms of whether people's access to, or experiences of using, a service differed according to their protected characteristics. In addition, researchers often provided very few details on the demographic characteristics of sample participants. This made it hard to tell whether information about a particular characteristic had been collected or if it had been collected but not reported.

The relationship between inequality and legislation may also play a part here. While discrimination on the grounds of race or sex has been outlawed since the 1970s, the rights of lesbian, gay, bisexual and transgender people were not legally recognised until the last decade. This is reflected in the way in which much mainstream research on ageing has neglected issues of sexual orientation and gender identity. Other research into the experiences of lesbian, gay, bisexual and transgender people seems only to concentrate on health risks or psychological problems, without identifying what factors contribute to their wellbeing.⁽¹⁷⁾ There is an emerging literature on the experiences of older gay men and lesbian women⁽¹⁷⁻²²⁾ but we know less about bisexual and transgender older people.

Under representation of certain groups

Study design, sampling strategy, and methods all influence the extent to which researchers achieve samples which reflect the diversity of the older population. There are a number of reasons why people with certain protected characteristics have tended to be under represented in research or why data about certain characteristics have not been collected.

Disability

People with disabilities do not generally have an equal chance of being included in research⁽²³⁾ and different data collection methods may be needed to support their participation. Because so many studies asking people about their experiences of services are based on interview data, people with communication issues tend to be

particularly under represented. This especially applies to people with dementia and other disabilities affecting people's ability to speak.⁽²⁴⁾ A growing number of studies focus on the experiences of people with learning disabilities but most of their participants tend to be under the state retirement age. We also now know more about developing more inclusive research methodologies to support people with a hearing⁽²⁵⁾ or visual impairment⁽²⁶⁾ but the extent to which this knowledge is applied in mainstream research is variable.

Gender reassignment

Policies specifically intended to reduce the inequalities and discrimination faced by transgender people have only been introduced recently and this is reflected in the lack of research funding for studies looking at their experiences.⁽²⁷⁾ Within the research that does exist, none seems to have explored transgender ageing, although this is expected to change as the number of post-operative transgender older people increases.⁽¹⁷⁾

Research has also been hampered by definitional issues. Medical research tends to be restricted to transsexual people - those living, or seeking to live, permanently in their new gender using hormone and/or surgical therapies. However, the transgender or 'trans' community also includes people who cross dress, people who define themselves as intersex, and people who do not identify permanently with any gender.

It is also important not to confuse gender identity with sexual orientation. As with cisgender people (individuals who feel aligned with the gender they were assigned at birth, their bodies, and their personal identity) transgender people may be heterosexual, lesbian, gay, bisexual, or asexual.^(17, 27, 28) While many transgender people choose to identify with lesbian, gay and bisexual people because of a shared experience of oppression and discrimination and the term LGBT is used widely, there are debates about whether the particular perspectives of transgender people can be fully included in wider LGBT research.⁽²⁷⁾

Researchers looking at the extent to which transgender people have access to a particular service are hampered by the fact that no systematic or reliable population data have been collected through the Census or other government-sponsored surveys,⁽²⁷⁾ although the Gender Identity Research and Education Society has begun work in this area.⁽²⁹⁾ It is unclear how experiences of discrimination may influence transgender people's willingness to answer questions about gender identity or take part in research more generally. An online survey by a team of researchers who had credibility in the transgender community attracted almost 900 replies.⁽²⁸⁾ However, researchers need to accept that some transgender people may only be prepared to participate provided certain conditions are met. In work undertaken for the former Healthcare Commission on older people's experiences of health and social care services,⁽³⁰⁾ participants in a focus group including older transgender people chose not to complete the project monitoring forms and were careful not to use each other's names during the discussions. They also asked the researchers to take notes rather than make an audio-recording.⁽³¹⁾

Race and ethnicity

Until recently people tended to use the terms 'ethnicity' and 'race' interchangeably and the Equality Act 2010 refers to race. Unlike race, ethnicity is a 'self-defined and fluid concept, which can embrace a number of features such as skin colour, national or regional identity, cultural, religion, country of birth, language, dress and political affiliation'.⁽³²⁾

The first time that Census data included a question on ethnicity was in 1991. Public authorities have also been required to collect ethnic monitoring data since the passage of the Race Relations (Amendment) Act 2000.⁽³³⁾ These developments have contributed to an increase in the volume of research relating to ethnicity. However, there are two reasons why it still remains limited in terms of the topics included in this review. The first is the under-representation of people from minority ethnic groups in clinical trials,⁽³⁴⁻³⁷⁾ the mainstay of research into falls prevention and hospital at home services. Research into trial participation suggests there is no evidence that people from minority ethnic groups are less willing to take part in clinical trials but recruiters' concerns about the increased time and resources to translate materials or employ interpreters leads them to choose people they perceive to be fluent in English and of a similar social class to themselves.^(37, 38)

The second is that research into topics such as befriending, handyperson schemes, and day opportunities tends to be small scale and limited in terms of funding. Researchers and organisations providing services face similar challenges in terms of identifying multiple ways of reaching out to different communities and ensuring that funding has been set aside to cover the costs of translation and interpreting services among communities where participants' preferred language is not English or where levels of fluency in English are low.^(39, 40)

The 2011 Census included a question on national identity. Our recent experience in a study of support for family carers suggested that, although there was a strong overlap between the way that participants defined their ethnicity and national identity, they were not the same. This is an emerging issue for researchers.

Religion and belief

The inclusion of a question on religion in the 2001 census was controversial as it represented the first time that this question had been asked in England, Scotland, and Wales. UK research into ageing, unlike research from the United States, tends to have neglected issues of religion, belief, and spirituality.⁽⁴¹⁾ Although questions on ethno-religious background are sometimes more useful in terms of revealing inequalities than questions on ethnicity alone⁽⁵⁾ and the overlap between religious and racial discrimination,⁽⁴²⁾ it was striking that so little research into the review topics considered participants' religion and belief. It has been suggested that faith communities are heavily involved in supporting older people but, because so much of this takes place at local level, it tends to be under reported.⁽⁴³⁾

Sexual orientation and sexual identity

A key barrier to knowing more about the needs of lesbian, gay and bisexual older people has been the lack of questions on sexual orientation and sexual identity in major surveys. In 2008, the Office for National Statistics made a landmark decision to include a question on self-perceived sexual identity in their major social surveys, in which participation is voluntary. The use of the term 'identity' rather than 'orientation' was to widen the focus from single elements of sexual orientation, such as behaviour or attraction, and make it broader.⁽⁴⁴⁾ This development means people may become increasingly used to answering questions about their sexual orientation and sexual identity.

However, many of the current older generation of lesbian, gay and bisexual older people have experienced considerable discrimination and have been used to concealing their sexual identities.⁽²¹⁾ In a Stonewall survey, almost half of respondents with experience of social care services said they had experienced discrimination,⁽¹²⁾ so some people may be reluctant to come out to service providers if asked questions about their sexual orientation.^(20, 45) Nevertheless, almost four fifths of respondents to a survey from *Opening Doors* said that they would not mind being asked about their sexuality as part of an assessment for health and social care services as long as they felt reassured that the professional conducting the assessment was not prejudiced.⁽⁴⁵⁾ Price⁽⁴⁶⁾ points out that the increasing numbers of lesbian, gay and bisexual researchers who can offer an 'insider' perspective on the topics being researched and the research process offers potential for improvements in the way that we engage with lesbian, gay and bisexual people in research.

Moving forward

This review has highlighted the challenges in looking at research on equality and diversity in terms of the protected characteristics included in the Equality Act 2010. Even when information on gender (recorded in a binary men/women division) and age is provided, the extent to which these characteristics are used to explore issues such as access, choice, and satisfaction are variable. Within certain limitations, issues of disability and ethnicity are discussed more frequently but information on sexual orientation, gender identity, and religion and belief are almost wholly absent. Guidance now exists on possible ways of asking about sexual and gender orientation^(44, 47, 48) but there has been controversy among secular organisations about the wording of the census question on religion. Further work is needed on how best to combine information on protected characteristics so that we understand more about the intersection between different characteristics in order to develop a multi-pronged approach to tackling inequality.⁽⁴⁾

An important issue for organisations and researchers is how to convey the importance of collecting information about protected characteristics while respecting people's rights to privacy. We actually know very little about people's preferences for being asked questions about their protected characteristics. Knocker's comments on collecting information about sexual orientation cited below has a wider relevance and highlights the need to collect information in ways that do

not create further barriers but open up opportunities to understand more about people's lives:

Clearly a tick-box approach to the question of disclosure is unlikely to be sufficient. Some LGB [lesbian, gay and bisexual] people will always be very open about their sexual orientation, others are much more reticent. Those in contact with older LGB people need to create an atmosphere of trust in which a person can be open if they want to be, without creating pressure for someone to come out. This is a skilled balancing exercise and one that many care professionals struggle with.⁽⁴⁵⁾

Falls prevention

Introduction and background

As people get older, they tend to fall more often. This happens for a variety of reasons including problems with balance, poor vision, and dementia. Estimates suggest around a third of people aged 65 and over living at home fall at least once each year. About one in five of these falls requires medical attention but fewer than one in 10 results in a fracture.⁽⁴⁹⁾ However, falls causing an injury are the leading cause of accident-related mortality in older people.⁽⁵⁰⁾ Recurrent falls – generally defined as happening at least three times in a single year⁽⁵¹⁾ – are a major reason why older people are admitted to hospital.^(52, 53) The total cost of falls to the NHS is thought to be £1.7 billion a year.⁽⁵⁴⁾ Falls and fear of falling often result in older people restricting their activities. This may have serious consequences for them and their families in terms of loss of independence and reduced quality of life.^(49, 55)

These are some of the reasons why falls prevention is now recognised as an important public health issue throughout the world, as well as in the UK. The Department of Health estimates that for every £2m invested in falls services regionally, £5m could be saved through reduced NHS costs.⁽⁵⁶⁾ Investment in falls prevention would almost certainly also reduce the social care costs of supporting people who have had a fall but this has yet to be evaluated. Despite this, falls receive much less attention and funding than common conditions of midlife.⁽⁵⁷⁾ Age UK has called for more priority to be given to falls prevention services and for evidence based exercise programmes to be available to all those who need them.⁽⁵⁶⁾

Description of the service

Falls prevention covers a number of interventions offered singly or in combination to help people who have fallen frequently, or who are at risk of falling, fall less often. 'Fallen frequently' is not always defined very consistently but generally refers to people who have experienced 'an unexpected event in which [they have] come to rest on the ground, floor, or lower level'⁽⁵⁸⁾ at least three times in the previous year.^(51, 59) Interventions designed to prevent falls include:

- Clinical interventions to identify and treat unmet health needs that are risk factors for falling, such as dizziness or sight problems
- Home hazard modification to make the physical environment safer, for instance by improving lighting or installing handrails
- Education to help people change their behaviour and so alter their risk of falling
- Physical therapy or exercise to help improve people's strength and balance so they are less likely to fall.

Clinical interventions are outside the scope of this review. Making the home safer is covered in the chapter on handyman services. Very little research has looked at

the effects of education alone^(60, 61) (as opposed to education provided alongside an exercise programme) and this has not been undertaken in the UK. As a result, this chapter is mainly about exercises designed to improve strength and balance among people who have fallen or who are thought to be at increased risk of falling. This is also the intervention for which we have most evidence on effectiveness.⁽⁶²⁾

Exercises can take place in group settings or individually in people's own homes. Not everyone enjoys group activities so it is important to be able to offer home-based interventions to people who are unable or unwilling to leave their homes.^(63, 64) Examples of different exercises used to develop strength and balance include the Otago Exercise Program (OEP),⁽⁶⁵⁾ T'ai Chi,⁽⁶⁶⁾ and Nintendo Wii.⁽⁶⁷⁾ A common approach is for people to attend a time-limited class led by physiotherapy, occupational therapy, or nursing staff followed by ongoing classes led by exercise instructors in community centres. People can also be taught exercises that they can continue at home on their own.

Most research is based on face-to-face instruction but there are alternatives – for example, DVDs,⁽⁶⁰⁾ teleconferencing,⁽⁶⁸⁾ or the internet.⁽⁶⁹⁾ However, we did not identify any studies comparing these methods with those delivered in person.

Gaps in the research

There is now a substantial body of research on falls prevention but much of our information comes from clinical trials designed to test the effectiveness of a particular intervention or group of interventions. These trials often have strict exclusion and inclusion criteria – for instance, people with sight problems or dementia may be excluded. They are mainly reported in medical journals where very limited demographic details of participants in terms of their protected characteristics are provided. They have also been criticised for focusing only upon the physical aspects of falls prevention and not giving enough attention to broader outcomes such as quality of life.^(70, 71)

Until recently, older people were rarely asked what they thought about falls prevention services. This picture is now changing.^(50, 55, 62, 72-78) However, further progress is needed to ensure that future research includes the full range of older people in terms of their protected characteristics. For example, we know that the costs of travel to classes or the costs of the classes themselves can be a barrier to using the service.⁽⁶⁴⁾ However, we do not know whether cost is a greater barrier for some groups of older people in terms of their protected characteristics than others.

We also know very little about how to transfer the results from clinical trials of falls prevention interventions into everyday practice.⁽⁷⁹⁾ At the same time, many of the successful ways in which organisations have developed inclusive and successful ways of running falls prevention programmes are not written up as research reports and journal articles, creating a research practice gap.

Levels of need and access to services

Age

The risk of falling increases with age because people are more likely to acquire new disabilities or find that pre-existing conditions become worse as they age.⁽⁸⁰⁾ Around half of people aged 80 and over fall each year compared with around a third of people aged 65 and over.^(51, 52) Most people using falls prevention services are over 75.⁽⁵⁰⁾ However, we could not find any research investigating whether the age profile of those using falls prevention services matched need within the population.

Disability

Older people who fall frequently almost certainly have at least one disability that contributes to their falls. Falls prevention is often targeted at people with osteoporosis, stroke, diabetes, and Parkinson's disease because they are more likely to experience poor balance and/or dizziness which increase their risk of falling. Medication, especially sedatives and antidepressants, can also contribute to loss of balance or dizziness. An emerging issue, given the lengthening life expectancy among people with a learning disability, is that falls also seem to be more frequent among older people with a learning disability.⁽⁸¹⁾

Vision and dementia are two other major issues in falls prevention. Sight deteriorates with age and as many as 37,000 falls in the UK each year could be caused by partial sightedness or blindness.⁽⁸²⁾ People with dementia are eight times more likely to fall than people of a similar age and gender who do not have dementia.⁽⁸³⁾ We know that people with dementia and/or sight problems are often excluded from research into falls prevention⁽⁴⁹⁾ but we do not know whether this also applies to their use of falls prevention services. Despite this lack of research, we can make some assumptions about whether environmental factors can make it more difficult for people with certain disabilities to take part in falls prevention exercises. For example, people who have developed sight problems in later life and those with mobility problems may find it harder to travel independently to classes held outside the home. People with dementia may need additional assistance and encouragement to follow instructions during classes.

Practice example: transport support to attend falls prevention classes

Transport to Tameside and Glossop Falls and Osteoporosis Service is provided by local volunteer drivers and falls prevention groups and exercise classes are held within local sheltered housing schemes to help reduce costs and allow clients from inside and outside the housing schemes to socialise.⁽⁵⁶⁾

Gender reassignment

We could not identify any examples where transgender people were reported to have taken part in research into falls prevention. Guidelines from the United States suggest that it is important to monitor bone mineral density and screen for osteoporosis in transgender people because of the potential long term effects of

taking sex hormones⁽⁸⁴⁾ but we do not know if taking these hormones places older transgender people at greater risk of falling or sustaining a fracture as a result of falling. It is possible that transgender people may be less likely to accept invitations to attend exercise classes. This is because a survey of transgender people, which included some people aged 50 and over⁽²⁸⁾ reported that 29 per cent of respondents felt that being trans adversely affected the way they were treated by healthcare professionals.

The example of developing falls prevention services with people from minority ethnic groups might help here.^(85, 86) In the Minority Ethnic Falls Prevention Programme (see section on race), different ethnic communities advised on ways of ensuring that exercise classes were culturally acceptable, such as choosing venues with suitable cubicles to allow people privacy when changing, and were instrumental in publicising services through community groups and places of worship. Approaches to local trans groups could work similarly well, although it is important to emphasise that this appears to be a totally under researched area.

Practice example: training in supporting transgender people

The Adult and Community Services Directorate within Lancashire County Council estimated that a significant number of transgender people in their area might not be accessing the care services they needed for fear of prejudice and discrimination. A rolling programme of training provided by an organisation for transgender people (including myth-busting, awareness and understanding of trans-specific issues) was arranged for staff across the county. As a result, staff felt more confident in supporting older transgender people and transgender service users felt that better consideration was given to maintaining their dignity because staff showed respect for their gender identity by enabling them to express it.⁽⁸⁷⁾

Race

It is important to monitor the ethnicity of people using falls prevention services because low awareness of falls prevention, and barriers in the form of language or lack of culturally sensitive services may mean that people who would benefit from falls prevention are not using the service. Older people's overall understanding or interest in falls prevention is generally poor, with one study concluding that there were more similarities than dissimilarities among a group of Asian and white older people.⁽⁸⁸⁾ However, language may act as an additional barrier to uptake of the service. One study including Chinese and what the authors defined as 'South Asian' older people found they preferred information to be given by person or via DVD rather than leaflets. As they did not use computers, they could not access the internet.^(88, 89)

The type of exercise on offer might also affect take up. In the study that included South Asian and Chinese participants, Chinese participants liked attending a T'ai Chi class because T'ai Chi originated in China and they thought it was more culturally appropriate than dance-based exercises.^(89, 90)

The Minority Ethnic Falls Prevention Programme (MEFPP)^(85, 86) aimed to put some of the ideas about improving access to falls prevention services into practice. This project showed that working with local community groups could help raise awareness of falls prevention and increase uptake of the service among groups who were previously under-represented in falls prevention programmes. Examples of ways that messages about falls prevention were delivered included:

- Consultation with community groups to help decide on such things as choosing the most suitable venues in terms of timing of classes, location, changing and catering facilities
- Recording publicity and exercise DVDs in community languages and translating leaflets
- Using local community groups and places of worship to disseminate information about the project.^(85, 86)

A trial of exercise promotion using some of the lessons of the (MEFPP) project which is underway⁽⁹¹⁾ has found that having single sex classes and allowing participants to bring along other family members has improved take up among Arab and Bengali participants (Iliffe, personal communication).

Practice example: falls prevention advice for people from minority ethnic groups

The EXTEND project in Birmingham was one of the projects funded under the MEFPP initiative aimed at improving knowledge of falls prevention among people from minority ethnic groups. It trained a group of people who came from different ethnic groups who were then responsible for running falls prevention services in their own communities.⁽⁹²⁾

An emerging issue is whether different ethnic groups have different risk factors in terms of falls prevention. Evidence from studies undertaken outside the UK^(35, 93) suggests there may be some differences in the frequency of falls among people from different ethnic groups. This arises from a complicated combination of different factors – including differences in socio-economic circumstances, genetic predisposing factors, and dietary customs. For example, vitamin D deficiency varies between ethnic groups,⁽⁹⁴⁾ and some researchers have suggested that Vitamin D can help reduce the risk of falls.⁽⁹⁵⁾ The National Institute for Health and Clinical Excellence (NICE) - the organisation that aims to help the NHS, local authorities and voluntary organisations make sure the care they provide is of the best possible quality and offers the best value for money - has suggested that this is an area in which more information is required.⁽⁵⁷⁾

Another example is that of osteoporosis. A study from the United States⁽⁹⁶⁾ showed that older women with osteoporosis have decreased balance and muscle strength compared to age-matched individuals without the disease. This placed them at greater risk for falling. Osteoporosis also causes reductions in bone density, making it more likely that bones will break as a result of a fall. A UK study⁽⁹⁷⁾ found higher rates of osteoporosis among white people than among any other ethnic group.

However, although their overall rates of osteoporosis were lower, similar proportions of men and women from black and minority ethnic groups were affected. This differs from white people, where osteoporosis is much more common among women.

Notwithstanding this, it is important to note that different studies have defined ethnicity in different ways and that it is notoriously difficult to ascribe differences to ethnicity when cultural, religious, and socio-economic reasons could also have played a part in shaping these variations.⁽⁹⁸⁾ What these examples do illustrate is the way in which attention should be given to deciding whether publicity material for different ethnic groups needs to contain different content as well as being translated into languages other than English.

Religion and belief

The key ways in which religion and belief might influence access to falls prevention services is how they shape people's ideas about the suitability of exercise classes, particularly group exercises. Important issues to consider are:

- Whether separate gender segregated classes are needed (including the gender of the instructor and whether the instructor needs to be bilingual)
- Ensuring that advice on what clothes to wear respects people's religious or cultural preferences
- Choosing an acceptable venue and ensuring that it offers sufficient privacy for those attending
- Materials may need to be translated for some communities.^(85, 86, 91)

Some religious and belief systems have more fatalistic ideas about health and ageing than others. Researchers have suggested that seeing falls as an expected event that 'happens' and cannot be prevented might mean they are less inclined to participate in falls prevention exercise.^(88, 90, 99) It is important to find ways of engaging people in discussions about the potential benefits of falls prevention in ways that are consistent with their beliefs, for instance by working through religious leaders and/or by using religious teachings.

Practice example: using religious teaching to promote falls prevention exercise

Age UK's *Fit as a Fiddle* programme takes messages from the Qu'ran to counter ideas among older Muslims that falls cannot be prevented.

Sex

Falls prevention policies need to take a gender perspective because older women are more likely to fall than men but men are more likely to have a fall that is fatal.⁽¹⁰⁰⁾ The World Health Organization suggests women fall more often than men because they are more likely to live alone and take multiple medication. Another

contributory factor is that women's muscle mass declines faster than men's, contributing to greater muscle weakness and loss of lower body strength.⁽¹⁰¹⁾ By comparison, older men tend to have built up more muscle mass through playing sport or being in occupations that are more physically active.

However, men are more likely to avoid seeking help until the underlying medical condition which has contributed to their fall has become severe. They also tend to undertake more risky activities, such as climbing onto roofs. This is why, when men fall, they are more likely to die as a result of their fall.^(98, 100)

Sexual orientation

We were unable to identify any studies looking at lesbian, gay and bisexual older people's experiences of falls prevention services. However, we can use information from a survey by Stonewall as a starting point for considering this issue. Nine per cent of older lesbian, gay and bisexual people have experienced discrimination, hostility, or poor treatment because of their sexual orientation when accessing information about health and social care services. Half of these incidents occurred within the last five years. Seventeen per cent of lesbian and bisexual women and 11 per cent of gay and bisexual men have experienced similar treatment when using GP services because of their sexual orientation. Slightly over a third of these incidents occurred within the last five years.⁽²⁰⁾ These negative experiences could contribute to a reluctance to seek out information about falls and to ask for treatment among some older lesbian, gay and bisexual older people.

The Stonewall survey also draws attention to the higher number of lesbian, gay and bisexual people living alone. Forty one per cent of older lesbian, gay and bisexual people aged 55 and over live alone compared with 28 per cent of their heterosexual counterparts.⁽²⁰⁾ Older people who live alone are at greater risk of falling.^(100, 102) It is not clear whether this is because they live in less suitable environments, their economic circumstances or health are worse, or if they are more likely to fall while undertaking personal or household tasks because there is no-one on hand to help them.

In the absence of any empirical evidence about older lesbian, gay and bisexual people's experiences of falls prevention services, we cannot assume that their risk of falls and willingness to engage with services are the same as for their age, gender, and ethnically matched heterosexual counterparts. Once more, the evidence from the Minority Ethnic Falls Prevention Programme^(85, 86) suggests that consultation with organisations representing local lesbian, gay and bisexual older people might help improve our knowledge in this area. American research reports that lesbian and gay people are more active on social networking sites than their heterosexual counterparts (results are not reported for bisexual people).⁽¹⁰³⁾ Although similar research does not seem to have been undertaken in the UK, targeted publicity via social networking sites might be a way of reaching greater numbers of lesbian, gay and bisexual older people.

Outcomes and user experiences

Existing published research has not been designed to measure whether falls prevention works better for some groups than others in terms of their protected characteristics. However, the results can be used to set a baseline and to suggest themes that could be explored more fully in future research with more diverse samples of older people.

Outcomes

A Cochrane Review – an independent review by a team of researchers designed to summarise the best currently available research evidence – concluded that:

- Group exercises which target at least two of the following four areas: strength, balance, flexibility, or endurance reduce the rate of falls and the risk of falling
- T'ai Chi as a group exercise reduces the rate of falls and risk of falling
- Individually prescribed exercise carried out at home reduces the rate of falls and risk of falling
- There is limited evidence about the effectiveness of modifications designed to improve safety in the home but they may help people at higher risk of falling⁽⁴⁹⁾

Researchers are beginning to suggest that reductions in falls may be too narrow a way of capturing the impact of falling and taking part in falls prevention programmes on people's lives and that we also need to consider if they improve people's quality of life or wellbeing.^(55, 70, 71)

Falling can result in loss of confidence and can lead to people restricting what they do in order to avoid the risk of falling again.⁽⁵⁵⁾ An important benefit reported by many older people from taking part in falls prevention exercises is increased confidence.^(63, 89, 104)

For some people, group exercises offer additional social and emotional benefits.^(55, 74, 89) Dickinson and colleagues found that, irrespective of gender and ethnicity, men and women and White, 'South Asian,' and Chinese participants valued the social aspects of falls prevention classes and the opportunities to make new friends.⁽⁸⁹⁾

User experiences

Interventions designed to reduce the number of falls will not be successful if older people do not want to take part in them.⁽⁶²⁾ Currently, uptake rates of community-based fall prevention interventions are very low, averaging about 50 per cent^(62, 89) but they can be as low as 10 per cent.^(89, 104) Some refuse to take up the service at all, while others try, but do not continue, it. These findings suggest that improvements are needed to the way in which older people are offered services and in the ways they can be motivated to continue to attend classes.

Falls are not simply about the risk of physical injury. We also need to consider people's emotional responses to falling, their views about risk and autonomy.⁽⁷⁷⁾ Some people feel embarrassed to talk about falling. Others may see the need to attend classes, make modifications to their home, or use mobility aids as a sign that they are becoming dependent. Older people do not reject falls prevention advice because of ignorance of their risk of falling, but because they see it as a potential threat to their identity and autonomy.⁽¹⁰⁴⁾ Others may not view themselves as being 'at risk' and so do not consider advice on falls prevention to be relevant.⁽⁶⁴⁾

Approaches that focus on the benefits of falls prevention in terms of taking exercise and living a healthy lifestyle and maintaining independence seem to work better than presenting it in terms of increasing safety and reducing the number of falls.^(64, 78, 88, 104) Psychological research suggests that people are more inclined to follow advice correctly if the advice is tailored so that it can be made relevant to the specific beliefs, goals and difficulties of the individual.⁽⁶³⁾ However, at the moment, we do not know enough about how to tailor advice on falls prevention in this way.

Because the social benefits of attending exercise classes are so popular, it has been suggested that ensuring additional time for socialising before or after the classes could help increase attendances.⁽⁵⁵⁾ Food was a feature of interventions attended by Asian and Chinese older people which was viewed very positively and made it more likely that they would continue to attend classes.⁽⁸⁹⁾

However, not everyone feels comfortable with the idea of doing exercises in a group, particularly if their previous levels of physical activity are low.⁽⁸⁹⁾ Of the 5,440 respondents to one survey, over 60 per cent said they would consider doing strength and balance training at home and 36 per cent said they would definitely do it. By contrast, 41 per cent said they would definitely not attend group sessions while just 23 per cent said they definitely would.⁽⁷²⁾ These results suggest that we need to know more about preferences for group versus home based exercises in terms of people's protected characteristics.

In some circumstances, instructors may need to be of the same gender as those they are teaching, speak a certain language, or understand the requirements of a particular faith. In others, the personal qualities of the instructor may be the most important factor. People can feel a sense of responsibility for carrying on with a programme if they have built up a personal relationship with the instructor and they feel that they have been treated as an individual.^(74, 89) However, we need to know more about where matching in terms of protected characteristics is needed and how classes can be made more inclusive.

User involvement

Falls prevention services have developed differently throughout the country and across different organisations so the way in which they have approached user involvement is very variable. However, there is more recognition of the need to use older people's experiences as a way of monitoring the quality of the service.⁽⁵⁰⁾ Although this is an important step, certain groups may be excluded from this process

if these findings are not supplemented with focused efforts to consult with groups who may be under represented among survey respondents. We know that some older people from minority ethnic groups, particularly older Chinese and Bangladeshi people, have lower levels of literacy in English and may not always be literate in their own language. Here, telephone or face to face own-language interviews and group discussions may be needed. People with disabilities such as severe arthritis or sight loss may also find it hard to complete postal surveys. Telephone or individual interviews would be another option here. There is a growing literature on engaging people with dementia⁽¹⁰⁵⁻¹⁰⁷⁾ which shows that people with dementia are still able to express their views, although time and skill are needed on the part of the researcher. An advantage of surveys is that their greater anonymity means that people tend to be more willing to disclose their sexual orientation or transgender status as long as they are reassured about the survey's confidentiality.

Key findings

- There are a large number of studies looking at falls prevention, although very few of these have looked at equalities issues. Almost all our knowledge comes from studies of falls prevention services for people from minority ethnic groups.
- Falls prevention – particularly exercises to improve strength and balance – can reduce the rate of falls, increase confidence and independence and enable people to engage socially. However, if services are not tailored to individual needs and preferences, people will not want to use the service.
- There are messages from the schemes that have been developed to improve access to, and uptake of, falls prevention services for people from minority ethnic groups that could be tested for their suitability for other groups in terms of their protected characteristics.
- We need to identify whether experiences of discrimination from health and social care services are discouraging lesbian, gay, bisexual, and transgender people at risk of falling from using falls prevention services.

Home from hospital services

Introduction and background

Over the past decade, a number of services have developed aimed at promoting faster recovery from illness, preventing unnecessary acute hospital admissions, supporting timely hospital discharge and maximising independent living.⁽¹⁰⁸⁻¹¹²⁾ Umbrella terms used to describe them include 'intermediate care', 'integrated care' and 'care closer to home'.^(108, 110, 113)

The government wants to introduce greater choice and to develop new and innovative ways of providing health care away from traditional settings.⁽¹¹⁴⁾ At a time of fiscal austerity, it has provided extra funding to help people leaving hospital.⁽¹¹⁵⁾ It also wants 'providers of health, housing and social care to work across the systems to develop innovative services, such as social enterprises, that can keep people independent at home, or help them return home from hospital more quickly'. In the context of an increasing number of emergency admissions to hospital among people aged 75 and over, there is potential to develop services aimed at early discharge or avoiding hospital admission in the first place.⁽¹¹⁶⁾

Description of the service

Home from hospital services offer a distinctive contribution to these services by meeting the emotional, practical, and social needs of older people who have been discharged from hospital. They provide a time limited service offering companionship, practical help, and some personal care to help people make a successful transition to returning home.⁽¹¹⁷⁾

Gaps in the research information

We identified just two published pieces of research specifically looking at home from hospital schemes which reported the demographic details of those using the service.^(108, 117-120) Neither was funded specifically to look at equalities. Other studies exist⁽¹²¹⁾ but these do not provide demographic details about people using the service.

There is a larger intermediate care and 'hospital at home' literature covering schemes led by healthcare professionals aiming to avoid hospital admission in the first place ('step up')⁽¹¹¹⁾ or to enable early discharge people who still need medical and nursing care ('step down').⁽¹¹²⁾ Findings from some of these studies have been included here because the evidence base on home from hospital schemes is so small. The key driver for the development of these services has been the need to reduce the pressure on inpatient services. This research provides similarly limited information on equalities. Furthermore, many of the original studies into hospital at home schemes^(109, 122) and reviews that draw on these studies^(110-112, 123, 124) use material that was collected some time ago when there was less recognition of the need to record demographic details of participants. We identified just one briefing

paper⁽¹²⁵⁾ and one letter to a medical journal⁽¹²⁶⁾ that focused on whether people with a protected characteristic (in both instances, ethnicity) received a different service.

These factors highlight why we know so little about whether some groups of people are more or less likely to use hospital at home services according to their protected characteristics, why they might choose not to use a service should it be offered, and if the experiences of those choosing to take up a service differ.

Demand for all types of intermediate care outstrips supply⁽¹²⁷⁾ and the availability of hospital from home schemes is patchy.^(108, 117) This suggests one important avenue for future research. Most older people from minority ethnic groups⁽¹²⁸⁾ and lesbian, gay and bisexual people⁽¹²⁹⁾ live in London. Brighton and Nottinghamshire are estimated to have higher proportions of transgender residents.⁽²⁹⁾ At the moment, we cannot tell whether the geographical variability in home from hospital services and the greater concentration of people with some protected characteristics in certain parts of the country has greater impact for certain groups than others.

Levels of need and access to services

Age

The average age of people using intermediate care services is 81.⁽¹²⁷⁾ Generally, most participants in research about home from hospital and hospital at home are aged 70-90.^(111, 112, 123) We do not know whether older people in different age groups are any more likely to be offered, or use, home from hospital services.

Disability

Certain conditions create greater risk of admission to hospital than others and almost everybody using home from hospital or hospital at home services is likely to have at least one severe disability or long term condition, such as chronic obstructive pulmonary disease, dementia, congestive heart failure, or stroke.^(109, 111, 112, 123, 130) Often people have multiple conditions. However, we do not know whether people with lifelong disabilities who develop additional health problems in old age, such as people with a sensory impairment or a learning disability, are more or less likely to be offered hospital from home services as an alternative to remaining in hospital or moving to a care home. There has been particular criticism of intermediate care support for people with dementia.^(131, 132) It has been suggested that people with dementia are not systematically excluded from intermediate care but may be under represented amongst intermediate care service users.⁽¹²⁷⁾ Department of Health guidance highlights this as a particular priority and suggests:

Without specialist help, people with dementia are particularly likely to have a prolonged stay in hospital, due to difficulties in determining their longer term care needs, as they often recover their physical functioning more slowly. Their hospital experiences can be doubly traumatic, as the surroundings are disorientating and they are separated from familiar people and places.⁽¹³³⁾

However, we were unable to identify any published evaluations of home from hospital services for people with dementia.

Gender reassignment

There does not seem to be any evidence about transgender people's experiences of home from hospital or hospital at home services but we know that fear of transphobia is a disincentive to using mainstream health and social care services for many transgender people.^(17, 28) Whittle and colleagues⁽²⁸⁾ report that some transgender people have had negative experiences in hospital, such as being placed on the wrong ward for their gender identity or feeling reluctant to use shared bathrooms. In this context, transgender people may prefer to be at home rather than remain in hospital provided the amount and type of support is sufficient. However, they may be reluctant to use home from hospital services unless they feel sure that they will be offered support that is person-centred and that there are no risks to their confidentiality.^(17, 134) Resources exist that could help home from hospital volunteers understand the specific support needs of transgender people.^(135, 136) Ensuring that volunteers receive specific training on transgender support needs is a way of demonstrating an organisation's commitment to offering an inclusive service for transgender people. However, separate research would be needed to evaluate the impact of this training.

Race

Glasby and colleagues drew attention to the lack of information on the needs of people from minority ethnic groups in the wider hospital discharge literature⁽¹³⁷⁾ and this is reflected in the lack of research looking at home from hospital services. Henwood and Waddington⁽¹²⁰⁾ surveyed 58 home from hospital schemes provided by the British Red Cross, receiving a total of 45 responses. McLeod and colleagues evaluated five hospital aftercare social rehabilitation schemes (HACSR) run by Age Concern.⁽¹³⁸⁾ In both studies, scheme co-ordinators commented that people from black and minority ethnic groups seemed to be under represented in their service.

The Integrated Care Co-ordination Service (ICCS) in Brent received additional funding to undertake outreach work to increase the numbers of people from minority ethnic groups using the service. An evaluation⁽¹³⁹⁾ found that it had some success in encouraging Black Caribbean people to use its service but that Asian people were still under represented. Unfortunately, the evaluation did not provide any details of the sort of outreach work that had been undertaken. It did note, however, that people using the service were more likely to live alone or in social housing and that fewer Asian older people lived alone or in social housing.

Although not strictly a study of home from hospital services, research into the discharge arrangements of people with diabetes living in Birmingham helps us think about why people from black and minority ethnic groups could be under represented. This found that patients from a black and minority ethnic group (which they defined as 'South Asian', 'Afro-Caribbean' and mixed race) had shorter hospital stays than their White counterparts. They offered two possible explanations for

their findings. The first was that black and minority ethnic patients were discharged prematurely and with less support; the second that they had better support networks at home. The researchers pointed out that, because they were using anonymised data that did not record information about patients' living or discharge arrangements, they had no way of identifying whether either explanation was true.⁽¹²⁶⁾

Henwood and Waddington⁽¹²⁰⁾ also reported being told that people from minority ethnic groups had better family support. In reality, the issue is much more complicated, with factors such as migration history, gender, health, expectations about care and support, and household living arrangements all contributing to the amount of support people receive from family members and friends.⁽¹⁴⁰⁻¹⁴²⁾

Research looking at the hospital discharge experiences of family carers also suggests that stereotyped ideas about access to support can lead to some carers from black and minority ethnic groups receiving less support.^(143, 144) For example, Carers UK estimates that carers from black and minority ethnic groups are more likely to be providing care for 20-49 hours a week than their White counterparts.⁽¹⁴⁵⁾ It has also found that only a minority of carers, whatever their ethnicity, feel they have been consulted about hospital discharge in 'plenty of time' and that they have been given a choice about caring for the person who is being discharged. However, 29 per cent of Black and Asian carers responding to the *State of Caring 2011* thought they were consulted in plenty of time compared with 35 per cent of White carers while 71 per cent of Black and Asian carers felt they had been given 'no choice' about caring for the person being discharged, compared with 63 per cent of White respondents.

Petch's review of intermediate care concluded that 'many of the generic failings around hospital discharge are magnified within black and minority ethnic communities'. The key problems she identified were stereotyped assumptions about the availability of support for people from minority ethnic groups which meant that professionals made assumptions about what family members and friends would be doing and a failure to find more effective ways of publicising services, for instance through places of worship. This meant that people from minority ethnic groups were less likely to know about alternatives to hospital care.⁽¹⁴⁶⁾

Within this negative picture, some positive examples can be found. Henwood and Waddington noted that some Red Cross home from hospital services had been successful in attracting people from minority ethnic groups to use the service. One service manager noted that:

'Getting clients and volunteers from different ethnic backgrounds is helped if this is replicated in the co-ordinator team.' She also recounted an instance where one of her schemes had put the name and contact details of one of their volunteers from an ethnic minority background on publicity material. This resulted in a more varied response to the advert. However, some co-ordinators believed that targeting these different communities was not helped

by standard British Red Cross literature and publicity material that tends to be 'very white middle class.'⁽¹²⁰⁾

Religion and belief

No information on the religious and belief systems of people using hospital at home services was identified. Although many hospitals and care providers do provide guides to the belief systems of the main world religions for their staff, we do not know how well these prepare staff to support people who may have a different belief system (including no religious belief) to themselves.

Sex

Women predominate among those using hospital at home schemes,^(109, 147) with one recent audit suggesting that almost two thirds of those using intermediate care services were women.⁽¹²⁷⁾ This gender difference may be partly attributable to the fact that women are more likely to live on their own and not to have a co-resident carer.

Sexual orientation

Two of the five hospital aftercare social rehabilitation schemes (HACSR) included in McLeod and colleagues' study were reported to be investigating how they could provide better support to lesbian, gay and bisexual people but no more information on how they were proposing to do this was provided.⁽¹³⁸⁾ Although there does not appear to have been any research into lesbian, gay and bisexual people's experience of home from hospital services, there are two factors which highlight how important it is for home from hospital services to develop inclusive approaches. 'Significant numbers' (the exact proportion is not recorded) of disabled lesbian, gay and bisexual people report that they have not accessed the health, mental health and social care services in the last year that they felt they needed. About a third will feel reluctant about being 'out' to health, social care or housing staff.⁽²⁰⁾ Other research has suggested that some lesbian, gay and bisexual people feel the need to 'de-gay' their home environment by removing books, photographs and pictures because they fear homophobic reactions from care staff.⁽¹⁹⁾ These findings suggest that some lesbian, gay and bisexual people might feel reluctant to access home from hospital services.

User experiences and outcomes

Within the very small literature on home from hospital services, the lack of information about the demographic characteristics of people using hospital at home services means that it is impossible to explore whether outcomes for users vary according to their protected characteristics. The wider hospital at home literature suggests a mixed picture:

For people discharged from hospital to a hospital at home scheme, compared with acute hospital in patient care at follow up:

- Hospital at home may reduce the risk that older people and/or people who have had a stroke need to move into a care home
- There is insufficient evidence to show whether people using hospital at home services are more likely to need to be re-admitted to hospital or to die
- There is insufficient evidence to show whether hospital at home services improve people's independence or quality of life
- Hospital at home services do not seem to be more cost effective
- Most carers do not feel that they are expected to do too much if the person for whom they care uses a hospital at home service
- People using hospital at home services tend to be more satisfied than those receiving in patient care⁽¹¹²⁾

Satisfaction with services

High levels of satisfaction reported by people using hospital at home services^(109, 111, 112, 117, 123) compared with in-patient care. Most of these studies are based on ratings of satisfaction, rather than detailing why participants had made their choices. However, Wilson⁽¹⁰⁹⁾ used both survey and interview information from people using a hospital at home service in Leicester. Most of the participants were women in their 80s but no further details about them were reported. Participants reported:

- Hospital at home staff were thought to provide a more personalised service. They were 'friendly' and less 'rushed' than staff in hospital.
- People liked being in their own home. Couples were pleased to be able to be together.
- The main disadvantage of hospital at home was feeling more apprehensive at night in case they needed care.

The limited information about the use of hospital at home services by people from minority ethnic groups^(126, 138, 139) and the absence of any information at all about lesbian, gay, bisexual, and transgender people suggests that knowing more about those aspects of hospital at home they value and those they would like to change, could form the basis for providing a more responsive service.

Supporting carers

Although it does appear that supporting a person who has care provided through hospital at home does not generally place undue pressures on carers,^(109, 111, 112, 123, 147) it is important to realise that this may not be true of *all* carers. Carers who are already providing considerable amounts of care, such as carers from black and minority groups,^(125, 145) may feel differently about hospital at home services. Although none of the studies included in this review appear to have recorded carers'

sexual orientation, we know that lesbian, gay and bisexual carers often feel that their needs are poorly met^(19, 22) so this is another factor potentially influencing how experiences of hospital at home may differ according to different protected characteristics .

Recruiting volunteers

Recruiting volunteers with similar backgrounds and experiences to potential service users is thought to help achieve greater diversity among those using the service. A study of volunteers recruited to an Age Concern Calderdale intermediate care service suggested that hospital at home volunteers may differ from other volunteers. For example, the time limited nature of contact was an attraction for some when compared with the lengthy commitment that they might be expected to make if they became a befriender. They were also more likely to have volunteered for at least five years and a high proportion (11/13 were retired nurses). Most of these volunteers had been recruited through traditional means, such as posters in libraries and hospitals being the main source of information or by recommendation by friends or others.⁽¹¹⁸⁾ The message from this study is that volunteer recruitment through networks of health professionals, such as RCN Out, may be an effective way of achieving greater diversity in the volunteer home from hospital workforce.

User involvement

Existing research does not report on the extent to which older people have been involved in developing hospital at home services. This means that ideas about how to promote user involvement have to be very general and draw on the wider hospital discharge literature. Manthorpe and Cornes report that user involvement in hospital discharge tends to be restricted to asking service users for help in preparing information leaflets. They give the example of a reading group which commented on material and made suggestions for amendments. However, service users still complained about the quality of information that was provided. This suggests that service users should not be expected to undertake this role without training.⁽¹¹⁹⁾ Examples of leaflets developed by other services, such as Opening Doors, could be used to develop inclusive publicity materials which show users with different protected characteristics. Carers UK recommend that organisations seeking to improve their uptake among people from minority ethnic groups should not rely on translated leaflets alone but should work with community groups and use the language skills of their staff to ensure that people who are not fluent in English are provided with information.⁽¹⁴⁵⁾

Reed and colleagues used a technique called Appreciative Inquiry (AI) to help professionals, researchers, and older people come together to talk about how hospital discharge could be improved over a series of three workshops. At the third workshop, participants were asked to consider their 'provocative propositions' - statements of aspirations challenging the way that things currently happen in the system and to turn them into an action plan. Participants felt that the AI principle of 'appreciating what is good' about the current service discouraged a blame culture in

services while the experience of working together meant that participants achieved a greater understanding of each other's views. However, the extent to which changes were possible was still dependent upon the commitment made by senior managers to achieving this.⁽¹⁴⁸⁾

Key findings

- Hospital at home services seem to have expanded with little attention to the equality aspects of the way that services are provided. There are some indications that people from minority ethnic groups are under represented among people using hospital at home services but we do not know if this applies similarly to other groups.
- Hospital at home schemes could consult with other local services, such as local outreach or wellbeing services about ways of indicating that their service is inclusive.
- Local lesbian, gay, bisexual and transgender organisations could provide advice on training for volunteers in diversity issues to ensure that personal care is delivered sensitively.
- Much of the research evidence about hospital at home schemes consists of clinical trials undertaken some time ago and small scale studies^(110, 137) Because they contain so little demographic information about participants, we cannot assume that services are equally effective for people with similar health needs but different protected characteristics.
- Although research does not suggest that hospital at home services place increased burdens on carers, we know that carers of people from minority ethnic groups and lesbian, gay and bisexual carers seem to have worse experiences of services. Hospital at home schemes need to consider how well they are meeting the needs of different carers in terms of their protected characteristics.

Handyperson schemes

Introduction and background

'Handy-person services are the gods of the older persons' world', Baroness Barker⁽¹⁴⁹⁾

There is much agreement with the sentiments of Baroness Barker expressed above. However, reaching an agreed definition of a handy person scheme is not easy and many schemes are so greatly tied to other services and change so frequently that the evidence base is fragmentary. While there is near universal agreement that older people value the help of such schemes, one key question remains, as posed by Adams:⁽¹⁵⁰⁾ *'...if handyperson services are so important why aren't they everywhere?'* She conjectured that a very simple answer to why handyperson service schemes are not available everywhere and are limited in scope or coverage in many areas is because they *'fall between the interests of different government departments, straddling housing, health and social care interests but no-one's core responsibility'*. In this context of profoundly unequal access to handyperson schemes across the UK, this review explores other strands of equalities and social exclusion.

Description of the service

Handyperson schemes (previously handyman and sometimes handyvan schemes) generally undertake small repairs for older people but may assist with fire and personal safety measures, insulation installation or upgrading and minor adaptations. The general aims of such schemes are to enable eligible older people to live independently for as long as possible and in greater comfort and security. Other public policy aims are to reduce the likelihood of a move to long-term care, and to reduce demand on NHS services by diminishing the risk of falls. These may be included under the heading of prevention. For many years there has also been interest in handyperson schemes and housing adaptations as a way to accelerate safer hospital discharge.⁽¹⁵¹⁾ There are further sub-themes around other aims; such as reducing the risks of fire (notably the fitting of fire alarms), victimisation (improving home security by the installation of spy holes and door chains), and reducing isolation/depression by improving living environments. The purpose of such schemes is often described as relating to three objectives, the maintenance, adaptation and improvement of a home, but support for major repairs or modifications is often part of the work of a larger body, a Home Improvement Agency or a Staying Put scheme.⁽¹⁵²⁾ The definition of a small repair is locally interpreted.

Handyperson schemes have always varied locally, with a further complication that they may be situated in the voluntary sector, within social housing providers or within local authorities. Recent and unprecedented central government investment in them has occurred in the past five years, with a rise in explicit expectations that schemes should be accessible in all parts of the country. In 2009 the Department for Communities and Local Government (DCLG) funded all English local authorities to

develop handypersons services where they did not exist and to build capacity in existing services:

From next year new rapid repairs and adaptations services will be introduced to support more handypersons schemes across the country. New funding will enable an additional 125,000 older people each year to get the repairs and minor adaptations necessary to help them carry on living in their own homes. This will be linked to the development of the Home Improvement Agency (HIA) sector and our 'Future HIA project.'⁽¹⁵³⁾

Funding of £33m was awarded, mostly (Part A funding) enabling local authorities to start up or expand handyperson services (although the term rapid repairs and adaptations were used, which may signify that the emphasis is on certain priorities such as accelerating hospital discharge). Under Part B, smaller sums (£50-200k) were awarded to 19 local authorities to enhance their housing support services for older people. Later, in October 2010, the Coalition Government announced continued funding of £51m over 2011/15 for handypersons services. From 2011, this funding has been rolled into the Formula Grant paid to local authorities. Individual local authorities are able to choose how much money to provide their local handyperson service. Local variations may therefore remain and have similarly been noted in Scotland:⁽¹⁵⁴⁾

Currently, access to Care and Repair services is unequal across the country. The level of investment in Care and Repair varies substantially and some areas are not currently served by Care and Repair (p1).

In contrast, Care & Repair services are provided in all 22 counties of Wales.⁽¹⁵⁵⁾

This brief history helps explain why handyperson schemes are subject to fairly frequent changes, particularly in England. Some of their work may have been funded by one off grants from central government or pilot projects; others from different strands of local authority funding or voluntary sector resources. This means that comparing, for example, an enhanced handyperson scheme, with extra money from whatever source, may not be fair on another scheme whose resources are limited. One example of this fluctuation in activity is described by Evans⁽¹⁵⁶⁾ where a handyperson scheme in Devon was able to draw on new money to expand its services to carers (the Carers' Health & Wellbeing Checks pilot) and to offer more activity around promoting home safety. The future of these activities was not guaranteed once the pilots ended. Likewise, some of the pilot programmes under the Department of Health Partnerships for Older People Projects (POPPs) funding initiative enabled handyperson activity to expand locally – a development that was generally seen to be highly successful by politicians:

We [the All Party Group] heard that the evaluation of Partnerships for Older People Projects (POPPs) found that low intensity practical support services, such as handy-person schemes, had by far the highest impact on health-related quality of life for all the service types examined.⁽¹⁴⁹⁾

One problem with such data is that primary prevention in the Partnerships for Older People Projects (POPPs), featured a range of 'upstream' community orientated interventions, generally being designed to help older people sustain independent living within their own homes and to improve their general well-being. Many of these services were 'universal' in being aimed at all older people and their carers within the POPP sites. Examples of such projects included: gardening/handy person/befriending schemes, crime prevention and awareness services, provision of internet facilities and learning opportunities, development of leisure opportunities, access to libraries and teleclubs, development of teleshopping, provision of housing and welfare benefit advice, and sign-posting or referral services. As can be seen from the case study below, the handy person scheme blended with other activities.

Case study: POPP national evaluation: Gardening, handy person and care and repair schemes (Wigan)

The project was provided by three voluntary organisations and was linked with existing schemes within Wigan. Referrals to the service could be made by older people themselves as well as project staff working within other POPP projects. Work that did not require the skills of professional craftsmen were undertaken for older people, within their homes and gardens, at reasonable cost rates. Such work included minor housing repairs, fitting hand and grab rails, and cutting grass and bushes and improving access to the garden.⁽¹⁵⁷⁾

As Smeaton and Vegeris⁽¹⁵⁸⁾ have suggested, low-level services are central to the preventative approach to health and are highly valued by older beneficiaries. This is a much-vaunted theme, and handy person schemes have been identified as typifying prevention and its cost-effectiveness.^(159, 160) The most recent and comprehensive evidence comes from the major evaluation of handy person schemes.^(161, 162) The Handy person Financial Benefits Toolkit was also developed as part of this evaluation and sets out how to use available evidence on the aims, objectives, outcomes and benefits of handy person services and similar interventions. It can be used to help put together a case for future funding of handy person services locally. The authors noted that this approach to estimating the benefits of social policy interventions has previously been used, such as the Supporting People Financial Benefits Model. Despite this major evaluation, there is little data on user characteristics and so the impact on equalities of handy person schemes remains to be further researched.

Gaps in the research information

One issue arising from research on handy person schemes is that by their nature they are intended to be practical and to be easy to access. Some information is required from potential users but this generally relates to the scheme's priorities and their focus on its activities. For example, data on housing tenure is generally collected, but not much on disability. Some personal data are collected but areas such as sexuality are not covered. There does not appear to be any study investigating what minimal information might be obtained that would be useful and acceptable to users. Furthermore, there are little data about those staff and volunteers who work with handy person schemes, offering information about their own characteristics and

their own views about access to schemes and their acceptability. As reported below, while there is some small discussion on race and ethnicity in respect of handyperson schemes, there is little research on how and by whom people from different cultures may prefer their homes to be modified, improved or repaired, although it is clear that schemes may have developed strategies from their own experiences which are not available in the form of published research.

Interestingly, we do not know anything about people who do not meet the different criteria for handyperson schemes and what happens to the matter for which they were seeking assistance. Are they happy with this, or do they regard it as 'bad luck' or injustice? Are they sign-posted to other agencies or commercial sectors? Is this satisfactory?

We do not know much about alternatives to handyperson schemes, such as voluntary sector listings of vetted or 'reliable' tradespeople. For the future, there may be a need for research on the impact of personal budgets for social care and the ways that older people may wish to use these for items or services that fall under handyperson schemes or choose to pay informally for such assistance. Similarly, future research may seek to identify if schemes seeking to promote social capital, for example, through time banks, are able to exchange services such as minor repairs. In all these developments, attention to equalities issues will be needed. Interestingly, currently there are no UK studies of the impact of timebanks on older people on Timebanking UK website but some of the examples given do involve activities such as gardening.⁽¹⁶³⁾

Levels of need and access to services

Brannelly and colleagues,⁽¹⁶⁴⁾ drawing on their evaluation of a handyperson scheme in Birmingham,⁽¹⁶⁵⁾ considered that even though many older people appeared to have a negative view of asking for help they were happier accessing a service that enabled them to remain in their own homes: '... [accessing the] handyperson service is not necessarily seen as 'weakness' or as the 'first step on the road to dependence' but rather as a strategy to maintain independence'. Their study found that the majority of handyperson service users they interviewed maintained a steadfast refusal to contact social care services for any other types of support.

Access problems with handyperson schemes mainly appear to relate to their patchy geographical availability. As Scott and colleagues⁽¹⁵⁴⁾ reported in relation to Scotland, many Care and Repair agencies cannot meet the potential demand for their services. Strategies employed, explicitly or otherwise, include minimal advertising or lack of self-promotion. Generally the study found that Scottish schemes did not always have transparent mechanisms to explain how they prioritised access to services. 'While many of the schemes consulted for this review provided explanations of their criteria on their website, which suggests that the situation may have improved, issues of accountability and equality will still arise in areas where practice may not have improved.'

Age

The English House Conditions Survey⁽¹⁶⁶⁾ demonstrated the correlation between poor housing conditions and older age, with people over 75 years in private sector housing disproportionately occupying non-decent housing. Care and Repair Cymru⁽¹⁵⁵⁾ reported that of the 50,000 older people it helped each year, 60 percent were over the age of 75 (30,000 older people), the majority also being in a high social priority category. However, it may not just be the age of the disabled or older user that is significant as there are increasing numbers of older carers who may find repairs beyond them. The Princess Royal Trust for Carers⁽¹⁶⁷⁾ (now Carers Trust) has pointed to the problems many older carers find in getting small repairs done and noted that this may diminish their ability to carry on caring.

Disability

Some disabilities impact upon people's ability to manage their home and garden. These include hearing and sight loss, conditions that affect mobility, depression, and dementia. However, studies of handyperson schemes have not collected information on users' health systematically, so we know very little about the severity and extent of disability among older people using such schemes. One challenge is to find easy ways of obtaining this information so that claims about prevention can be investigated or to enable data sharing between services subject to permissions. Currently, while there is great emphasis on the potential of handyperson schemes to facilitate hospital discharge by getting repairs done promptly or minor adaptations accomplished,⁽¹⁵⁵⁾ data on disability are not always recorded. Indeed, because some handyperson schemes focus on hospital discharge support, users may have health problems that are temporary or fluctuating. The Healthy Homes Rapid Response Care and Repair Service, based in Sefton Merseyside and hosted by Anchor Staying, for example, featured in the evaluation of Help the Aged funded projects providing assistance to intermediate care users who were expected to recover from illness, to some extent.⁽¹⁶⁸⁾ Disability therefore may have been temporary and users were not asked for such information specifically. Other data potentially able to capture details of disability is receipt of disability benefits, although this only tends to capture information about severe long standing disability and so may under represent the number of people with a disability needing or using the service.

The following sections provide two case studies about two types of disability derived from research and service development around users with specific disabilities. Easterbrook⁽¹⁶⁹⁾ has pointed out that more attention needs to be paid to the housing- and life-skills related needs of older learning disabled owner occupiers. These may be people in their 50s and 60s wishing to continue living in the family home following the death of a parent(s). They could also include households where the boundaries between the cared for person with a learning disability and his or her parent carer(s) are becoming increasingly blurred. She suggested that such older people might be receiving support already if they lived in social housing as necessary repairs and maintenance would be done and contact sustained, but that older owner occupiers might not have similar levels of contact with helping agencies, indeed they might be largely unknown to local services. As a result, minor repairs

could escalate and other visible symptoms of neglect to the house and garden might attract the wrong kind of attention (for example, from criminals). She has described the potential for housing support to break the cycle of crises and to prioritise prevention among a particular group that may slip through various services such as social care and the NHS:

Practice example: support for people with a learning disability

Coventry Care & Repair's starting point was that although short-term crisis intervention was of some use, it was not tackling the root causes of problems. Through this initiative it is demonstrating the cost effectiveness of a long term, lower level, and preventative intervention approach. Through the provision of crisis support, Coventry C&R is helping vulnerable adults sustain their independence and well-being. By making sure that individuals have access to a range of services when needed, people are being enabled to live independently in their own homes, with the added security of knowing that there is help available to support them through any future difficult times as these first arise.⁽¹⁶⁹⁾

Practice example: support for people with dementia

Specific work with older people with dementia is a further example of the way in which handyperson schemes can go beyond traditional one off activity, such as a repair. The example below is drawn from two reports of one handyperson scheme whose services had been enhanced by extra, one-off funding:

Handypersons from the Housing Improvement Agency in Wirral were given additional training on how to work with people with dementia by the Alzheimer's Society. The handyperson will do work in the garden or support people who want to do their own garden – with different abilities - but need some help. A charge is made to service users. Many service users have opted to have a regular gardening service, because, apart from helping people keep their gardens tidy and secure; it provides a regular visit from a known and trusted handyperson and sometimes a break for carers.^(152, 161)

Gender reassignment

The discrimination that many transgendered people have experienced throughout their lives can mean that they may be reluctant to access services not specifically for transgender people, especially if their previous experiences of health and social care services have been negative. Transgendered people live in the most vulnerable of housing provision. Whittle and colleagues⁽²⁸⁾ found that a quarter of the trans people responding to their survey were living in private rented accommodation, which is twice the proportion for the UK general population. The researchers noted that private sector housing is often of poorer quality and has less security of tenure than other forms of housing. A total of 873 participants completed an online survey for this study, making it the largest survey of trans people in the UK although only about 10 percent of respondents were aged over 60 years. There does not seem to be any evidence from the literature about transgender people's experiences of handyperson schemes or about the ways in which such schemes promote themselves as accessible and accepting to transgender people.

Race

It is widely recognised that there will be a significant growth in the numbers of black and minority ethnic older people over the next 10-15 years in the UK. Adams⁽¹⁵⁰⁾ observed that black and minority ethnic groups are over-represented in non-decent housing and that there is above average level of owner occupation amongst certain ethnic groups – particularly amongst Indian origin households. A recent Social Care TV programme has provided some further illustrations of the links in particular between poor housing and mental health problems among black and minority ethnic groups.⁽¹⁷⁰⁾ Since black and minority ethnic groups are also more likely to be living in low income households and in disadvantaged neighbourhoods not surprisingly many have poor health overall. There is clearly potential for handyperson schemes to contribute to improvements:

Targeted improvement to tackle these issues is thus important and handyperson services can play an important role in delivery of acceptable, culturally appropriate practical support services.⁽¹⁵⁰⁾

Research into access to housing advice services by Shelter⁽¹⁷¹⁾ has also found that people from black and minority ethnic groups are generally more likely to ask friends or family or approach a community group for advice than to contact the council or a specialist advice provider. If advocates or ‘cultural mediators’ are not available, it can be very difficult for many older people to make informed decisions about their housing and care options.⁽¹⁷²⁾ Manthorpe and colleagues⁽¹⁷³⁾ recommended greater publicity for handyperson schemes in light of views expressed that not all black and minority ethnic communities might know about them, especially in areas where community groups might not have a focus on older people or where communities are very dispersed.

One exception to the general lack of engagement with black and minority ethnic communities about the development of a handyperson scheme was a study undertaken in Newcastle.⁽¹⁷⁴⁾ The views of approximately 300 local older people, including over 200 people from black and minority ethnic groups, were obtained through contact with other local researchers who agreed to consult people in their networks about a proposed handyperson scheme during their own research projects. Eight link workers from the local black and minority ethnic communities were recruited and trained to carry out focus groups across the City on housing research issues. While the aim of the link workers’ study was to explore the long-term aspirations of black and minority ethnic community members across all age groups with regard to housing, the link workers agreed to use the focus groups as an opportunity to explain about the proposed handyperson scheme and find out how participants felt about it. The link worker team provided a summary of the findings from focus groups. Such methods have the advantage of not burdening communities with consultation requests, which can be burdensome among those ethnic groups who feel over-researched.⁽¹⁷⁵⁾

In respect of expositing schemes, there is a variety of ways of establishing if they are meeting black and minority ethnic older people’s needs although the literature does

not show examples of this being used. HOPDEV (the Housing and Older People Development Group) (2006), for example, developed the *At Home: Audit Tool for Housing and Other Related Services for Older Minority Ethnic People*.

We have little evidence about the possibility of cultural barriers around housing improvements, modifications, or repairs. Catton and Gauntly,⁽¹⁷⁶⁾ from wide ranging discussions with older people in Bradford, many of whom were from Pakistani backgrounds, concluded that there was a strong sense among this community that older people's individual preferences were not being acknowledged by professionals because of a lack of understanding and sensitivity to the influence of lifetime experiences and cultural background. Current handyman schemes may have much to add to this debate from their own substantial experiences.

Practice example: support for people from black and minority ethnic groups

Care & Repair Leeds maintains awareness of, and responds to, the diverse needs of its potential client groups. The agency reviewed gaps in service provision for its local Asian and Black communities, and undertook projects to meet the needs of potential clients from these communities. Care & Repair (Leeds) employs two caseworkers who speak a range of Asian languages as the majority of the black and minority ethnic community is Asian. Clients are offered literature in a range of minority languages as well as English. This not only helps overcome language barriers, but also cultural barriers which may prevent effective service provision.⁽¹⁷⁷⁾

Religion and belief

Blood and Bamford⁽¹⁷⁸⁾ have recently interviewed researchers and other experts to find out more about the evidence base for diversity issues among older people with high support needs. They note that services for people with high support needs, mainly in social care, might help meet religious needs by providing food prepared in a certain way; celebrating religious festivals and holy days; providing space to pray or worship; arranging transport to places of worship; making appropriate funeral arrangements (for those who do not have a religious belief as well as those who do) and so on, organising access to pastoral care, books, music and artefacts; or considering aspects of physical design (for example, orthodox Jews do not permit the active use of electricity on the Sabbath, so lifts, lighting and doors need to run automatically). Little is available from the literature about ways in which handyman schemes are able to respond to users' religious needs but there may be examples of this to be gleaned from practice.

Sex

Most studies have observed that more women than men use handyman services. Crouched and colleagues, in their national evaluation of handyman schemes observed:

Handyman service users are predominantly older women with health problems or disabilities, living alone on low or modest incomes in older

properties. However a significant number of service users live with and care for their spouse or partner.⁽¹⁶¹⁾

They found that women made up 75 per cent of survey respondents.⁽¹⁶¹⁾ The actual proportions varies across schemes. Eighty five per cent of those using the Greater Belfast Handy Van were women.⁽¹⁷⁹⁾

However, it is important to avoid stereotypes which may portray women as unable to learn new skills in later life. Bennett and colleagues⁽¹⁸⁰⁾ interviewed 21 widows at home from urban, north western England. When asked about traditional male-orientated tasks, both pre- and post-bereavement, the study revealed that some women were able to take on tasks that had previously been undertaken by their partners and enjoyed the independence this gave them. The literature does not contain examples of whether any handyperson skills are linked to projects that offer women the opportunity to develop household repair skills or how to remain able to tend their gardens despite possible frailty or disability.

Men using handyperson schemes comprise about 15-25 percent of users. In one of the local evaluations of a POPP schemes, an example was presented of an older man receiving a series of improvements to his home, such as central heating, loft insulation, and cavity wall insulation - as well as some minor repairs from the handyperson scheme:

... through [Partnership for Older People] POPP Mr A had gained access to a handyperson scheme, which had managed to secure his front door as well as the front step, which had been unsteady and had caused him to fall. All of these improvements to Mr A's quality of life had served to give him an enhanced sense of confidence.⁽¹⁸¹⁾

The complex chain of referral and support for this man was apparently from a local Age Concern, the catalyst, to an outreach worker under the POPP scheme, to the housing and insulation schemes (accessing a grant), successfully claiming benefits, accessing specialist meal on wheels, and then referral to the handyperson scheme. Interestingly, this man was not apparently extremely isolated as he had a nearby family with whom he was in frequent contact and he was a car driver. Such accounts draw attention to the interrelation of services at local levels and also the importance of psychological support in changing long-standing habits and thinking. While Mr A's daughter knew of the existence of handyperson schemes, the evaluation noted that she had initially been told by social services that there were none in their area. Other schemes might not have provided support to Mr A. Durie's evaluation of a scheme in Moray noted that it was restricted to people who did not have any family members living nearby.⁽¹⁸²⁾

Sexual orientation

We did not identify any examples where schemes were reported to have monitored sexual orientation. Research by Stonewall has found that older lesbian, gay and bisexual people are more likely to live on their own and are less likely to have

children than their heterosexual counterparts.⁽²⁰⁾ This suggests that some older lesbian, gay and bisexual people may have an unmet need for handyman services. However, this research also found many would not feel comfortable being 'out' to health, housing and social care organisations so it is important for handyman services to be able to demonstrate inclusive policies.

User experiences and outcomes

User views

There is near unanimous appreciation of handyman schemes. All evaluations point to the positive views of older people who have received their services, both in terms of the quality of the work and in terms of the service – such as the politeness of the staff or volunteers. This stands in great contrast, of course, to the chorus of criticisms of other services for older people and allegations that staff do not respect the older people's dignity nor their wish to be independent. A telephone survey by an independent market research company⁽¹⁸³⁾ was conducted as part of the most extensive and detailed evaluation of handyman services.⁽¹⁶¹⁾ This found that the overwhelming majority of the 173 participants were satisfied with different aspects of the service they received. Satisfaction levels did not vary between those who paid for the service and those who did not. Further examples include the evaluation of the HandyVan service in Greater Belfast which showed 95 per cent client satisfaction with the application process, and with the workmanship of the fitter (this scheme undertook much home safety and security work).⁽¹⁷⁹⁾ Case studies of providers have revealed that they generally use feedback from clients/users to fine tune their service.⁽¹⁶²⁾ However the Belfast scheme is illustrative of the ways in which high user satisfaction may not be enough to sustain a scheme – it closed in 2010 on the expiration of Lottery funding.⁽¹⁸⁴⁾

Other views from older people are presented under the banner 'that little bit of help' which is developed from research with and by older people about low level support and prevention.^(185, 186) This research has provided a valuable background to the more instrumental policy debates concluding that prevention is a cost-saving measure.

User involvement

Although commissioners may increasingly expect schemes to consult with older people using their service,⁽¹⁸⁷⁾ it is not clear how frequently this takes place currently – older people's voices seem generally to be confined to that of an appreciative beneficiary.

In its response to the review of Care and Repair services,⁽¹⁵⁴⁾ the Scottish Government (2009) made the following observations:

We believe that all projects should be supported and advised by independent members of the community (including service users where possible) to ensure that services are tailored to local needs. For projects without their own dedicated management board, and which have no formal way of canvassing

professional advice or views of service users, we recommend the (re-)creation of an advisory group. For those projects which have their own management board, we recommend that the advisory group role is best delivered as a function of the (legally distinct) independent/charitable board. This should serve to reduce duplication but projects will want to consider how this dual role impacts on the make-up of their board.⁽¹⁸⁸⁾

In her report on the social impact and value of a volunteer handyman scheme in north Scotland, Durie (2009) noted that the members of the Board running the scheme were involved in the umbrella organisation because they wished to see a better future for people their own age, specifically a more secure set of supports in retirement. She commented that this meant that Board members were therefore 'emotionally connected' with the issues of the handyman scheme and contributed to its social return on investment. There may be more opportunities to publicise the involvement of older people from all backgrounds in such schemes, especially since many older people value such schemes for their trustworthiness. This comment suggests that some older people may wish to take on more active direction of handyman schemes and the potential for older people to shape such services.

Key findings

- Very little research into handyman schemes has paid attention to equality issues so we know very little about the need for, and access to, handyman services in terms of people's protected characteristics.
- Most handyman services are highly localised; all need to ensure that their service is an inclusive one in which all older people, whatever their background, feel welcome.
- Providing equalities training and promoting accessibility, especially if services choose to enhance what they offer, for example, by offering regular gardening or de-cluttering services, may help ensure that services maintain their high reputations.

More systematic attention to user views and involving older people from a variety of backgrounds and communities in designing and delivering services may help ensure that some groups of potential users are not indirectly discouraged from using the service.

Befriending

Introduction and background

Befriending has been defined as:

A relationship between two or more individuals which is initiated, supported, and monitored by an agency that has defined one or more parties as likely to benefit. Ideally the relationship is non-judgemental, mutual, purposeful, and there is a commitment over time.⁽¹⁸⁹⁾

A key aim of befriending is to reduce isolation and loneliness, often following bereavement or illness.^(190, 191) We tend to use the words 'isolation' and 'loneliness' interchangeably but they are not the same. Isolation refers to separation from social or familial contact, community involvement, or access to services. Loneliness, by contrast, can be understood as an individual's personal, subjective sense of feeling that these things are wanted or needed. While people can be isolated without feeling lonely and feel lonely without being isolated,⁽¹⁹²⁾ in practice, people using befriending services tend to experience both loneliness and isolation.^(190, 191, 193-199)

While the emphasis is on 'companionship and conversation',⁽²⁰⁰⁾ the precise nature of the support provided is negotiated between the person being befriended and the volunteer who acts as the befriender. It can also change as relationships between the person using the service and the befriender develop.^(194, 200) There is currently renewed interest in befriending schemes as offering a comparatively low cost preventative service to a wide range of people.^(197, 201-203)

Description of the service

A study looking at the different ways in which befriending services could be organised concluded that befriending could help people participate in their community by:

- using local services and facilities;
- creating a new social link;
- developing wider social networks;
- meeting others through clubs and groups;
- meeting people with similar needs/experiences and gaining support; and
- changing social attitudes so that people become accepted and valued as members of the community.⁽¹⁸⁹⁾

The first three activities were the most frequent.⁽¹⁸⁹⁾ The terms befriending and mentoring are often used interchangeably and both forms of support include social elements to the relationship. The main difference between befriending and mentoring is the emphasis placed on goals. Although most befriending schemes ultimately aim to promote independence and recovery or re-ablement,⁽²⁰¹⁾

mentoring tends to be a more goal-oriented, time-limited process that supports learning and development, whereas befriending tends to develop more informal and supportive social relationships, often over a longer – usually open ended - period of time.^(191, 204, 205) However, emerging evidence from within the sector suggests that some funders are now choosing to commission time-limited befriending services. It is not clear whether this decision is based on cost considerations or if they have any empirical evidence that this is a more cost effective model.

The three main models of befriending are:

- individual;
- group; and
- telephone befriending.

Traditionally, the most common model of befriending is individual whereby a volunteer visits a person in his or her home.⁽¹⁹⁴⁾ The person can then choose to stay in or go out with the volunteer's assistance. Group befriending provides opportunities for individuals facing similar problems to exchange information and discuss worries with others who have a shared understanding and can offer solutions based on their own experiences.⁽²⁰¹⁾ It can also involve taking part in shared social or leisure activities, such as playing sport. Telephone befriending (sometimes called telebefriending)⁽¹⁹⁸⁾ can be delivered on an individual⁽¹⁹⁰⁾ or group⁽²⁰⁶⁾ basis. Compared with face to face befriending, it is thought to offer a lower level, lower cost, and lower risk intervention, with befrienders offering support from their home or workplace.^(190, 193) Set against this, calls may be shorter and with more of a focus on 'checking up' than on developing a meaningful relationship.⁽¹⁹¹⁾ On the whole, individual and telephone befriending seem to be the most common ways of befriending older people but we do not know whether this is what they themselves would prefer. While the internet and other social media have also been proposed as ways of offering befriending support,⁽²⁰⁷⁾ we did not identify any UK-based empirical research in which older people were offered this type of befriending. Whether delivered face to face or by telephone, most befriending services for older people focus on those living alone.^(199, 208, 209) However, there is increasing awareness of the need to support people living in care homes^(191, 210, 211) or sheltered and extra care housing,⁽¹⁹¹⁾ many of whom are not in regular contact with family members or friends.⁽¹⁹⁶⁾

With the exception of services for people with a specific condition or disability, very few befriending services specialise in providing services to a group of people based on another protected characteristic. A search of the Mentoring and Befriending Foundation⁽²¹²⁾ database showed that, of the 1000 befriending schemes accredited as having met their Approved Provider Standard (APS), only 39 provided a service specifically to people from black and minority ethnic groups while just five provided a service specifically for lesbian, gay, bisexual and transgender people. This means that a key challenge for the overwhelming majority of befriending services is ensure that their generic services are fully inclusive.

Not everybody likes the word 'befriending' because it can come across as patronising and implying that the relationship is one sided.^(193, 200) Suggested alternatives include 'friendship circle',⁽¹⁹³⁾ 'friendly visiting' or 'peer support'.⁽²⁰⁰⁾ However, while relationships between befrienders and those who are befriended can eventually evolve into friendship,⁽¹⁹⁴⁾ using the word 'friendship' carries the risk that some of those who are befriended may see befriending as the same as friendship when this may be neither desirable nor possible.⁽²¹³⁾

Gaps in the research information

As discussed in the chapter on challenges for the review, we have very limited research-based information on the needs of different groups of older people based on their protected characteristics. There are more than 500 different befriending projects for older people in the UK.⁽²⁰⁴⁾ Their sheer variety in terms of size and purpose makes it difficult to generalise. Schemes may have a good record in meeting the needs of different groups of older people but if they are provided by small organisations with limited resources for evaluation, their successes are not always written up and published information about their effectiveness is hard to find. Even where published research exists, participants' demographic details are not always provided^(190, 193, 206, 211) so we do not know whether certain groups are more likely to access the service than others or if different users have different experiences.

Another problem is that researchers may not distinguish between participants on the basis of age. Studies of people with disabilities – for example, severe depression impacting upon participants' abilities to carry out their day-to-day lives,⁽²¹⁴⁾ learning disability⁽²¹⁵⁻²¹⁷⁾ and schizophrenia⁽²¹⁸⁾ clearly include some older participants but do not report whether older and younger participants' experiences differed. In other instances, the number of participants with certain protected characteristics is too small to enable separate analysis. Even in the largest published study of befriending undertaken so far – a randomised control trial (RCT) of a befriending scheme for carers of people with dementia in Norfolk and Suffolk - 99 per cent of the intervention and 98 per cent of the control group are described as 'white'.^(200, 219-221)

Researchers are generally very dependent upon the agencies with whom they are collaborating. Widespread acceptance of the importance of equalities monitoring is comparatively recent so one study based on data collected in 2001 was only provided with an overall estimate of the age and gender (recorded in binary form) of people using the service.⁽¹⁹⁴⁾

Many schemes have waiting lists so we know that there is probably a greater demand for befriending services than can be met currently.⁽²¹⁵⁾ What we do not know is whether people sharing a protected characteristic are more or less likely to be *offered* befriending services or whether they are more likely to *accept or refuse* a befriending service. In one study, almost half those offered the service chose not to take it up but as demographic details of potential participants were not collected until after they had agreed to take part in the intervention, it was not possible to compare those who refused with those who accepted.⁽²⁰⁰⁾ Until we collect better

information of this sort, it will be very difficult to identify whether one group is being less favourably treated than another. This should be a priority in future research on befriending.

Levels of need and access to services

Age

The majority of older people using befriending services are in their 80s or 90s.^(191, 194, 199) This is unsurprising in that 18 per cent of people aged 85 and over report they often, or always, feel lonely compared with 13 per cent of those aged 75-84 and six per cent of those aged 65-74.⁽²²²⁾ However, their greater loneliness is not simply the result of age but rather because they are more likely to have experienced events such as the loss of a partner, changes to their social networks as a result of bereavement or illness, or poorer physical health than people aged 50-74.⁽²²²⁻²²⁴⁾ Victor and colleagues^(222, 224) also identified a small group of people who had felt lonely throughout their lives.

Most befriending services set broad limits for accessing their service (for example 50 plus), or do not set any age limits at all. We did not identify any UK-based published research specifically comparing the needs and preferences of differently aged users of befriending schemes. While it is probable that people aged 50-64 using befriending services share another protected characteristic, such as disability, we could not find any research-based evidence on this topic.

Disability

Some disabilities impact upon people's ability to manage their social networks independently and are associated with increased loneliness.⁽²²⁵⁾ These include hearing and sight loss, conditions that affect mobility, depression, and dementia.⁽¹⁹²⁾ Almost all research about befriending services draws attention to the high levels of disability experienced by participants, including sight loss,⁽¹⁹⁸⁾ dementia and other long term conditions,⁽²¹¹⁾ heart disease⁽¹⁹⁹⁾ and learning disabilities.^(215, 226) Others use less specific terms such as 'frailty'.^(194, 210) However, because these studies have not collected information on participants' health systematically, we know very little about the severity and extent of disability among older people using befriending services or if they have unmet physical and health needs. One study that did attempt this found that participants were deterred by the health questions that the researchers wanted to collect⁽¹⁹³⁾ so a challenge for future research is to find simpler and better ways of obtaining this information.

People's health and social care needs need to be considered as a whole. Victor and Bowling have shown that improvements in physical health and social relationships are linked to reduced levels of loneliness. They argue that better treatment of long term health conditions, as well as social interventions such as befriending, might result in reduced levels of loneliness.⁽²²⁴⁾ This is another reason why future research into befriending needs to improve the way that information on participants' health is collected.

Some schemes offer a service to people with a specific disability while others are aimed at older people in general. However, we could not find any research identifying whether older people with disabilities prefer one type of service over another or if one type of service is better at meeting their needs.

Gender reassignment

The absence of research into the social networks of transgender older people means that we do not know about their potential need for befriending services. Hines⁽²²⁷⁾ research suggested that some people who have had gender reassignment lose contact with other transgender people and no longer choose to identify with the transgender community. Discrimination can lead to high levels of isolation, particularly those who have been rejected by family and friends as a result of their choices.⁽²⁸⁾ However, some transgender people may be reluctant to access mainstream services, especially if their previous experiences of health and social care services have been negative.⁽²²⁸⁾ Researchers evaluating a befriending scheme for lesbian, gay, bisexual and transgender people reported that the scheme had yet to recruit any transgender participants at the time of the evaluation,⁽¹⁹⁵⁾ although it was hoped that this would change as the scheme became more established.

Race

The relationship between ethnicity, social support, and loneliness is very complicated with factors such as socio-economic status, household size, and health playing an important part in influencing people's experiences, leading to differences *within* as well as *between* different ethnic groups.⁽¹⁴⁰⁻¹⁴²⁾ Victor and colleagues found that around eight per cent of Indian older people aged 65 often or always feel lonely – similar to the nine per cent reported in their earlier study of White British people aged 65 and over. However, this proportion rose to 24 per cent among Caribbean people, 40 per cent among Chinese, and 50 per cent among African, Pakistani, and Bangladeshi people. They concluded that more research was needed to try and find an explanation for these differences.⁽²²⁹⁾

It is rare for studies of befriending to report participants' ethnicity – with a few notable exceptions^(191, 200, 215) but it does appear that higher rates of loneliness may not be reflected in increased use of befriending services. Lester and colleagues recruited participants from five Age UK befriending schemes and commented that although their research did not include any participants from a minority ethnic group, this reflected the ethnic background of those using the scheme.⁽¹⁹¹⁾ By contrast, a study of Asian carers living in an unspecified part of England found that befriending services were 'greatly appreciated'. In some instances, befriending was seen as a more culturally acceptable service than offers of help with personal care. Having the service enabled the carer to have time off for other household tasks or for a break.⁽²³⁰⁾

Two short accounts of befriending schemes for people with stroke⁽²³¹⁾ and Type 2 diabetes⁽²³²⁾ from the Bengali and Somali communities in Tower Hamlets were identified. Although these accounts did not include details of participants' age,

these conditions occur more frequently among older people. Both schemes are aimed at helping people manage their long term conditions and become more active in their community. Examples of activities include befrienders helping people go shopping, attend exercise classes, and hospital appointments.⁽²³²⁾

An issue that could be explored in future research is how to improve take up of befriending by people from minority ethnic groups. This may be easier in areas that are already ethnically diverse. In Heslop and Robinson's research into befriending for people with learning difficulties in Bristol, one scheme was reported as having exceeded its target in terms of how well befrienders' ethnicity reflected the ethnic distribution of the local population as a whole but the reason for its success was not reported.⁽²¹⁵⁾ In the Tower Hamlets research, a community advocacy group⁽²³²⁾ and consultancy⁽²³¹⁾ service were respectively used to help recruit and train befrienders. However, better uptake might also be achieved by ensuring that details of the service are advertised to all groups – including using word of mouth and alternatives to written leaflets, such as DVDs⁽⁸⁹⁾ (see falls prevention chapter). Publicity emphasising organisations' commitment to diversity and detailing what steps have been taken to achieve this, (for instance by training) can also help.⁽¹⁹⁵⁾ It is especially important that service users and befrienders are ethnically matched (perhaps for language reasons), then it may be easier to recruit a telephone befriender.⁽¹⁹⁸⁾ Telephone befriending calls tend to be shorter than face to face visits,⁽¹⁹¹⁾ so one befriender may be able to support more than one person.

Practice example – working with local community organisations

NHS Tower Hamlets wanted to improve their service to local residents with diabetes. They commissioned Women's Health and Family Services (WHFS), a community-based health advocacy organisation with experience of working with black and minority ethnic women to develop a befriending project to provide people with Type 2 diabetes with the practical and emotional support they needed to become better at managing their condition and to feel more empowered.⁽²³²⁾

Religion and belief

Religious affiliation was only recorded in one of the published studies we found.⁽²³⁰⁾ In this study, almost all the participants were Muslim. Many faith-based organisations do provide befriending services but, as noted by one team of researchers looking at services provided by the Catholic Church, these services vary locally and their diversity is hard to capture. This study also noted that these services were also being used by people of other faiths, and none. The broad scope of this study meant that there was very little information specifically on befriending.⁽⁴³⁾

Beyond these examples, we could not find any published accounts exploring whether people of different faiths or none are more or less likely to need or access befriending services.

Sex

More women than men use befriending services aimed at older people.^(194, 199) This is because heterosexual women tend to marry men older than themselves and currently have higher life expectancy – meaning that they are more likely to experience widowhood than men. However, rising divorce rates and changes to men’s life expectancy may change this pattern. When differences in marital status, health, and living arrangements are controlled for, the number of men and women experiencing loneliness is very similar.⁽²³³⁾ However, there is no evidence on whether men experiencing loneliness are less likely than women to be offered befriending services or if they are more likely to refuse them. We do know that women are more likely to be befrienders^(234, 235) so it is possible that some men who would like to use a befriending service choose not to do so because they would prefer to be matched with a male befriender.

Practice example: encouraging men to use a befriending service

The Octavia Foundation and Octavia Housing are delivering a new outreach and befriending service on behalf of the City of Westminster and NHS Westminster. When they realised that very few men were using the service, they took steps to try and improve this. Leaflets and publicity material were changed so that, instead of a single photograph of a person using the service, they had more photographs of men. Men befrienders were asked to talk to men in their social networks to encourage them to consider becoming a befriender too.

Sexual orientation

Research with older lesbian, gay and bisexual people has emphasised the existence of both risk and protective factors for social support and loneliness as they age. The risk factors come from the experience of discrimination which may impact upon their relationships with some family members, neighbours, and the wider community and deter people from accessing services not specifically for lesbian, gay and bisexual people while the protective factors result from strong links with the lesbian, gay and bisexual community.⁽²³⁶⁻²³⁹⁾ However, older lesbian, gay and bisexual people are more likely to live on their own, not to have a partner, and to have smaller social networks than their heterosexual peers.⁽²⁰⁾ They may also experience ageism in some settings for lesbian, gay and bisexual people but fear discrimination and prejudice should they try to use services not specifically aimed at them.^(20, 195, 236, 239) This could lead to isolation,⁽¹⁸⁾ suggesting that some older lesbian, gay and bisexual older people may have an increased need for befriending services.

Almost all the research-based evidence on lesbian, gay and bisexual older people’s needs for, and access to, befriending comes from a single source – an account of the ‘Opening Doors’ project based in London.⁽¹⁹⁵⁾ Since this project was started, other similar schemes have developed⁽²⁴⁰⁾ but have yet to be evaluated. The Opening Doors evaluation found that the people who used the befriending service regularly had significant physical or mental health problems which prevented them from building or sustaining their own social support networks. They also experienced

social exclusion due to their sexual orientation and health problems, so they did not feel confident accessing mainstream services.⁽¹⁹⁵⁾ At the time of the evaluation five gay men and two lesbian women used the befriending service. Two issues that could be explored in future research are whether there is an unmet need for befriending services among older lesbian women and whether other schemes could learn lessons from Opening Doors on how to encourage men to use their service.

Practice example: encouraging uptake among lesbian, gay and bisexual people

Stonewall has provided a guide for care and support providers. Tips to improve gay, lesbian and bisexual older people's experience of services include:

Make sure that promotional literature and information packs include pictures of, and accounts by, lesbian, gay and bisexual people.

Encourage staff to use open language rather than assume potential users are heterosexual

Train staff on the law and on lesbian, gay and bisexual issues including same-sex partner rights

Display clear policies which set out how you handle discrimination and anti-gay bullying

Make sure that service users know about any codes of conduct that include sexual orientation discrimination and can complain if necessary.⁽¹⁴⁾

User experiences and outcomes

User views

Almost all the accounts of user experiences of befriending services are extremely positive, with those being befriended often reporting that they value their relationships with volunteers more highly than those with professionals.⁽²⁰⁵⁾ Overall, users report the following benefits:

- providing support and friendship that helps reduce feelings of isolation^(189, 194, 205, 206, 241)
- reducing depression⁽²⁴²⁾
- feeling more confident^(190, 193)
- feeling more connected to the community^(190, 191, 193)

Befriending services were ranked fifth out of a total of 13 'Baker's Dozen' services chosen by members of the Joseph Rowntree Foundation 'That Bit of Help' Inquiry into services for people living at home.⁽¹⁸⁶⁾ Most of the Inquiry members were older people. However, some researchers argue that more evidence on effectiveness is needed^(208, 209, 221) and that this should involve changes to research design so that it is possible to identify some of the complexities of befriending support, such as what contributes to successful matches between befrienders and people using the service.^(200, 209)

We do not know whether these positive views about befriending are shared equally across all service users in terms of their protected characteristics. This is because - irrespective of study design – the research that is currently available does not make these comparisons. Neither does it include the views of those who have given up the service. A new area of inquiry is whether the intended outcomes of befriending need to become more tailored to the needs of different users, for example, how befriending for people with dementia can focus on the ‘quality of the moment’⁽²⁴³⁾ but more work is needed in this area. Two areas in which existing research can inform good practice in creating an inclusive befriending service are:

- ‘matching’ befrienders with the person being befriended; and
- equalities training for befrienders.

Matching

Accounts suggest that matching is made on the basis of a combination of shared interests and backgrounds and practical issues such as preferences for the frequency and timing of visits or whether or not the befriender needs to be a car driver.^(191, 193, 194, 215, 217) In a sample of white older people aged 55-92 using befriending services, participants thought befrienders’ friendliness and social skills were more important than what they had in common – they thought that shared interests often emerged over time and could develop together.⁽¹⁹¹⁾ For younger service users, being matched with a person of a similar age is important. This seems to be less important for older people and there are examples where young befrienders are welcomed for providing inter generational contact.⁽²¹¹⁾

However, at other times it may be more important for befrienders and those using the service to share the same protected characteristic. In some instances, the need to speak a community language may be an important criteria in befriender recruitment^(231, 232) and this generally means that befrienders and service users are ethnically matched. In a study of a befriending scheme in Bristol, ethnic matching was ‘a particular factor’ but no further details were provided.⁽²¹⁵⁾

The sexual orientation of the befrienders in the Opening Doors Project⁽¹⁹⁵⁾ is not recorded. In the absence of any research looking at matching gay, lesbian and bisexual befrienders and service users, two other studies provide some relevant insights. The first is based on research about a telephone helpline run by Friend where the callers were almost all men aged under 50. Callers were mostly gay, bisexual, or transgender, but included a number of heterosexual transvestite men. When the caller and telephone operator were matched in terms of sexual orientation, calls were slightly more successful in terms of the length of time they lasted and the number of calls received. The authors suggested that matching in terms of age was less important when talking to people over the telephone.⁽²⁴⁴⁾

In the second study, a gay man participating in study of lesbian, gay and bisexual older people whose social life had been affected when he was a distance carer for his father reported that becoming isolated from the gay community had a

detrimental effect on his self identity.⁽¹⁹⁾ He suggested that having a gay care worker could be especially helpful for housebound lesbian, gay and bisexual people.

Among younger people with disabilities, peer befriending is common but this model seems rarer in services for older people, although examples exist, such as a RNIB Outreach Peer Support project for people with sight loss⁽²⁴⁵⁾ and the diabetes peer support scheme in Tower Hamlets.⁽²³²⁾ Telephone befriending may offer new opportunities for peer support among older people who have difficulties leaving their homes.^(193, 198) However, there is no evidence as to whether older people prefer peer support or if it is more effective. Similarly, while we know that religious or cultural backgrounds may mean that having a befriender who shares the same religious affiliation is important for some users or potential users of befriending services, we do not know how this impacts on their experiences.

We do not define ourselves just by our protected characteristics. For example, many lesbian, gay, bisexual and transgender volunteers want to volunteer for a non-LGBT organisation.⁽²⁴⁶⁾ This suggests that we cannot assume that matching in terms of a protected characteristic will work in the absence of other shared interests.

An important area that research into befriending seems not to have explored is what happens when users or potential users of the service express views or preferences that are discriminatory. We know that this happens in social care - most often in terms of people's preferences for workers of a certain ethnic background^(247, 248) so it is unlikely that this does not happen to those managing befriending schemes. More openness about this topic could help establish a consensus about good practice in terms of how to respond to such requests.

Equalities training

The Opening Doors⁽¹⁹⁵⁾ evaluation reported that befrienders were all given training in LGBT issues and that feedback about them was described as 'exceptionally positive'. One potential topic that could be covered in equalities training is the concept of 'disenfranchised grief' whereby a bereaved person does not have the opportunity to grieve in the way they would wish. For example, lesbian, gay, and bisexual people may find that the loss of a partner is not treated the same way as the loss of a heterosexual spouse.⁽²⁴⁹⁾ Although not a study of befriending, findings from a participatory action research project with older gay and lesbian people in Dorset⁽²⁵⁰⁾ have relevance for befriending services. This study found that participants had been, or were afraid of being, treated less sympathetically than their heterosexual peers when it came to bereavement. These findings suggest that bereaved lesbian, gay and bisexual older people may be deterred from using befriending services or gain less from their relationship with a befriender if they feel that their loss will be treated less sympathetically than the loss of a heterosexual partner.

While most schemes do provide equalities training for befrienders, we do not know how useful the befrienders find it or whether the training makes a difference to the way that they support the people they befriend.

User involvement

Research points out that power imbalances tend to occur in befriending, especially when a person has just started to use the service,⁽¹⁹⁴⁾ although this may be less of an issue insofar as peer befriending is concerned.⁽²⁵¹⁾ In the process of matching, befrienders may be given more choice than the people being befriended in terms of being provided with background information and choosing whether or not to go ahead with befriending.⁽²¹⁵⁾ This highlights the need for sensitivity on the part of scheme organisers and befrienders not to replicate the inequalities and discrimination that potential service users may have experienced already.

It has been suggested that interventions designed to reduce social isolation among older people are more likely to be successful if older people are involved in the planning, implementation and evaluation stages^(208, 209) but specific advice on how to achieve this is lacking. While there does not appear to be any information on how people using befriending services have played a role in influencing the service, material from organisations such as the Social Care Institute for Excellence^(252, 253) and Shaping Our Lives⁽²⁵⁴⁾ could help in developing ideas about how to increase opportunities for service users to become involved in developing services. One approach that might be especially helpful with service users who have a disability that limits their involvement in making decisions about what to do during visits is to keep a diary or logbook about a person's interests and which activities seem to have been most successful.

Practice example: befriending diary for person with dementia

...During the whole time I was there, she kept telling me that she didn't know me, kept asking my name and where I lived. I don't think she really understood why I was there, but hopefully, after a few visits, it might all begin to fit into place. While we were there, Mrs Brown's nephew, John arrived. We discussed with both of them what manner of things might be of interest of benefit to Mrs Brown...[Project worker] pointed out that Mrs Brown had a large record collection. I didn't look through it, but this is something I can do on another visit. I told her that I liked Scottish country dancing...Before I left; I gave Mrs Brown a note with my name and the time for my next visit and then saw myself out. I've decided that it would be useful to keep a logbook of each visit – at least in the early stages. Hopefully, Mrs Brown will be happy to see me again (if she remembers me)'.⁽²⁵⁵⁾

Key findings

- Most befriending services for older people are generic and so they need to ensure that their service is an inclusive one in which all older people, whatever their background, feel welcome.
- Very little research into befriending has paid attention to equality issues so we know very little about the need for, and access to, befriending in terms of people's protected characteristics.

- Providing equalities training and thinking more about what makes a good match between befrienders and service users could help ensure befriending services are effective and accessible to all people who need them.
- More systematic attention to user views and involving service users in designing and delivering services is needed to ensure that some groups of service users are not indirectly discouraged from using the service.

Day opportunities

Introduction and background

The term 'day opportunities' is recent in origin and infinitely elastic. It is being used as an umbrella term to cover activities with a purpose, leisure activities, social engagement, day services, community activities, and so on. Almost anything could be classed, so it seems, as a day opportunity – if it does not take place at night. One particular usage of the term is as an antithesis or opposite to perceptions of 'traditional' activities in day centres. In some circles, these centres are being referred to as building-based services, in contrast to day opportunities which may be used to refer to ordinary life activities that are not part of formal social care services. Of course all this can lead to fairly fruitless debates, is playing a game of bingo in a day centre a building-based service, or is playing a game of bingo in a commercial bingo hall a day opportunity? Is the distinction that is being constructed between an activity that is organised for older people as a group and an activity that is chosen by an individual? This would make shopping a day opportunity and a University of the Third Age meeting not. After all many day services offer a range of choices, albeit sometimes limited, to people using the service (such as dancing, wheelchair exercise, and music). Does a lunch club count as a day opportunity or not? These distinctions could be debated further but for the purposes of this review we will consider day services in a day centre or similar setting and activities that are funded to meet social care outcomes relating to social or leisure choices (for example through personal budgets or people's own resources). Some of these settings will be registered or authorised to provide personal care (for instance, help with bathing or going to the toilet) and others not. As a further complication, while many current changes are being linked to the implementation of the policy of personalisation and to the consequences of financial cutbacks in the public sector, in some areas changes in day services were already underway, with the term 'modernisation' being used to describe shifts in various directions, such as re-ablement or prevention. In the voluntary sector, developments such as volunteers offering 'day care' to small groups of older people were described by Age Concern England⁽²⁵⁶⁾ and some of these survive.

Practice example: day opportunities in a homely setting

Age Concern Sutton's Homeshare volunteer scheme provides care and companionship for isolated or lonely people in a domestic environment. It offers day services for those who are unable to cope with a traditional day centre for various reasons while also ensuring a regular break for carers. Homeshare volunteers provide their own homes to offer support and companionship, social stimulation and activities and the opportunity to make new friends to a small group (up to 5) of vulnerable older people with special dependency needs. The service provides a hot cooked lunch, tea, coffee and cold drinks for each client.⁽²⁵⁶⁾

At the time of writing (Autumn 2012) there are specific changes afoot in many parts of the UK with day centres changing or closing in many areas. This may be much

more profound than has been realised. This is because the 'buildings' housing such services may be being taken out of the public weale and not simply changing their user base. Once a building is sold, the service cannot be re-created there. There has been some public and staff opposition to this but the changes continue.⁽²⁵⁷⁾ Some of the material making the case for or against such changes has exposed the slight evidence base for the outcomes of day care services related to equality and diversity. It is, of course, important to assess if these changes are as extensive as they are being portrayed. There has been much change in day services (broadly defined over the past decades) and some evidence that they are under-used - Whillier⁽²⁵⁸⁾ cited 30-40% under-use. There have also been changes in ownership and management with local authorities, in particular, commissioning from or transferring day services to the voluntary sector and private sector providers offering day care as part of the activities of a care home.

Description of the service

As mentioned above, a distinction is often made between 'day services' that are delivered outside people's own homes and are generally building-based and 'day opportunities' which may or may not be building-based. Day services cover a diverse range of services and activities. They cater for a variety of people and needs, and serve a number of different purposes, most of which are broadly preventive including:

- providing social contact and stimulation; reducing isolation and loneliness
- maintaining and/or restoring independence
- providing a break for carers
- offering activities which provide mental and physical stimulation
- enabling care and monitoring of very frail and vulnerable older people
- offering low-level support for older people at risk
- assisting recovery and rehabilitation after an illness or accident
- providing care services such as bathing and nail-cutting
- promoting health and nutrition
- providing opportunities for older people to contribute as well as receive⁽²⁵⁹⁾

'Day opportunities' are not necessarily communal, and may be of any duration. There seems no need for a day opportunity to be outside the home - an activity can be brought to the individual:

Practice example: what is meant by day opportunities?

Day Opportunities are being developed to provide a flexible response to older people's needs. These services will offer support either within an individual's home, and/or support to access social and recreational activities in local communities. The services are not based on attendance at a day care centre. The services, purchased or provided, consist of a range of opportunities designed to promote ordinary living through developing and maintaining links with existing community services.⁽²⁶⁰⁾

Nonetheless, policy continues to portray day centres as part of the local or community resource for older people. The Care and Support White Paper outlines the expectation by government that:⁽²⁶¹⁾

Leisure centres, libraries, day centres and community centres should be open, inclusive and culturally sensitive venues (p.24).

We may be witnessing a paradox. Older people unable to access leisure centres, libraries, day centres and community centres in their current form, even with assistance, may be at risk of further social care exclusion if there are no buildings-based alternatives that meet their needs. This tension makes it important to be conscious of equalities so that people who are at risk of social care exclusion are not further disadvantaged.

It is therefore very important to have clarity over terminology and definitions so that comparisons are not meaningless or confusing. This is particularly so when one form of support seems to be cloaked in value-laden terms that are suggesting superiority, such as choice, flexibility, or opportunity.

Gaps in the research information

McVicker⁽²⁶²⁾ observed that day care has been very neglected within both research and policy fields and consequently little research-based information is available to inform the debate. In some respects, this reflects an overall lack of research into social care services in the UK. In a recent scoping review on good social care for people with complex needs, such as dementia, Gridley and colleagues⁽²⁶³⁾ looked in detail at 86 papers identified from a sizeable 5,098 potential studies. Of these 86, 35 advocated person-centred support for people with complex needs but no robust evidence was found to support any particular model. They did find some examples of promising practice but none of these had been formally evaluated. This means that attempts to develop or sustain services are not easily evidence based.

In other respects, it can be attributed to the uncertain nature of day services. The past decade has seen many references to the possible demise of formal day services, linking this to the changes arising from the policy of personalisation.⁽²⁶⁴⁾ For example, the social work magazine *Community Care*⁽²⁶⁵⁾ asked 'Are day centres outdated in the personalisation era?' While some research looks at the use of personal budgets among older people,^(266, 267) the effects of major reductions on day centre provision in localities in terms of older people's choices about what support they would like remains under-researched. Day services are also widely used as a

form of short breaks by carers⁽²⁶⁸⁾ and the implications of these closures on support for carers remain to be established.

Other changes include the rise in day centre charges for users – both those contributing all or part of the costs met by the local authority and those older people paying the full cost themselves.⁽²⁶⁹⁾ This too may affect the survival of day centres if they are seen as poor value for money or other options are more affordable.

In a recent report for the trade union UNISON (whose members include those working in day care services) on the subject of day care centres, Needham⁽²⁵⁷⁾ concluded:

Some high profile campaigns against day centre closures have made local headlines. There is a need to continue to build a national picture of what is happening to day centre provision, and what issues staff and service users are experiencing in their localities. There is also a need to share examples of where positive alternatives and service improvements are emerging (p.17).

Some of the implications of the changes to day care services are reported in the Equalities Impact Assessments (EIAs) conducted by local councils prior to making major changes to a service. These potentially provide the means to consider if there are differential effects of proposed changes. Two such EIAs are reported below and these may be of use locally as a baseline of information and as a way of seeing what the arguments for change are built upon.

Practice example: two Equality Impact Assessments

The long-term vision for day opportunities for older people is being developed in partnership with older people themselves, with service providers and other key stakeholders. The aim of the project is to ensure that future day services and day opportunities for older people are more personalised and focused around reablement. Day services for older people and older people with dementia or other high support needs (including physical and functional mental health needs and or sensory loss) play an important supporting role in maximising opportunities for well being, improving quality of life and promoting independence.⁽²⁷⁰⁾

From the data currently available to us there are three groups that appear to have a very low take up of the low level services offered. [These] are older people from BME [black and minority ethnic] communities, men and people on low income.⁽²⁷¹⁾

A particular challenge will be to identify the longer term effects of these closures on former users and prospective users which are, as yet - and may continue to be, unknown.

However, other gaps in the literature are not necessarily associated with the complexities of the current context. Age UK in a detailed overview of the evidence on outcomes, concluded that while very few studies have specifically evaluated the impact of day services. those that have done so have found that older people attending day services benefited from doing so, as did their carers.⁽²⁵⁹⁾ Sadly, there is

little detail in such studies and descriptions that can be related to protected characteristics other than age. At local level, many evaluations and work related to day care provision remain inaccessible and unknown, largely because they consist of 'grey literature' and are not deposited in any national data collection. For example, see Age UK Maidstone's observation that it sends a questionnaire to the 180 users of its day care service twice a year⁽²⁷²⁾ but about which no details are publicly available. Information of this sort may be compiled as part of a competitive tendering process, thus it may be viewed as commercially sensitive.

A further difficulty in relation to day care services is that reports covering usage and user experiences are often small scale and the context of the service is not always clearly described making it difficult to know what is offered at the service, what is used and by whom. As the example from London Borough of Kingston above illustrates, some day care is 'low level' and therefore comparisons with other day care centres would need to ensure this was taken into account. Few studies enable us to see the people using day care services in the context of other parts of their lives; so we do not always know whether the person has support from other parts of the social care system or family networks, for example. Some studies are now reflective of service contexts that have changed considerably, such as the decline of day hospital provision.⁽²⁷³⁾ Others reporting on psychosocial interventions in a day care setting do not always mention what is happening in the rest of the service. Thus we might know something about the benefits of dancing or art therapy, but not about the rest of someone's day. One example of an extensive study of older people's views of day centres in Oxfordshire undertaken by older people themselves interviewed 44 users.⁽²⁷⁴⁾ However, no detail was reported and perhaps not collected about several of the protected characteristics.

Levels of need and access to services

Age

Many users of day care facilities are, not surprisingly, in late old age. However there are some forms of day care where service users are significantly younger. For example, people who have experience of homelessness have poor health and social support and many of them may be users of day care services which take people of all ages.

Practice example: day centre for homeless, vulnerable and excluded

Most clients of St Wilfred's Centre in Sheffield 'are aged 36-60 (78%) reflecting the core service users at the Centre...We work with men and women (at a ratio of around 75:25) broadly described as "vulnerable." This means that some people who come to us are homeless or are likely to have accommodation that they are struggling to manage. Mental health problems affect a significant number here; caused by abuse, mild spectrum disorders, loneliness, or just the basic inability to cope with day to day living in our society. Over the past three years we have gradually adapted the focus of St Wilfred's away from the strict day centre model to a more holistic approach as we now find that at any one time around 70% of our clients are coping with mental health issues and will not engage with other providers. Many struggle with life skills and

literacy and many cannot cope with structure. If we were not here for them, they simply would not go anywhere else. We give practical support to overcome barriers of social exclusion particularly for those with high support needs often shunned by other agencies'.⁽²⁷⁵⁾

Crane and colleagues⁽²⁷⁶⁾ have concluded that such centres can be highly personalised and have good outcomes because they offer more intensive, individualised and flexible support than many other mainstream services.

There is some evidence that other people who are classified as being 'older' may be excluded on grounds of age from services they have previously used, such as day centre facilities for working age adults. The Mental Health Inquiry into Later Life, for example, heard that funding criteria used by local authorities have led to people aged over 65 years being 'kicked out' of day centres for people with mental health problems. The consequence is reported to be inadequate support at a time when their mental health needs may be increasing.⁽²⁷⁷⁾

Disability

The majority of people using day care services are described as 'frail', although there is disagreement about what this term describes precisely⁽²⁷⁸⁾ and many have a long term condition or disability. Within this are traditional divisions between day care services organised by age (younger and older adults), and by disability or long term conditions, for example, mental health problems (particularly dementia) or stroke. Some of these latter services may have evolved from former day hospitals.

The intersection between gender and disability can impact upon people's willingness to use day services. Practitioners often report that men with dementia are reluctant to attend day services. Archibald⁽²⁷⁹⁾ concluded that 'special' places for men with dementia in service settings may help them feel less constrained and may enable them to talk about shared interests or backgrounds. This may be assisted by the presence of male workers, creation of opportunities to do what men might value, reflections on opportunities to recreate aspects of their social role, whether this relates to sport, games, socializing, or other parts of their biography. Where day services cannot create spaces of this sort, a lack of suitable alternatives can create an issue for family carers over and beyond the person with dementia's unmet need for social activities because day services have traditionally being a way of giving carers a break.⁽²⁶⁸⁾ Manthorpe and Moniz-Cook⁽²⁸⁰⁾ argued that more thought needs to be given about how men are welcomed into early dementia services, such as day services and peer support groups, and the images that such services convey through their publicity and illustrative activities.

The example below, from a research study investigating support for people with complex needs in the current policy environment of personalisation,⁽²⁶³⁾ is of Essex Dementia Care. It shows that a day care service can also be nested in other services providing day opportunities.

Practice example: a flexible dementia service

The Essex Dementia Service aims to help people with dementia to maintain an active lifestyle and remain at home. It specialises in both dementia and use of activities therapeutically. There are two main service areas: a one-to-one service where a practitioner meets with a client and engages them in an activity, or series of activities, depending on their mood and preference and two activity centres in different localities, each open one day per week. People may come to the activity centre in the early stages of dementia, and move through to the one-to-one service as their needs become more severe and complex. The activity centres are a useful way for people to get to know all of the Essex Dementia Care staff, which in turn supports continuity.⁽²⁸¹⁾

Participants at a seminar in Scotland⁽²⁸²⁾ sought to investigate what might be the implications of the rise of the baby boomer generation on day care provision. They noted that most current or traditional day care providers prioritised their services to meet the needs of the frailest older people. In discussion with a range of providers and older people, the potential of new types of day support that would meet the needs of a wider group of people, and offer support, care and opportunities for a fuller, more productive and interesting life was raised. This rather inconclusive debate did not identify any risk that the needs of very disabled and frail older people might not be met in such settings (such as, ostomy care, medications, wound care and reablement). These might include use of specialist equipment and nursing care.

Gender reassignment

There is a almost complete absence of research on transgender people's access to any sort of social care⁽²⁷⁾ and none on the experiences of older transgender people. This means that we do not have any research evidence about their levels of need for, and access to, day services. Whittle and colleagues⁽²⁸⁾ and Pugh⁽²⁸³⁾ report on the risks faced by transgendered people in public situations in terms of exposure to transphobia and hate crime. They may also have experienced discrimination from health and social care staff.⁽²⁷⁾ These factors may influence their willingness to attend mainstream day services.

Race

Historically data on the ethnic origin of social care users have not been good,⁽²⁸⁴⁾ partly because of variable ethnic monitoring and recording and partly because of differences in the way that ethnicity is defined. Published research is now more likely to include information on participants' ethnicity than in the past but older studies of day services are less likely to include this information.

The biggest barriers to using general social care services among black and minority ethnic older people are lack of information and fears that they will not provide culturally acceptable care.^(172, 175, 285) The comparatively long established nature of some culturally specific day services may mean that day services – in whatever form – are more popular than home care or other residential support. A large research study that took place in Leicester found that day services were the preferred option. The researchers concluded that this was because it did not necessitate overnight

stays and home care staff did not have to enter people's own homes and thus cross the boundaries of cultural space. In the researchers' opinion this helped explain why there was high take up of day care services among the Asian older population of Leicester.⁽²⁸⁶⁾

Older people from black and minority ethnic groups are not evenly distributed across UK, although this pattern is changing.⁽¹²⁸⁾ This may explain why in some areas day services for black and minority ethnic older people may continue to be part of intergenerational, community or family centres or groups and not develop into a service restricted to older people.

A combination of experience in dealing with greater ethnic diversity among users, training, regulation, and legislation appears to have improved providers' awareness of the need to provide more culturally sensitive care, especially around the provision of food, assistance with personal care, such as bathing and dressing, and religious worship.⁽²⁸⁷⁾ Alongside these improvements lies the risk that unquestioning assumptions about 'food and faith'⁽¹⁷³⁾ could lead to stereotyping and a tendency to ignore other aspects that are important to individuals. For instance, when asked where they wanted to go on an outing, a group of older Asian women attending a mental health day service chose to visit a pizza restaurant.⁽¹⁷³⁾

Given that levels of fluency in English vary among the current generation of black and minority ethnic older people, possible feelings of isolation can be accentuated when no other users or staff members speak their language. We do not know how many culturally specific day services are supporting people who are not fluent in English. It is also important to remember the language preferences of Welsh, Irish, Gaelic, and Ulster Scots-speaking older people. From Wales, a recent overview observed that social and health care services appeared to be premised:

...on the expectation that service users or carers will identify the need and create the demand for Welsh-medium services, rather than on the basis that service providers have a duty to offer and provide.⁽²⁸⁸⁾

Practice example: day care for people speaking Gaelic

The Cobhair Bharraigh Day Care Centre is 'welcoming, comfortable and homely, designed to meet the needs of Cobhair Bharraigh service users [living in the islands of Barra and Vatersay]. We presently offer four sessions of Day Care each week to sufferers of Dementia, Alzheimers and the frail and elderly (sic). Each session runs from 10.30am—3pm enabling carers to have some much needed extra time to themselves, and maintain their social and economic roles within the community. A nutritious meal, which is freshly prepared on the premises, is provided each day. Service Users have the opportunity to get involved in meal preparation and we provide a wide and varied range of Day Care activities at each session. As Gaelic is the preferred language of many of our service users, we have both Gaelic and English speaking staff to ensure that the communication needs of all service users are met.'⁽²⁸⁹⁾

Religion and belief

Although many faith based organisations do provide day opportunities for local residents, research-based information about those using these services is lacking. The very limited existing discussion about this support is usually discussed in terms of ethnicity or culture, for instance the services of Jewish Care, and more attention needs to be paid to drawing out the implications of social care developments and changes for faith based organisations.

In the UK a small number of specialist day care services exist for some faith groups and some of these are held in religious buildings. In his description of the work of two mosques in Bradford, McLoughlin⁽²⁹⁰⁾ noted that both offered day services for older people as well as other specific support for other age groups.

We know that the government is hoping that faith-based organisations will play a bigger role in delivering the 'Big Society'. If faith-based organisations become increasingly involved in the delivery of services that were previously delivered by non-denominational organisations, it is not clear what impact this will have on access to and uptake of services^(291, 292)

While adherence to a formal religion tends to be higher among black and minority groups than among the White British population, the highest proportion of people stating that they do not have a religion are Chinese.⁽²⁹³⁾ This highlights the risks of making global assumptions about religion or belief among people from minority ethnic groups.

Sex

Women are generally the majority of day centre users. Their longer life span, greater prevalence of long-term disability, and greater likelihood of outliving a male partner among heterosexual women help explain this gender difference. Interestingly, there seems an inverse research law, in that much research either does not observe that users are women, or concentrates on the men in the minority. Local contexts are also likely to be important in residents' demographic profiles; in areas where men die early, notably in poorer parts of the UK, men may be an even smaller minority of those accessing day services.

Men who have lost partners or never had partners, often have more restricted social networks, engage in more risky health behaviours, and are more materially disadvantaged than married older men.⁽²⁹⁴⁾ Offers of day care may be very welcome, even if they have family or other carers, leading to real improvements in their quality of life, mood, nutrition, self-care, and reductions of loneliness. Studies of the experiences of being widowed in later life have found that some men find it hard to sustain their former contacts and friends and that their support networks may further decrease in size as they age.^(295, 296) Some studies have shown that many men prefer different forms of social involvement than women, of a type that seems useful and supports their identity⁽²⁹⁷⁾ but this may need to be proactively maintained, with access to transport, for example.

Care practices that address gender dynamics and the needs of men as minorities need to ensure men have the space they wish to express aspects of their masculine identities. Being a minority in any group may be a cause of anxiety; the only man may feel very isolated or self-conscious; the more so if he is, for example, gay or from a minority ethnic or religious group.

As well as making up the majority of service users, women also form the overwhelming majority of staff working in day services.⁽²⁹⁸⁾ In some day services, social activities may be associated with activities traditionally associated with women, such as cooking or sewing. Being conscious of this, some care settings have developed men's rooms, or areas, recreating, for example, the setting of a pub, or a workshop. Others have developed men's groups, often facilitated by male members of staff, students, or volunteers. There has recently been great interest in the potential of men's sheds which support men who want to meet together and socialise or share and learn skills. In Australia, these have been successful in attracting diverse groups of men, particularly those who would be reluctant to attend a 'traditional' day service.⁽²⁹⁹⁾ An evaluation of three men's shed that have been developed in England is currently taking place but has not yet reported its findings.⁽³⁰⁰⁾

Practice example: men in sheds

'I worked for 34 years at a desk job in London and came up to Kendal to spend my retirement years here 15 years ago. My wife had heard about Men in Sheds, and suggested I give it a try. On my first day [I was shown]...the 'tools of the trade' and taught...how to use them...I have already learned several new skills after just four sessions. The atmosphere and camaraderie in the place are also very pleasant. Speaking for myself, as a practitioner of Buddhism I found that the stillness of mind that is experienced when working with my hands with full attention is something that I never experienced working in an office.'⁽³⁰⁰⁾

Care practices that address gender dynamics and the needs of men as minorities need to ensure men have the space they wish to express aspects of their masculine identities. Archibald⁽²⁷⁹⁾ concluded from her study of dementia care that 'special' places for men in service settings, may help them feel less constrained and may enable them to talk about shared interests or backgrounds. This may be assisted by the presence of male workers, creation of opportunities to do what men might value, reflections on opportunities to recreate aspects of their social role, whether this relates to sport, games, socialising, or other parts of their biography.

Not all men, of course, wish to socialise with other men and a cautionary note is made in the research report from Age Concern Surrey that practitioners may sometimes over-emphasise men's desire to mix in male company:

Professionals were inclined to stress the need for men to be able to meet other men, but many (by no means all) of the men interviewed were keen to meet with women as they missed female companionship.⁽²⁹⁴⁾

Sexual orientation

Although day services have traditionally been used by high proportions of people living alone and we know that proportionally more lesbian, gay and bisexual older people live on their own,⁽²⁰⁾ we could not identify any research looking at gay, lesbian and bisexual older people's need for, and access to, day care. This reflects a wider lack of research into the needs of older lesbian, gay and bisexual older people, and in particular the needs of those living outside large cities.⁽¹⁸⁾ However, we do know that many lesbian, gay and bisexual older people feel excluded from gay organisations aimed at younger people and mainstream organisations aimed at older people.^(20, 239) Taken together, these factors suggest that there is an unmet need for welcoming and inclusive day services.

Price^(22, 301, 302) is one of the few researchers who has sought accounts from carers of older people with dementia of service use and perceptions. She found that carers, both lesbian women and gay men, mediated disclosures of their sexualities to health and social care service practitioners. For many carers, initial professional responses to these disclosures and hints of disclosure affected their decisions about 'coming out' further. She concluded that service providers were at best accepting of gay and lesbian people, but generally there was 'pervasive disregard' of their needs.

Although not based on formal research, experience from other services that have been successful in recruiting older lesbian, gay, and bisexual service users could be useful in ensuring that they are not deterred from using day services. A checklist from *Opening Doors* includes:

- Using pictures of same sex couples in promotional materials and around the building
- Ensuring that interview areas are private and that people are reassured about confidentiality
- Avoiding questions and terms that assume people are heterosexual
- Using open questions about people and activities that are important to the service user so that people feel free to discuss them
- Recording sexual orientation using a recommended format (see chapter on challenges)⁽³⁰³⁾

User experiences and outcomes

User views

The lack of research into day services for people with different protected characteristics means that it is impossible to examine whether people's experiences of day care differ according to their protected characteristics. Almost all those who use day services generally feel very positively about it. The lack of information about those who are offered the service but decide not to take it up or use it for a

short period means that we do not know whether equalities issues have played a part in their decision to stop, or not use, the services.

The main benefits reported by people using the service are improved social contact, physical and psychological benefits from taking part in activities, a break for family carers, access to a hot meal, and help with personal care, such as help bathing or cutting toenails.^(259, 274) many older people attending day care, especially those living alone, have health problems that make it more difficult for them to cook a meal or undertake personal care activities independently. Asian carers may prefer day care to other alternatives for getting a break, such as overnight stays or home-based support.⁽²⁸⁶⁾ Although some men are deterred by the gender imbalance in traditional day services, extending the number of activities on offer and encouraging men to take up roles as workers or volunteers may help improve their experiences.^(300, 304, 305) The lack of attention to sexual and gender identity in research into day care means that we do not know about lesbian, gay, bisexual and transgender people's experience of the service.

Day care and personal budgets

Changes to commissioning and the advent of personal budgets raise important issues about whether the benefits of day care can be equally, or better, met by other types of service. Unfortunately, the size of the evidence base on person centred approaches is still too small to indicate which types of approach work best in what circumstances.⁽²⁶³⁾

Early research about day opportunities emerged from the evaluation of the individual budgets (IBs) pilots.^(306, 307) This extensive research found that outcomes for older people were not always improved by the greater choice and control offered by personal budgets in the form of direct payments. This study found that older people tended to make less use of innovative approaches to support and deployment options than other users of social care. One reason for this may be that *per capita* social care funding for older people is lower than for equivalent levels of impairment in younger age groups. Netten and colleagues⁽³⁰⁸⁾ questioned whether, when funding is comparatively low for the level of need, it will simply not be possible for many older people to take advantage of the potential flexibilities of personal budgets. They suggested that this might help explain the lack of a positive impact of personal budgets on older people and, if so, this challenges the potential for achieving better outcomes through personalisation at a time of financial austerity and cuts to local authority social care funding.

This is an important study because many other studies reporting older people's views on different types of support have consulted people who are not using social care services.^(309, 310) Unlike the evaluation of individual budgets, studies of this sort rarely analyse participants' views in relation to different levels of disability. Older people who are very frail tend to be excluded from consultations of this sort and it is not clear if their views may differ from those with fewer needs.

However, recent evidence on day opportunities among older people using personal budgets (funded by local authorities) offers some illustrations of the ways in which men, in particular, may use such money to choose activities that are tailored to their interests. In a study of carers' support, Moriarty and Manthorpe (in press) provided one example of a man with dementia who had been working in the construction industry whose wife arranged for a young man to take her husband round various DIY superstores and shops as part of their walks and outside activities in clear preference to a day centre place. Comparing uptake of, and views about, personal budgets according to people's protected characteristics may be one way of investigating the extent to which they are able to promote equalities.

User involvement

Much of the research about day care was undertaken before user involvement was a priority and so it is not surprising that we did not find any evidence on the ways in which different service users had been involved in running day services. The former Commission for Social Care Inspection (CSCI)⁽¹²⁾ offered advice on how care providers should ensure that lesbian, gay and bisexual people receive an equal service. This could be used as a framework for evaluating the involvement of all groups according to their protected characteristics:

- creating an ethos in the service where LGB people are valued;
- reviewing policies and procedures and assessment processes to ensure that they do not discriminate;
- providing training and support to staff;
- positive action to make LGB people feel welcome and able to come out, for example by including them in publicity;
- ensuring that LGB people have a choice of which staff support them;
- enabling LGB people to have contact with their communities and friends;
- valuing LGB people's relationships;
- taking appropriate action when discrimination does happen; and
- listening to the views of LGB people and monitoring progress.(p. 6)

Key findings

- While monitoring and reporting of service users' ethnicity appears to have improved, this does not apply to other protected characteristics such as sexual orientation and religion and belief. Gender is usually recorded in a binary way as man/woman. This makes it difficult to know how successful day services are in providing support to all sections of the community. This

applies to research, to service providers, and older people's groups undertaking scrutiny of local provision.

- Most traditional day services are generic. Culturally specific day services or services for older lesbian, gay, bisexual and transgender older people are only likely to develop in large cities. Venues offering generic day services need to be able to offer space for a choice of activities, culturally acceptable menus, and ensure that lavatories and bathrooms offer sufficient privacy.
- There is some evidence that Asian carers prefer day services to other types of service giving them a break. We need to be better at identifying whether people with other protected characteristics have similar or differing perspectives on day care than those found among older people as a whole.

Personal budgets may offer increased opportunities for people to have greater choice in terms of how they spend their day. However, it will be important to see whether closures of traditional day services have a differential impact on people with very severe disabilities and their carers who may still be unable to access mainstream social and leisure activities even with very intensive support.

Conclusion

This document contains new information about the extent to which five key services – falls prevention, home from hospital, handy person services, befriending and day opportunities – used singly or in combination by many older people can be said to offer an inclusive service in terms of seven of the nine protected characteristics included in the Equality Act 2010 (age, disability, gender reassignment, race, religion and belief, sex and sexual orientation). While some of these services are associated with use of health and social care services, others relate to other important wider elements of wellbeing, such as home repairs and modification, or a community support service that has long-standing roots in the voluntary sector – befriending. Many of the areas considered are found across different sectors – statutory health and social care; the voluntary and community sector and even commercial bodies who may offer such services for a fee or be commissioned to run them.

The key conclusion of this scoping review is that, despite the longstanding nature of equalities legislation in terms of sex, race, and disability, the number of studies specifically designed to measure inequality in terms of these characteristics remains tiny. Although legislation designed to protect people in terms of their sexual and gender identity or religion and belief is more recent, these aspects of people's lives are rarely measured in mainstream research. That which exists is usually funded by pressure groups such as Stonewall or Press for Change. Without it, we would know even less about the experiences of lesbian, gay, bisexual and transgender people. Within these groups, the experiences of older bisexual and transgender people are conspicuously absent.⁽¹⁸⁾ In the UK, religion and belief has traditionally been thought of as a personal issue. Although it has been shown that there are some instances in which religio-cultural factors are more important than ethnicity in explaining differences between groups,⁽⁵⁾ religion and belief has been very under researched.

The second conclusion is that, despite the absence of a substantial research evidence base in each of the services included in this review, there are some commonalities *across* services that give greater weight to the findings than if they were restricted to a single service. Recurrent themes include:

- The value of developing inclusive publicity that shows a full range of service users in terms of their protected characteristics.
- The link between recruitment policies and support for different types of service user. Recruiting a diverse workforce of employees and volunteers helps send the message that the organisation is an inclusive one and contributes to the overall strength of the workforce in terms of its skills and experiences.
- The need to take account of how experience of other health and social care and housing services can impact upon people's willingness to try falls prevention, home from hospital, and handy person services, befriending and

day opportunities. In particular, previous experience of discrimination can influence people's preconceptions about a service – making it important to create environments in which people feel accepted as an individual, in which they feel their confidentiality will be respected and in which they feel confident that should they experience discrimination, action will be taken.

- The lack of information about people using services in terms of their protected characteristics spanned across falls prevention, home from hospital, handyperson, befriending, and day services, different types of research in terms of methodology, and different disciplinary bases in terms of medicine, nursing, gerontology and so on. This made it very difficult to draw firm conclusions in terms of access.
- Information on different protected characteristics is also needed to look at outcomes. Recent research has emphasised the importance of social interaction in terms of maintaining wellbeing and preventing loneliness.^(223, 224, 277) Take up at falls prevention classes can be improved if people feel they are going to be enjoyable⁽⁸⁹⁾ and reports about befriending and day opportunities are worded similarly in terms of their impact upon social isolation.^(194, 259) Where take up appears to be less among different groups in terms of their protected characteristics, it is important to identify whether this is because they have different experiences of the service.
- The area in which we found least information was on user involvement. Although there is a growing literature on user involvement, information on how to ensure that participation is inclusive remains limited. Government plans for care and support emphasise autonomy and choice⁽²⁶¹⁾ so it will be important to develop this area in the future in order to demonstrate service effectiveness.

Our final conclusion is that if we are to improve the way that information on people's protected characteristics is collected, we need to know more about how best to do it. If staff and volunteers ask for more information on people's protected characteristics than they do currently, we need to know more about how to do this in a proportionate way and which formats and questions are acceptable to older people. Older people may feel some questions are intrusive and staff may be wary of seeming to be driven by the requirements of 'paperwork' or bureaucracy. Returning to the theme of user involvement, older people will need to be engaged in the processes that will help ensure that services and support are fairly offered and personally acceptable to all older people.

We have set out our remaining thoughts as a series of messages for different readerships but, of course, many of these readerships and messages are overlapping.

Messages for older people

Further emphasis on equalities will need to be based on accurate information and older people are likely to be asked for further details about themselves than they are used to. Some of these enquiries may seem unnecessary or even impertinent. There may be concerns about the use to which such personal information is being put. Older people can play their part in explaining why this is necessary, in taking part in opportunities to assist in compiling or producing information that is accessible to other older people, and can reassure professionals and volunteers that they understand the importance of good information and why it is being collected.

Messages for older people's groups, advocates and campaigning groups

Members of such groups will need to develop skills in understanding their local population profiles and considering the implications and limitations of data that seeks to offer some insights into whether services and support are sensitive to equalities issues. They will need to be confident in supporting individual older people and different groups who are questioning service providers and policy makers. Different groups will likely have different interests and may need to work with other groups to ensure that they are able to compile a more complete picture of the subject in question.

Messages for researchers

On the whole, reporting standards in terms of participants' personal characteristics were very variable. Researchers will need to justify why they choose to collect and report certain data and not others. Some researchers may find that funders and advisory groups wish them to collect more while others may find that there is pressure to reduce the burden on participants. We hope that researchers will discuss these tensions with older people and that funders will encourage them to collect data and to report such information with a view to equalities and reflecting the diversity of older people. The implications of achieving good enough samples of different groups should be explored in developing research and evaluation proposals and funders should talk with researchers and evaluators about ensuring that the diversity of the older population is reflected in their work.

One suggestion is that editors of academic journals could play a role in increasing awareness of this issue by requiring authors to include more details about the demographic characteristics of their participants or at least explain why they have been unable to provide these details.⁽³⁵⁾

Messages for practitioners and volunteers

In common with messages for other groups above, practitioners and volunteers will need to be assured that there is a point to collecting information related to equalities and that it will be used. Asking older people to provide personal information requires skill and understanding if it is not to cause distress. Both practitioners and volunteers could be supplied with information giving examples of why collecting such data is important and how it is used. Audits of notes and

records may be a helpful way of improving data collection and need to be approached constructively. Data about volunteers and practitioners are also important and their collection should be similarly respectfully undertaken.

Messages for decision makers and policy makers

Collecting information about equalities is only the beginning and not an end in itself. Policy makers and decision makers will face new data and will need to apply this to the subject and to their locality. One major challenge will be how to respond to data around multiple diversity and how to assess the impact of policies that affect people with several protected characteristics, not just one. Older people will be watching to see how new information about equalities will be incorporated into decision making and how transparent this will be. Our final conclusion is that the UK research and reports on equalities issues and older people often have their limitations but the UK has a strong tradition in collecting and using information about diversity that compares well with other areas. This has been fostered by policy makers and is most evident in official statistics. This should be recognised, sustained, and developed.

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