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# The causes and consequences of neglect and self neglect amongst vulnerable older people.

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# The causes and consequences of neglect and self neglect amongst vulnerable older people


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# Executive Summary

The Big Lottery Fund (BIG) commissioned the Policy Studies Institute (PSI) to conduct a review of the causes and consequences of neglect and self neglect amongst older people**.** The study aimed to investigate how people are affected by isolation, social exclusion, neglect by others and self neglect. The report also focuses on current government policy and practice and the potential role of BIG in meeting the needs of older people in vulnerable circumstances. Identification of gaps in provision highlight specific types of project which BIG could fund to make an impact on and improve the lives of older people in need. Findings from the report address: the causes and consequences of neglect in the fourth age; older people and the UK policy context; and funding gaps and the potential role of BIG.

## Neglect in the fourth age

By 2031 it is expected that the population aged 80 and above will grow to 4.9 million. Health is improving in general but the incidence of health problems among the oldest is actually increasing. As a consequence, both men and women can expect to live longer but also longer in poor health. The fourth age, from around the age of 75, is marked for some by an increased risk of frailty, degenerative ageing and declines in social participation. Becoming less mobile and dependent upon others for basic needs can heighten the risk of older people experiencing neglect or abuse.

Neglect can be conceptualised as: social neglect; abusive neglect; and self-neglect. Abusive neglect and mistreatment is estimated to affect around 5 per cent of the older population with many high profile cases emerging in institutional settings. Self-neglect accounts for a large number of referrals to adult protective services and is more common than caregiver neglect and physical abuse. 12 per cent of older people (over 1.1 million) feel trapped in their own home while 17 per cent have less than weekly contact with family, friends and neighbours. The scale of neglect as a problem is therefore considerable, which warrants BIG's strategic consideration.

Neglect can be associated with social isolation but also arises in institutional settings. Isolation can precipitate a lack of care, disinterest in food and can trigger depression with implications for lifespan.

A number of factors can coalesce to heighten the probability of neglect, loneliness, and isolation among the old, including:  ill health, disability, poor transportation, childlessness, family breakdown, ageism, loss of friends and relatives, poverty and transitional events such as bereavement, hospitalisation or moving into a care home. Living within a family or care home setting does not preclude neglect, despair or a sense of isolation if quality of relationships are not good.

## Older people and the UK policy context

In response to concerns that current systems will be unable to cope with an ageing population, the last Government undertook a number of reviews to establish key areas for reform affecting the older population, with a focus on health, social and personal care, social inclusion and pensions. Active ageing, choice and control over services, social inclusion, partnership working and a preventative agenda were prioritised. These principles remain at the forefront of the Coalition Government's approach to the needs of older people but, in practice, significant changes are on the horizon, prompted by budget deficits and a devolutionary philosophy. Services are likely therefore to be increasingly delivered by a mix of statutory, private, third and informal sectors with implications for BIG in the funding arena.

The last Government was committed to the introduction of a framework for legislation and the establishment of an inter-departmental Ministerial group on adult safeguarding but the future remains uncertain under the coalition government. A new regulatory system for adult health and social care providers was introduced by the Care Quality Commission from April 2010 and from October 2010, adults who fund their own social care, including care home placements, will have access to an independent complaints review service provided by the Local Government Ombudsman. Despite frameworks and guidelines setting out good practice and expected standards of care, neglect and cases of abuse regularly come to light, whether in older peoples own homes or in institutions such as hospitals and care homes. Many instances of abuse also remain unreported, whether associated with self neglect or neglect by others.

In terms of elder abuse services, while there are a wide range of adult protection arrangements, evidence suggests that Adult Protection Teams are often under-funded, under-staffed and under-resourced. Hence, a great deal of abuse may be going on unchallenged or unreported.

## Funding gaps and the role of BIG

Despite wide ranging health and social care developments, the statutory sector continues to face resource challenges, leading to rationing and considerable unmet need. Social support in particular remains underfunded and is, in practice, a low priority. BIG can therefore benefit older people most effectively by funding a highly diverse range of day support activities, low level services and outreach activities to identify neglect and the most socially excluded.

### *BIG activities targeting older people*

A range of initiatives to benefit older people have been supported since BIG was set up in June 2004. Few specific programmes have targeted older people,

but the Community Fund treated older people as a priority group and the New Opportunities Fund also ran a number of strategic programmes reflecting the needs of older people. In addition, the Awards for All England and Reaching Communities programmes devoted a large number of grants to causes and projects benefiting older people. More recently, a programme targeting befriending and advocacy needs among older people, ‘AdvantAge’, was established in Wales.

There are many examples of good practice projects, focussed on the prevention of and responses to neglect, that have been funded by BIG over the years. Several have also emerged from the LinkAge Plus initiative. Some schemes are provided by the VCS, others have been set up in care home settings, while mutual-support type schemes are gaining ground as a means of meeting needs without incurring excessive costs.

An overview of good practice schemes highlights a number of common characteristics, such as the adoption of holistic approaches to fourth age needs, recognising their multiplicity, combined with outreach activity to identify those in need who have not necessarily come forward to ask for help. Each of the good practice examples also put into practice the principles of promoting independence and treating older people with dignity, many recognising that older people in their fourth age wish to continue making a contribution to their communities, perhaps by volunteering, and are not to be treated simply as vulnerable, passive recipients of services. User led services can therefore be ideal models of support.

***Gaps in provision***

The range of statutory support is fairly comprehensive in principle, seeking to meet the social support, personal care and health needs of older people. In practice, however, access is severely restricted and for those who do secure state support, as resources are increasingly restricted, provision becomes focused on personal care services rather than social support and costs can be prohibitive. Social support therefore represents a key gap within the overall provision of statutory support for older people. There are indications that local authorities may cut support for people with moderate needs even further, increase charges and reduce care provision. There will therefore continue to be both acute needs and lower level needs for care, befriending and day-to-day services but it remains unclear who will pay for these services and what mix of formal and informal service provision will emerge. Focussing on neglect, the following represent key gaps in provision which BIG could seek to fill: outreach activities; transport; volunteers; carer support; and social activity.

Initiatives and volunteers to assist older people access mainstream facilities and simply get out of the house are in notably short supply. Of particular value would be support for schemes that provide multiple services, for example social/recreational activities, befriending schemes and advisory/information services. To meet issues of sustainability and capacity, grants for self-help, mutually supportive groups could bring long term benefits and allow older individuals to both give and receive help.

Devising a programme of support will need to recognise the different contexts and support needs of abusive neglect, self-neglect and social neglect or exclusion. The first two have been associated with statutory provision to date, with local authority social services and police services required to intervene. However, as new models of care increasingly emerge at the local level, the role of the VCS within a broader framework of care will change, giving rise to a shift in the profile of projects which BIG may wish to support. Statutory provision in relation to social inclusion support has been far more limited, with rationing restricting access to opportunities.

***How and when BIG could deliver funding***

Additional questions the report sets out to consider are: how can BIG deliver funding; what types of organisations would be appropriate; when would be the best time to invest funding considering the current economic climate and Government reforms; and how could BIG engage active older people to volunteer to assist vulnerable older people?

A wide range of joined up services are necessary to ensure the well being and welfare of older people. Services have been delivered by a variety of organisations including: Health Trusts, Housing Associations, LAs, the VCS and private sector. Regardless of the precise welfare mix and funding levels of the future, safeguarding older people and service delivery is likely to continue in partnership form with collaborations between public and private sectors, the VCS and private individuals.

Given the reluctance of older people to discuss abuse and their reluctance to approach formal or ‘official’ avenues of help, funding directed toward VCS organisations that are known and trusted and are more locally based, are likely to be more effective for older people at risk of, or experiencing, neglect and mistreatment. Grants are therefore best directed toward VCS groups in the first instance, who in turn are likely, or may be encouraged, to forge relationships with other sectors, whether private or statutory.

In terms of investment timing, BIG may wish to wait until the service delivery and funding shake-up is resolved, when a clearer picture will have emerged of

the funding needs and role of the VCS and which VCS organisations have proved resilient, with a continued presence in the delivery of services for older people. An alternative option is for BIG to act quickly, to provide funding assistance during this transitionary period, supporting organisations in their efforts to change their funding base, perhaps moving to social enterprise models. Organisations may need funding to develop new strategic business plans and seed money to initiate organisational change. The sooner such funding becomes available the better, as change can take time to be introduced, tested and eventually bed down.

Finally, the VCS is highly dependent upon the available time and goodwill of volunteers but demand for volunteers has been rising at the same time as supply has been shrinking in some areas. Volunteering in care home settings are a particular gap for example. BIG can improve engagement of older volunteers by funding charitable schemes that promote Volunteering. Volunteering organisations can provide a central repository of information, signpost to opportunities and run courses to promote confidence and opportunity specific skills. With funding, local VCS organisations can also formalise the search for volunteers with resources to recruit, train, provide support and encourage social engagements within the volunteering community. Good practice projects ensure the experience is 'fun' and sociable, and include social events for the volunteers.

In summary, large numbers of older people across the UK are in need of support to remain socially included, with widespread isolation in both cities and rural locations. To promote social participation and prevent neglect, a variety of stimulating activities and regular contact with peer groups are required. For the less mobile, opportunities to leave the home which currently can be few and far between, are in great demand. For the frail who live alone, opportunities to have visitors, telephone based friendships or internet communications are also critically important to prevent neglect and the associated adverse mental and physical health consequences.

At a time of unprecedented uncertainty in terms of future funding and sources of welfare provision, the scope for BIG to improve the well being and quality of life of older people is considerable. BIG can benefit older people most effectively by supporting the VCS and funding a highly diverse range of day support activities, low level services, transport, and outreach activities to identify the most socially excluded and those at risk of neglect.

# 1. Introduction

The Big Lottery Fund commissioned the Policy Studies Institute to conduct a review of the causes and consequences of neglect and self neglect amongst vulnerable older people in the fourth age**.** The study aims to investigate how people are affected by isolation, social exclusion, neglect by others and self neglect. The report also focuses on current government policy and the potential role of BIG in meeting the needs of older vulnerable people. Identification of gaps in provision will highlight specific types of project which BIG could fund to make an impact on and improve the lives of older people in need.

The research will inform BIG's plans for an older people funding programme, to be launched in 2012, and identify the specific role which the third sector can play in supporting people in the fourth age.

The study, based on a policy and literature review, aims to investigate the determinants and consequences of neglect and identify those most at risk. Specific research questions include;

- What are the causes and consequences of neglect and self neglect amongst vulnerable older people? (abuse, alcoholism, not eating properly etc)
- Are there particular sub groups who suffer from neglect or self neglect?
- What is the current government policy on older people and is there anything specifically about neglect and self neglect?
- What has BIG done to target older people through its funding?
- What is the current provision in this area?
- What effective approaches or good practice has been funded by BIG or other organisations to address neglect or self neglect?
- What are the gaps in provision which BIG could potentially target through the funding? Should we focus on prevention as well as cure or only one of these areas considering that we only have a finite amount of money available?
- How can BIG deliver the funding? What types of organisations would be appropriate?
- When would be the best time to invest the funding considering the current economic climate and Government reforms?
- How could BIG engage active older people to volunteer to assist vulnerable older people?

In chapter 2, the dimensions, causes and consequences of neglect are discussed, followed, in chapter 3, by a review of government policy and local provision relating to older people and neglect. Having set out the issues and the current context in terms of policy and practice, chapter 4 explores BIG funding for older people to date, identifies gaps in provision which BIG could potentially target and discusses funding orientation (prevention or cure), delivery (organisation types) and timing (immediately or post welfare delivery reforms). The challenge of attracting volunteers is also addressed.

## 2. Neglect in the fourth age: causes and consequences

- Neglect can be conceptualised as: social neglect; abusive neglect or mistreatment and self-neglect.
- At older ages, with the onset of frailty, withdrawal from community life and social participation can arise, with many older people feeling trapped in their own homes. Isolation can trigger depression, self-neglect and has implications for lifespan.
- Abusive neglect and mistreatment is estimated to affect around 5 per cent of the older population with many high profile cases emerging in institutional settings.
- Self-neglect accounts for a large number of referrals to adult protective services and is more common than caregiver neglect and physical abuse.
- The scale of social neglect, abusive neglect and self-neglect is considerable, warranting BIG's strategic consideration.
- The probability of neglect, loneliness, social exclusion and isolation among the old is heightened by ill health, disability, poor transportation, poverty, childlessness, family breakdown and transitional life events such as bereavement, hospitalisation or moving into a care home.

The retirement years have come to be conceptualised in terms of two phases, classified as the third and fourth age. The third age is typically a period of withdrawal from paid work, but most older people still enjoy active lives in good health at this stage. The fourth age, from around the age of 75, is marked by an increased risk of health difficulties associated with degenerative ageing and is also accompanied by declines in social participation. On average, frailty starts at around 75 years.

By 2031 it is expected that the population aged 80 and above will grow to 4.9 million from 2.5 million in 2002 (Dean, 2004). Average life expectancy has increased over recent decades, for women from age 77 in 1981 to age 84 in 2008 and from age 71 to age 81 for men (National Statistics online). Growth in life expectancy is continuing with one in five children born so far this century expected to survive into the next.

Health has also improved over this period but less markedly, and the incidence of health problems among the oldest is actually increasing (Middleton et al, 2007). As a consequence, both men and women can expect to live longer but also longer in poor health. Health concerns and longstanding illnesses become increasingly prevalent among men and women aged 65 and above. In 2005, more than half the population of 65-74 year olds (60 per cent) reported a long-term illness, a figure which increases to two thirds (64 per cent) of those aged 75 and above (Age Concern, 2007). There are currently 700,000 people with dementia in the UK and by 2025 it is anticipated that this figure will rise to over one million. The proportion of people with dementia doubles for every 5 year age group, such that by the age of 95 one third of people are affected (Alzheimers Society).[1] Approximately 2.5 million older people in the UK have a care need (CSJ, 2010).

Policy solutions are needed to provide for those most in need today but must also take into account projected expansions in the numbers of elderly people who are likely to require support in the future. Implications arise for community planning, provision of services, benefits and pensions as governments, individuals and financial institutions consider the optimal arrangements for achieving long and healthy lives with an emphasis on quality, dignity, choice and well being.

With the ageing of the UK population, elder abuse, which includes neglect, is also increasingly recognised as a social problem which needs to be identified, understood and resolved. Abuse and mistreatment can arise at any age and afflict all social groups, but ageing can exacerbate the risk of abuse due to dependence on others, social isolation and frailty. Identifying abuse can be a challenge however. As noted by the World Health Organisation (WHO, 2008), older generations are often reluctant to discuss private issues, compounded by the fact that elder abuse continues to be a taboo subject. One study of the

[1] http://www.alzheimers.org.uk/site/scripts/documents_info.php?categoryID=200120&documentID=341

views of older people on elder abuse (WHO/INPEA, 2002), indicated that older people differentiate between three catergories of mistreatment;

- neglect (isolation, abandonment and social exclusion)
- violation (of human, legal and medical rights) and
- deprivation (of choices, decisions, status, finances and respect)

While there are a wide range of adult protection arrangements, an Age UK report suggests that Adult Protection Teams are often under-funded, under-staffed and under-resourced. Hence, a great deal of abuse may be going on unchallenged or unreported (AgeUK, 2010).

## 2.1 Neglect – elder abuse

Despite a considerable body of research on the experiences, challenges, health and aspirations of older people, the issue of mistreatment and neglect is under-researched. Estimating the incidence of neglect, self-neglect and other forms of elder abuse is therefore a challenge. To improve understanding of the types and pervasiveness of mistreatment in the UK, a dedicated 'prevalence' survey was commissioned by Comic Relief and the Department of Health (O'Keefe et al, 2007). The study found that around 227,000 people aged 66+ (2.6%) experience mistreatment each year at the hands of family, friends or care workers. Broadening perpetrators to include neighbours and acquaintances, the figure increases to 342,400 older people. The definition of elder abuse is widely recognised as complex and dependent on the conceptualisation of a 'relationship of trust'. The prevalence survey used the definition developed by Action on Elder Abuse and adopted by the World Health Organisation: *"A single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person".* Five types of mistreatment were identified:

- ***Neglect*** – e.g. repeated failure of a designated caregiver to provide help with personal care and day to day activities;
- ***Financial abuse*** – e.g. theft, fraud, misuse of power of attorney;
- ***Psychological abuse*** – e.g. persistent insults and threats;
- ***Physical abuse*** – e.g. physical violence, physical restraint, over-medication;
- ***Sexual abuse*** – e.g. verbal harassment, touching in a sexual way or intercourse without consent.

Among the five types of mistreatment, neglect was the most common, affecting nearly half of those reporting an experience of abuse or mistreatment. Not all neglect is deliberate however, particularly if a ‘carer’ is an elderly partner – the circumstances of neglect may reflect failing mutual support. Neglect can refer to a lack of help with: day to day activities (e.g. shopping or meal preparation); personal care (e.g. washing, dressing or eating) or help with medication (doses or regularity). These are the aspects of neglect which the ‘prevalence survey’ focussed upon.

Help the Aged (2009) estimate that more than 500,000 older people in the UK are abused (roughly 5% of the older population) and that every hour, over 50 older people are neglected or abused in their own homes by family members, friends, neighbours or care workers.

## 2.2 Self-neglect

The extent of neglect is more widespread than indicated by the prevalence survey, cited above, insofar as the survey did not address self-neglect or self-harm which may include alcohol abuse, deteriorating home circumstances or not eating properly. Self-neglect may be associated with chronic mental illness, older alcoholics, older developmentally disabled adults, or elderly people with chronic diseases and conditions. Self-neglect in older adults may not be evident outside of the home and can be hard to detect, as a result many cases go unreported or are unknown to social service departments.

Self-neglect is recognised as a dynamic and complex phenomenon which can be defined as “the inability (intentional or non-intentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the self-neglecters and perhaps even to their community.” (Gibbons, 2006).

Day and Leahy-Warren (2008) describe the following characteristics and behaviours associated with self-neglect:

- Living in very unclean circumstances;
- Hoarding large numbers of pets;
- Neglecting household maintenance;
- Portraying eccentric behaviours/lifestyles;
- Poor self-care leading to a decline in personal hygiene
- Poor nutrition,
- Failure to take medication

While some of these examples of self-neglect may be due to cognitive impairment, others may be attributable to poor eyesight, financial constraints, or poor access to services. Poor environmental and personal hygiene may also reflect personal choice or lifestyle rather than an ageing problem (Dyer et al, 2000). Issues of personal dignity and independence therefore arise, and outside intervention may not be welcomed.

Self-neglect accounts for a large number of referrals to adult protective services and is more common than caregiver neglect and physical abuse (Day and Leahy-Warren, 2008).

Alcohol abuse is a further dimension of self-neglect. Data is scarce however in the UK, with a need for further research. The issue was explored in a seminar convened in December 2008 by Age Concern and the Institute of Alcohol Studies, at which elderly alcohol misuse was observed to often be associated with depression (Merrick et al, 2008)[2].

According to an Institute of Alcohol Studies (IAS) Factsheet; 'Alcohol and the Elderly'[3] , 17 per cent of men and 7 per cent of women aged 65+ exceeded the 'sensible limits' of regular consumption[4]. IAS identify three 'types' of elderly drinker:

- Early-Onset drinkers or 'Survivors' - have a continuing problem with alcohol which developed in earlier life. Around two thirds of elderly problem drinkers are estimated to have had an early onset of alcohol misuse.
- Late-Onset drinkers or 'Reactors' - begin problematic drinking later in life, often in response to traumatic life events such as the death of a loved one, loneliness, pain, insomnia, retirement and decreased social activity. Sleep disruption at older ages can also trigger alcohol misuse.
- Intermittent or Binge drinkers - use alcohol occasionally and sometimes drink to excess which may cause them problems.

Investigating the use of alcohol in old age is warranted, as the consequences of misuse can be more severe compared with younger drinkers. Consumption is more likely to adversely affect older people due to their lower ability to metabolize alcohol (Moore, 2003). The IAS Factsheet suggests that "*Alcohol depresses the brain function to a greater extent in older people, impairing*

[2] For a list of presentations see: www.ias.org.uk/resources/events/elderly/london081208.html
[3] www.ias.org.uk/resources/factsheets/factsheets.html
[4] Data source - 2005 General Household Survey

*coordination and memory, which can lead to falls and general confusion. It can also heighten emotions leading to moodiness, irritability or even violence. Alcohol in excess affects digestion, making it more difficult to absorb vitamins and minerals.*" (p5)

In recognition that older people have specific needs in relation to alcohol advice and assistance, some organisations such as DASL (Drug and Alcohol Service for London) - a London based charity that helps communities tackle problems caused by drug and alcohol misuse – have dedicated services for older people[5].

## 2.3 Social neglect

Neglect also has an emotional dimension, associated with isolation and loneliness. Half of all older people cite the television as their main form of company (CSJ, 2010). Neglect as isolation may not involve abuse or deteriorating personal or home conditions but nevertheless does carry psychological and physical implications. This form of social neglect, whereby the social or emotional needs of older people are not being met, is also conceptualised in the literature as 'social exclusion' and 'isolation'.

Abusive neglect, social neglect and self-neglect have a direct impact on quality of life, which is described as poor by 11 per cent of older people in the UK, with 24 per cent claiming their quality of life had got worse over the past year (Age Concern and Help the Aged, 2009). Isolation is a key cause of poor life quality and reduced well being and affects large numbers of older people;

- 12 per cent of older people (over 1.1 million) feel trapped in their own home (Help the Aged, 2009).
- 17 per cent of older people have less than weekly contact with family, friends and neighbours while 11 per cent have less than monthly contact (Victor et al, 2004).
- Nearly 200,000 older people in the UK do not receive the help they need to get out of their house or flat (Help the Aged, 2009).
- In England, 8 per cent of those aged 75-plus say they have very difficult access to a corner shop; 10 per cent to a supermarket; 10 per cent to a post office; 9 per cent to a doctor's surgery; and 17 per cent to a local hospital (Help the Aged, 2009).

[5] see www.alcoholeast.org.uk/bexley-services.html

Outreach activities at a local level are critical to prevent neglect and self-neglect as older people do not necessarily recognise that they are isolated or neglecting themselves and the 80+ group can be particularly vulnerable as noted by one VCS organisation employee, reported in Smeaton (2009);

> *"Most people in that age range don't feel that they are lonely and isolated …older people themselves don't recognise it and when I looked at our befriending services its quite interesting , the vast majority, almost 90% of referrals have come from either family or professionals ….For me that's one of the big issues, individuals themselves aren't seeing it…..And if you think about the effects of loneliness, lack of care, lack of interest, leading to depression, lack of interest in food, it is a spiralling effect….The later bereavement happens the bigger the effect it has on you…in their 60s they adjust more easily to being on their own than in their 80s"*

Isolation can lead to a downward spiral, affecting mental and physical health, contributing to mental illness in older age (Andrews et al, 2003). Social exclusion can precipitate self-neglect, a lack of care, disinterest in food and can trigger depression with implications for lifespan. One recent study of mortality rates among individuals aged 65+ over a period of 20 years (Bowling and Grundy, 2009) found that factors associated with increased longevity included positive life satisfaction and regular participation in crafts, social visiting and other activities. Overall, social participation was associated with survival in older age. People with adequate social relationships therefore live for longer than those with negative social relationships. This is comparable with the impact of giving up smoking , and has a more significant impact on mortality risks than like a lack of exercise and obesity (CSJ, 2010: 28). Consequences of neglect include 'loss of independence and quality of life... suicide, self-harm and deteriorating physical health' (Mowlam et al, 2007: iv). Neglect by others and self-neglect can therefore be inter-related.

A number of factors heighten the probability of neglect and isolation among the old, including: bereavement, ill health, disability, poor transportation, ageism, loss of friends and relatives, family breakdown and poverty (Victor et al, 2004; CSJ, 2010). In addition, events such as a hospital stay or a fall can trigger cycles of vulnerability, isolation and exclusion.

## 2.4 Correlates of neglect

Neglect is typically associated with being over 80, in poor health, depression, living alone in rented accommodation, childlessness, low income and no access to a telephone (Walker et al, 2006). Women are more likely than men to report

neglect or other forms of mistreatment (O'Keefe et al, 2007) and neglect increases sharply with age. Family breakdown can also precipitate social exclusion, particularly among the 80 plus (CSJ, 2010)

Other aspects of peoples' lives that can increase vulnerability and the risk of abuse, identified in ADSS (2005), include:

- Lack of inclusion in protective social networks
- Dependency on others (who may misuse their position) for vital needs including mobility, access to information and control of finances
- Lack of access to remedies for abuse and neglect
- Social acceptability of low standards for care and treatment
- Social acceptability of domestic abuse
- Dynamics of power within institutional care settings

Adults who are receiving community care services can be at risk whilst receiving them, both in care settings and in their own homes. ADSS (2005) acknowledges that successful prevention of adult abuse and neglect demands that service providers tackle the factors which contribute to its occurrence at all levels. Implementation and monitoring of care standards are therefore critical. Of concern, however, are older people, supported perhaps by family members, who do not fall under the radar of community care professionals and institutions. For these individuals, outreach work by the voluntary sector may help, as would information leaflets posted, or in GP surgeries, which can alert victims to help that may be available. Publicity campaigns can raise the profile of adult abuse within the local community by means of the distribution of public information leaflets, posters, local press articles and other media coverage.

The majority of men and women over the age of 65 live in private households (95 per cent), rather than care homes or other communal residencies (Del Bono et al, 2007). In 2005, among those aged 65-74, one fifth of men (19 per cent) and one third of women (33 per cent) lived alone (Age Concern, 2007). The equivalent figures among men and women aged 75 and above were 29 per cent and 60 per cent - raising the risks of loneliness and isolation for women in particular. People living alone may not be at higher risk of having unmet essential needs, but, according to a Young Foundation report (2009: 103) are at higher risk of; poor general psychological wellbeing, lack of worth, lack of control, lack of social support and more at risk of abusive relationships and violence generally.

While older women live longer, they also tend to have poorer health and mobility after age 80. Older women are also at an economic disadvantage with fewer assets and lower incomes than older men. Social participation among older women is also more restricted as substantially fewer women in the age

group have a driving licence. The loss of a spouse makes older women in particular more vulnerable because of the resulting negative impact on their income and access to services. In comparison, older men tend to be more disadvantaged in measures of social contact, particularly those who live alone. Older women tend to have more extensive and supportive friendship networks than older men.

Although older women are more likely to be isolated and report neglect, a number of studies have observed that men have less extensive social networks compared with women, are less likely to join groups and there are difficulties finding appropriate social venues with appeal for men (Godfrey et al, 2004, Davidson et al, 2003). Quotes from interviews conducted for a study by Smeaton (2009) highlight the challenges faced in meeting the needs of older men and in identifying their preferences;

> *"We have to be careful about how we manage it because we can become self excluding without even knowing it. So I would argue if you came here 10 years ago there were hardly any men around at all it was ....all pink and knitting.. Now there is beer tasting, a pool table ....we deliberately added men's groups. That's the way you combat exclusion, you think about who we're not targeting, how do we target groups…."* (Chief Executive, Large Charity, South East)

> *"One of the problems we have identified is men, we need activities specifically aimed at men…and men only groups might be the only way…..and if you can focus it on a local pub or something like that....we need to find out what it is that would stimulate men" (Rural VCS staff)*

Living within a family or care home setting does not preclude despair or a sense of isolation if quality of relationships are not good. Extending social networks beyond the home should therefore be a goal for all older people.

***Deprived neighbourhoods***

In some neighbourhoods, two-thirds of older people are socially excluded in terms of social relationships, access to basic services or cultural activities (Walker, 2006). Poverty and disadvantage are most common in deprived neighbourhoods, areas and specific regions including the North East, the North West, the West Midlands and London in particular (Botham and Lumley, 2004). Black and minority ethnic older people are also more likely to be excluded (White, 2002). Spatial location with poor access to transportation, high rates of crime and antisocial behaviour in some deprived areas can curtail a wide range of opportunities for older people (Phillipson and Scharf, 2004) and can lead to feelings of loneliness and isolation (Victor et al, 2004). Of increasing concern is

financial exclusion, with Post Office and local bank closures, particularly in rural areas, disproportionately affecting older people (Help the Aged, 2006).

***Rural Isolation***

Rural isolation is a recognised risk and where voluntary organisations attempt to provide help, a number of practical difficulties can arise. One member of a befriending organisation which arranges group gatherings for tea and a chat observed;

> *"There is a problem in rural areas …where you've got the problem of rural isolation which is huge, it's a big problem for us too in operating there …as people are so dispersed, actually transporting people to the parties is much more difficult …"* (Befriending organisation staff, reported in Smeaton, 2009)

Problems can emerge for people who move around retirement age to more beautiful parts of the country but then have no networks of support, particularly if their partner dies.

In response to specific problems experienced by rural residents one of several pilot schemes within the DWP POPPS programme specifically targeted rural communities. People living in rural areas tend to be hard to reach and despite comparative affluence "these communities are often isolated with high levels of social deprivation and poor transport links. They are usually very 'self contained' and because of this, are reluctant to find help outside of their local community" (GCC, 2008). In order to find a means to reach these groups and provide them with a wide range of information to support well-being, deliver services promoting independent living and to ensure the frail and vulnerable feel more secure and cared for, the Village Agent was conceived. An evaluation of the project (GCC, 2008) concluded that the concept was successful and the Village Agent performed an important role in rural communities, promoting service access, falls prevention, safety, benefit receipts, social networks, access to transport and active ageing. In evaluations of the project it has been recommended that the Village/Community Agent role be extended from information giving and signposting functions, to include building social networks, encouraging sustainable volunteering and good neighbourliness.

Transport is a particularly acute problem facing older people in rural areas, particularly those in the fourth age who are most likely to experience mobility problems. Reliable, safe and accessible transport networks are therefore essential to enable older people not only to engage in social life but also to access basic services such as shopping, visiting GPs, dentists and hospitals. Reviewing the challenges faced by older rural residents, a CSJ report (2010) notes that around one quarter of older people live in rural areas and nearly half must travel more than 2-3 miles to reach a supermarket. Hospitals also tend to

be much further away compared with urban locations. As a consequence, those living in rural areas often spend 20 to 30 per cent more on transport, including, public transport, taxis and cars compared with their urban counterparts. Some local authorities offer subsidised taxi schemes which are welcomed but at risk with budget cuts.

Transport is not only an issue for rural residents. For many older people, adequate and affordable transportation is a prerequisite for access to community life. A study of older people without private transport found that for important trips such as shopping or hospital/GP visits alternative means of travel were found but discretionary leisure or social trips were often forfeited (Davey, 2007). Attendance at arts and cultural events declines dramatically after the age of 60 (Fenn et al, 2004), primarily due to health problems and lack of transportation (DWP, 2005). Interviews with individuals working with older people also emphasised the importance of 'appropriate' transport;

> "*Thinking of Day Centres, they are often put off from going to these places, a minibus would go and pick several of them up but a 5 minute journey could take half an hour because you're collecting so many people and then the journey back and they're not terribly comfortable …what people were saying was about appropriate transport ..tokens for taxis, more local and personalised to them…"* (Rural VCS staff, quoted in Smeaton, 2009)

***Care home neglect***

The Care Quality Commission (CQC) is responsible for regulating and maintaining standards in local authority, private and voluntary health and social care services including care homes, which must be registered with them. Nevertheless, there have been many media exposes of poor treatment in care home settings over recent years. Mistreatment may involve abuse of medication in controlling and sedating patients, physical abuse, malnutrition, dehydration, neglect and behaviour designed to degrade and humiliate. Other examples of neglect arise in relation to basic human rights and respect for choice and dignity. A study by Bowers et al (2009), within the Joseph Rowntree Foundations's Independent Living programme, has explored the experiences and aspirations of older people living in residential and nursing care homes. It highlights the desire of older people to increasingly influence decisions about their own care and support. The study describes how some older people experience 'frightening and difficult times: moving into residential care as the result of sudden illness or disability; being moved quickly without advance preparation; or not returning home from hospital before moving'. The study further observes that in care homes there is considerable imbalance of power between the residents and those providing care or support to them which can

leave older people vulnerable to mistreatment and can lead to low self-esteem and low expectations of their quality of life.

In recognition that older people with high support needs require a higher profile voice and empowerment, the Joseph Rowntree Foundation launched a five-year programme in 2009, *A Better Life*. The programme is designed to challenge attitudes, develop best practice in residential care homes and housing with care schemes, and consider alternative approaches . In a summary of 11 preliminary reviews (Blood, 2009), social isolation was recognised as a key challenge and that maintaining good social relationships is central to quality of life for older people. Isolation and loneliness however are common among those with high support needs (Manthorp, 2010; Cattan and Giuntoli 2010) and residing in a communal setting need not prevent social isolation. Those with mobility, cognitive and/or sensory impairments were identified as being at particular risk of being excluded from the social life of housing with care schemes (Callaghan, 2009). The review listed several potential barriers to full inclusion including; time and inclination of staff (Burke, 2010); language/ cultural barriers and access, transport and funding to participate in activities in the community (Manthorp, 2010).

## 2.5 In summary

The fourth age, from around the age of 75, is marked by an increased risk of frailty, health difficulties associated with degenerative ageing and declines in social participation. Becoming less mobile and dependent upon others for basic needs can heighten the risk of older people experiencing neglect, mistreatment or abuse. The incidence of self neglect also increases. Neglect can be associated with social isolation but also arises in institutional settings.

Neglect is typically associated with being over 80, in poor health, depression, living alone in rented accommodation, childlessness, low income and not having a telephone. Women are more likely than men to report neglect or other forms of mistreatment and neglect increases sharply with age. Family breakdown can also precipitate social exclusion, particularly among the 80 plus.

Estimating the incidence of neglect, self-neglect and other forms of elder abuse is a challenge, however, given the extent to which these are taboo subjects and older people are often reluctant to come forward and ask for help, particularly from strangers. A number of barriers can inhibit older people from reporting neglect or abuse including: isolated environments with little contact with others; fear of the repercussions of reporting incidents and; lack of awareness of who to approach or

the role of different agencies or care providers such as GPs. Signs of self neglect, such as poor environmental and personal hygiene or alcohol abuse may reflect personal choice or lifestyle rather than an ageing problem. Any attempts to intervene may therefore be interpreted as unwelcome interference, posing an obstacle for potential support.

From the perspective of BIG, devising a programme of support will need to recognise the different contexts and support needs of abusive neglect, self-neglect and social neglect or exclusion. The first two have been associated with statutory provision to date, with local authority social services and police services required to intervene. Statutory provision in relation to social inclusion support has been far more limited with rationing restricting access to opportunities. BIG has supported large numbers of projects which have targeted social support needs. Demand for social support initiatives will continue to expand as the population ages. It is also likely that VCS activity will increasingly become involved in areas previously restricted to the statutory sector. Outreach activities in particular are likely to assume a higher profile.

## 3. Older people and the UK policy context

- In terms of older care needs, active ageing, choice and control over services, social inclusion, partnership working and a preventative agenda are priorities for the coalition government.
- Research suggests that despite policy objectives, preventative practice has failed to materialise, largely due to budget constraints which direct resources to emergency and crisis situations alone.
- Preventative support in practice therefore tends to fall to the VCS which leads to patchy provision across the country and often incurs costs which can be prohibitive for those in poverty.
- Significant changes in social and health care are on the horizon, prompted by budget deficits and a devolutionary philosophy.
- Services are likely to be increasingly delivered by a mix of statutory, private, third/civil society and informal sectors with implications for BIG in the funding arena.
- Given the extent to which neglect and abuse can remain hidden, it is important that different agencies, local communities and the VCS all work together to recognise, prevent and treat cases of neglect.
- The need for funds is also time sensitive for many groups who are at risk of demise as local authorities withdraw their traditional financial support for many VCS organisations.

Several key white papers and strategy documents have been published over recent years, by various government departments, setting out service aspirations, legislative reform and targets. Policy developments represent a response both to an ageing population which makes more demands on local services in terms of quantity and also to a perceived need to improve the quality of service provision. The last UK Government agenda on an ageing society prioritised active ageing, choice and control over services, social inclusion and well-being. Initiatives introduced over the past few years remain in place and the aims of independence, dignity, personalisation, prevention and decentralisation remain core to the new coalition's strategy for older people.

## 3.1 Older people initiatives

Developments in Government policy from 2005 to the present include:

- ***Opportunity Age*** (DWP, 2005) launched a cross departmental national strategy on an ageing society that promotes a focus on independence, well-being and citizenship in later life.
- ***A Sure Start to Later Life*** (Social Exclusion Unit, 2006) set out a strategy for tackling inequalities, poverty and isolation and for streamlining services for older people, particularly in deprived areas. This includes addressing living standards, physical and mental health, housing issues, community inclusion, and ageism. The report set out a number of pilot schemes designed to provide opportunities for and information about lifelong learning, volunteering, preventative health care, independent living and leisure activities – all of which can function, in part, to promote community participation and inclusion among older people. The aim is to establish a single multi-agency gateway for services and assessment in the community and to design effective and sustainable support arrangements for older people.
- A Sure Start launched the **Link-Age Plus initiative** which seeks to build partnerships for disseminating information and providing services in local areas. Other local initiatives that follow the Sure Start model are; ***Partnerships for Older People Projects*** (**POPPs**) funding innovation in person centred care, prevention and well-being for older people. ***Local Area Agreements*** **(LAAs)** have also been established between central and local governments to enhance healthy living and independence for older people.

- **Our Health Our Care Our Say,** this white paper on primary and community care (DOH, 2006) advocates a new direction for community services with priority given to preventative measures and individual choice for improving the well-being of older people.
- **The *National Service Framework (NSF) for Older People*** (Department of Health (DoH), 2001; 2006a) sets out the expected scope and direction of improvements in health and social care. Eight target areas were identified: Age discrimination, Person-centred care, Intermediate care, Hospital care, Stroke, Falls, Mental health and Active ageing
- ***A New Ambition for Old Age: next steps in implementing the NSF for Older People* (2006)** Developing the 2001 NSF the renewed aim is to ensure that within 5 years older people will be treated with respect for their dignity and their human rights, outcomes will be improved for older people's health, independence and well-being and, by means of a preventative service, savings may be achieved by reducing the overall demand for hospital and long term care services
- ***Putting People First* (2008)** Building on the Darzi review of the NHS, the Department of Health and its partners have recognised that the relationship between health, social care and wider community services is integral to the creation of a personalised care system. The aim is to replace reactive care of variable quality with a system focused on prevention, early intervention, and high quality personally tailored services.
- ***A Vision for Adult Social Care*: *Capable Communities and Active Citizens*** (Department of Health, 2010) sets out the coalition government's vision for the future, prioritising; prevention, devolution and mutuality. Prevention depends on low-level support services to assist people to remain independent in their own homes and communities. A shift of power from the state to people and communities is to enable individuals to 'choose the services that are right for them from a vibrant plural market' by means of personal budgets and direct payments. The final strand promoted within the document is the concept of 'responsibility' with communities and wider civil society expected to run innovative local schemes and build local networks of support such as timebank schemes.
- ***Equity and excellence: Liberating the NHS*** (Department of Health, 2010). Following this white paper the new Coalition Government set up a Commission on the Funding of Care and Support to look into funding social care services and it will report in the summer of 2011.
- **Scottish government (2010) *Self directed support: A National Strategy for Scotland*** The Scottish government has also launched a

personalisation strategy - a 10-year plan to promote individual budgets which mirrors the Putting People First programme for England. Councils are expected to give users choice over how their needs are met, improve information on care and invest in prevention. The aim is for self-directed support, personal budgets and direct payments to become the mainstream delivery of social care throughout Scotland.

The coalition government is also committed to extend the rollout of personal budgets and break down barriers between health and social care funding. Councils are expected to provide personal budgets, 'preferably as direct payments' for everyone who is eligible by April 2013 (DoH, 2010a). Individuals will then have the freedom to purchase services from a variety of sectors (state, private or VCS) which will lead, in theory, to greater diversity of provision, improving the match between demand and supply. Reservations have been expressed in relation to direct payments and older people though. Take-up among older people has been slower compared with younger recipients and there is a concern that so-called 'DIY care' may be unrealistic for the most frail and socially excluded older people, "the most socially isolated might find themselves further isolated by personalisation reforms, no longer adequately supported by Social Services" (CSJ, 2010: 204).

Individuals are advised they may need additional support to organise and manage their individual budgets. Some support has been provided by LAs to date, but given the costs associated with this form of help it is an 'at risk' service. The VCS therefore play an important role in providing this extra support which might include;

- advocacy - to provide support in discussions to ensure individuals get what they need
- communication support - to help with, for example, spoken or written communication, including where English is not a first language;
- third party person (unpaid agent) - a third party may be nominated to receive the money on behalf of an individual. They can deal with many practical arrangements.

Where third parties are involved in receipt of financial support, the risk of financial abuse arises. The charity Age UK has also warned that it has concerns over individual budget plans as many older people will not want to become employers of carers or shop around for provision.[6] Evidence suggests that older people feel that planning and managing their own support is a burden and a

[6] http://www.guardian.co.uk/society/2010/nov/16/1m-elderly-get-personal-care-budgets?intcmp=239

potential source of anxiety which can lead to lower wellbeing than having traditional services provided (Glendinning et al, 2008).

The ethos running through the various reports cited above, continues to inform thinking by local authorities and the new coalition government, with a recognition that health and social care need to be blended to assist individuals as whole people. Dignity, choice, social inclusion and empowerment also remain central goals. The extent to which these ideals have translated into concrete practice, however, is less clear. The Centre for Social Justice, for example, notes that "in policy terms, reforms to tackle loneliness, isolation and social exclusion have been lukewarm, with the Government largely failing to act on the implementation of its *Sure Start to Later Life* report" (CSJ, 2010; 28). In other reports, such as *Our Health Our Care Our Say***,** and *Putting People First***,** a preventative agenda is set out, arguing the value to individual well being and the public purse of early care and 'little bit of help' interventions to avoid costly subsequent deterioration. As discussed below, however, preventative practice has failed to materialise, largely due to budget constraints which direct resources to emergency and crisis situations alone. Preventative support in practice therefore tends to fall to the VCS which leads to patchy provision across the country and often incurs costs which can be prohibitive for those experiencing poverty.

The Partnership for Older People Projects (POPPs) pilots set up 147 new projects across the country from lunch clubs to more ambitious and formal preventive initiatives such as hospital discharge and rapid response services. Many schemes were acknowledged as innovative, cost effective and appreciated by a wide range of older people in different circumstances. Yet, despite the success of the pilots, only 20 per cent of the projects are to be continued locally (CSJ, 2010).
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The precise nature of care services in terms of funding, delivery and content are undergoing a process of change, as responsibility for provision becomes increasingly devolved (discussed further below). Therefore, the extent to which policy developments, introduced over the past decade, will continue to apply, remains unclear.

## 3.2 Focus on neglect

The policy agenda outlined above covers a wide range of concerns facing older people, including: social care, health, active ageing***;*** consultation and involvement***;*** discrimination; housing, independent living and autonomy***;***

poverty, finance and benefits and volunteering. The key legislation and policy documents with a more direct focus on neglect and the protection of adults include;

- **No Secrets (2000),** published by the Department of Health and the Home Office, this report provides guidance to statutory agencies on how vulnerable people should be protected against abuse whether physical, psychological, financial or sexual. Responsibility for co-ordination rests with the Local Authority.
- **Safeguarding Adults (2005)**, a National Framework documents published by the Association of Directors of Social Services (ADSS). The 'Safeguarding Adults' policy includes a clear statement of every person's right to live a life free from abuse and neglect. Since the publication of 'No Secrets', at least 90 local authorities have appointed a lead officer for 'adult protection work' within a multi-agency partnership context. The document collects best practice and aspirations together into a set of good practice standards – which is intended to be used as an audit tool and guide by all those implementing adult protection work.
- **Safeguarding Adults - Report on the consultation on the review of 'No Secrets' (Department of Health, 2009).** The report provides analysis of the responses it received to the consultation, but no policy responses have emerged. The last Government was committed to the introduction of a framework for legislation and the establishment of an inter-departmental Ministerial group on adult safeguarding but the future remains uncertain under the coalition government.
- **Review of In Safe Hands: Guidance on the Protection of Vulnerable Adults in Wales (Welsh Institute for Health and Social Care 2010)**. Building on the 2000 report In Safe Hands, the document aims to highlight where improvements are needed and, in particular, sets out to;
  - develop a culture in Wales that does not tolerate abuse;
  - raise awareness about abuse;
  - prevent abuse from happening wherever possible;
  - support victims to stop abuse continuing, access services they need, including advocacy and post-abuse support and support over-stretched carers;

  The overall aim of the review was to consider and assess the continuing effectiveness, appropriateness and robustness of the In Safe Hands guidance, reach conclusions and make recommendations about where improvements can be made. 16 recommendations are provided.
- **Adult Support and Protection (Scotland) Act 2007**, implemented in Scotland in 2008 has pioneered the introduction of legislation in the UK

> to protect adults from harm. The Act makes new provisions intended to protect those adults who are unable to safeguard their own interests, such as those affected by disability, mental disorder, illness or physical or mental infirmity, and who are at risk of harm or self harm, including neglect.

Reports produced in the last couple of years tend to highlight the need for new concepts and terminology to reflect the fact that individuals do not like to be treated or discussed as passive victims. Instead, policy increasingly aspires toward the co-production of services, empowerment, voice and the full engagement of citizens;

> "People do not like being labelled as 'vulnerable'. People are not intrinsically vulnerable: some situations make people vulnerable. Vulnerability fluctuates over time as situations change. A new statutory definition is needed of people who are at risk of harm from abuse and who are not in a position to protect their own interests. There should be more of an emphasis on prevention as well as protection and on post-abuse support. The phrase 'Safeguarding Adults' has a broader scope than 'adult protection' that better reflects this wider agenda" (WIHSC, 2010)

The use of terminology such as 'abuse' and 'perpetrator' is also of concern when referring to the spouses of older people with dementia and other conditions. Instead, in many cases, a greater emphasis on the support needs of carers is a more appropriate response to resolving emotionally charged and physically challenging circumstances.

## 3.3 Provision

Understanding the scope and emphasis of current provision for older people is important in order to avoid duplication of services, and meet BIG's requirements for additionality, by which funding seeks to complement rather than replicate statutory provision. The voluntary and community sector often steps in where statutory provision is either missing or falls short of expectations and need in terms of quantity or quality. BIG plays an important role in supporting the VCS, encouraging innovation and helping to fill the gaps either vacated by or beyond the remit of the statutory sector.

Community care services designed to ensure that older people are not neglected and their physical needs are met can include care home placements or services to help people carry on living independently in their own homes. In

order to access these services contact must be made with social service departments with referrals being made either by individuals, their friends and family, organisations such as Age Concern, or by GPs. The need for care services may also be initiated by a hospital visit, following illness or a fall for example. Many older people struggling to cope may not, however, come to the attention of social services, prompting the need for outreach activities.

There is a wide range of community care services including, but not limited to:

- Home care services
- Home helps
- Recreational activities.
- Meals on wheels (or frozen food delivery)
- Home adaptations - such as grab rails and stair lifts
- Housing support services - such as wardens
- Day care
- Residential care homes
- Support for carers - including respite care

Some of the above meet the physical needs of older people while other services are designed to ensure social inclusion, quality of life and emotional well being. The range of support is fairly comprehensive in principle, seeking to meet the social support, personal care and health needs of older people. In practice, however, access has been severely restricted for a number of years, a situation likely to deteriorate further in the current economic climate.

For those who do secure state support, as resources are increasingly restricted, provision becomes focused on personal care services rather than social support and “any activity that might form greater social connections, making individuals ever more dependent on the state” (Cottam, 2009). As noted in Smeaton (2009), social support represents a key gap within the overall provision of statutory support for older people. The extent of unmet need is highlighted by a number of key statistics;

- In the UK, 457,383 people received home care services in 2008 (Help the Aged, 2009)
- Between 2000 and 2008, the number of households in England receiving home care services decreased by 18 per cent (NHS, 2009)
- In England, only 59,148 households were receiving low level care in 2008 at 2 hours or less per week (NHS, 2009) compared with 2,450,000 older people in England who have care needs (Wanless, 2006).
- 80 per cent of people in need of home care do not get it from the state (Wanless, 2006)

- 1.5 million people in England have care and support needs that the state does not meet (CSCI, 2008)

While some of these statistics are a few years old, the scale of unmet need has not been reduced with the passage of time and stakeholders in government and frontline services all recognise that a different approach is needed to solve the problem of growing demand accompanied by shrinking budgets. These new approaches have yet to materialise on a large scale.

## 3.4 Eligibility

Social services provide support on the basis of need, but eligibility criteria and costs vary geographically. The first stage to secure care is an interdisciplinary assessment which focuses on health and personal care needs plus a consideration of social support needs. Social and personal care needs are initially assessed by a local authority social services department which will conduct a Community Care Assessment to identify;

- particular physical difficulties, for example, problems with walking or climbing stairs
- particular health or housing needs
- current sources of help such as carers, family or nearby friends, and their willingness to continue providing care
- the needs that people who provide care may have.

Once an assessment has been carried out, the local authority social services department will decide whether an individual is entitled to services. Eligibility is based on level of need, not on wealth. Implementation of rules of eligibility is a key source of gaps in provision for older people, potentially risking widespread neglect of a range of needs among older members of the community.

Eligibility criteria for adult social care since 2003 was set out in '*Fair access to care services - guidance on eligibility criteria for adult social care*' (2002). This was replaced in February 2010 by revised social care eligibility guidance; *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care, Guidance on Eligibility Criteria for Adult Social Care* (DoH, 2010c). The new framework is still based on risks to independence that arise from various forms of disability, impairment and difficulty. The new guidance also continues to prioritise risk and need into four bands - critical, substantial, moderate and low. There is a new emphasis on recognising the needs of carers, and the importance of prevention is re-iterated

on the basis of growing evidence that early interventions can prevent or delay older people from needing social care.

The Personal Care at Home Bill was announced in the Queen's Speech on 18 November 2009, introduced to Parliament on 25 November and received Royal Assent on 8 April 2010. Regulations within the Bill included provision for those with the highest personal care needs (which are 'critical' and needing help with four or more activities of daily living) to receive their personal care free from 1 October 2010. The new Government however has confirmed that it will not be commencing the Personal Care at Home Act[7]

This system has been condemned, as growing demand has forced approximately three quarters of councils to ration their support and confine help to people with substantial or critical need only. It means many vulnerable people who need social care simply do not receive it. The Commission for Social Care Inspection admits that social care is seriously underfunded (Hudson and Henwood, 2008)[8], a situation that is likely to worsen.

A further key controversy is that when implementing care services guidance, councils are advised to take account of locally allocated resources. Thus, individuals with similar needs are not expected to receive similar services up and down the country because, despite a common eligibility framework, the different budgetary decisions of individual councils will mean that some councils will be able to provide services to proportionately more adults seeking help than others. In addition, service provision is configured differently in different parts of the country. This permissible difference in funding outcomes has raised objections that the care system involves a post code lottery (Hudson and Henwood, 2008). With councils handed more discretionary power by the current government's approach to adult care, discussed above, this type of lottery will become more extreme with priorities locally determined. As a consequence of locally permissable differences in funding priorities, gaps in provision have a geographical dimension, reflecting local resources, deprivation and political will.

## 3.5 Looking to the future

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[7] http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/DH_110405

[8] http://news.bbc.co.uk/1/hi/health/7684716.stm

In addition to the publication, in December 2010, of *A Vision for Adult Social Care: Capable Communities and Active Citizens*, a consultation on a new strategic approach to quality and outcomes in adult social care has been launched – *Transparency in outcomes: a framework for adult social care (DoH, 2010b).* Paying for social care is a high profile, challenging and disputed issue which will be addressed in a White Paper later in 2011, to be followed by legislation. The vision presented in these documents represent a continuation of the adult care philosophy introduced by the last government, with an emphasis on 'independence' 'prevention' 'personalisation' and 'quality'. Care service delivery is to be partnership based , between individuals, communities, the voluntary sector, the NHS and councils. The agenda for adult social care is therefore described in terms of a power shift from the state to the citizen.

The Comprehensive Spending Review (2010) has emphasised the need to reshape public services, continuing and strengthening the shift of power and responsibility to local authorities. The Government is due to announce further details of its reform programme in a White Paper in early 2011.[9] The decentralisation agenda emphasises the benefits to local government and service users in terms of improved freedom and flexibility at a local level. The extent to which this greater freedom to set budgets and priorities will translate into improved frontline services remains a moot point however, given that councils are to face an average loss of grant of 7.25 per cent in real terms in each of the next four years. The cuts are to be front-loaded with a reduction of about 11 per cent expected in the first year, while overall revenue funding from Government will reduce by 26 percent in real terms between 2010-11 and 2014-15 – excluding schools, fire and police.

Almost three-quarters of councils now believe they will need to make compulsory redundancies, with more than a third of upper-tier authorities expecting to slash their workforce by more than 20 per cent by 2015/16. In terms of meeting the needs of older people, an additional £2 billion to support adult social care by 2014-15 has been guaranteed[10]. Yet, despite this additional funding, finance directors at upper-tier councils said this was the service likely to be hit most by the cuts[11]

## 3.6 Implications for the VCS

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[9] www.hm-treasury.gov.uk/spend _index.htm.
[10] www.communities.gov.uk/documents/localgovernment/pdf/1745945.pdf
[11] www.publicfinance.co.uk/news/2010/12/scale-of-local-government-cuts-took-fds-by-surprise/

Community groups and charitable organisations are to take centre stage in what is described as a Big Society. The coalition government launched their civil society programme within the first week of taking office, spelling out how charities, voluntary groups and a new generation of community organisers will be tasked to help tackle some of the most stubborn social problems. The reform agenda is set out in the publication *Big Society Not Big Government: Building a Big Society* (2010)[12]. Initiatives include; the establishment of National Centres for Community Organising and the training of 5,000 independent community organisers to help people set up and run neighbourhood groups.

Given the coalition government's commitment to partnership approaches and a 'Big Society' philosophy, solutions to the budget deficit are likely to lead to an expansion of welfare pluralism, with services increasingly delivered by a mix of statutory, private, third/civil society and informal sectors. This plurality may accelerate over the next few years as solutions to unprecedentedly rapid budget cuts are implemented. The precise mix remains uncertain however. While there is likely to be greater demand for VCS organisations, local Authorities and NHS trusts are already taking steps to reduce grants to community groups (Butler, 2010). The Office of Civil Society has had an £11m cut and a further £4m incubator fund to help community groups in London win public service contracts has been scrapped. Clearly a tension is emerging between the Big Society ethos and budgetary objectives.

Local solutions to budget restraints may take a number of forms depending on political will and local socio-economic conditions; some services may be lost altogether, some reduced and others passed from local authorities to the private sector, social enterprises or other branches of the voluntary and community sector. A variety of models for change will emerge as Local Authorities decide whether to provide, finance or regulate services (or combinations of all three). As the scale and range of provision for older people undertaken by the VCS evolves, implications for the type of project and size of funding requested from BIG will emerge.

The resulting shape, extent, costs and nature of support for different local groups is likely to differ across the country. Of particular concern are the potential consequences of change for more vulnerable groups within disadvantaged communities. Older people can be particularly vulnerable to social exclusion and poverty, their voices are often hidden and they are a prime group of service users. Both eligibility for and costs of services are therefore of concern particularly in light of evidence which is emerging that the costs of

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[12] www.conservatives.com/News/News_stories/2010/05/~/media/Files/Downloadable%20Files/Building-a-Big-Society.ashx

services are being passed on to local users by means of fees; "*rather than making cuts in their spending as was intended, local authorities are instead raising their prices to make up the shortfall in grants from central government. The 'stealth' charges introduced by some councils include:..extra bills for home helps and meals on wheels*...[13]" (Flyn and Chittenden, 2011)

## 3.7 In summary

In terms of policy related to social inclusion and social care needs, the agenda relating to older people has increasingly moved toward independent living, active ageing, dignity and better integration of service provision. Low-level services and preparing for the future are recognised as the route to a longer, healthier and more independent life. A shift toward increasingly collaborative ventures between the statutory and voluntary sector are also being encouraged with implications for BIG. Despite wide ranging health and social care developments, the statutory sector continues to face resource challenges, leading to rationing and considerable unmet need – a situation which is predicted to worsen.

In terms of abusive neglect, a number of bodies and agencies exist to safeguard and adults. A new regulatory system for adult health and social care providers was introduced by the Care Quality Commission from April 2010 and from October 2010, adults who fund their own social care, including care home placements, will have access to an independent complaints review service provided by the Local Government Ombudsman. Despite frameworks and guidelines setting out good practice and expected standards of care, neglect and cases of abuse regularly come to light, whether in older peoples own homes or in institutions such as hospitals and care homes. Many instances of abuse also remain unreported, whether associated with self neglect or neglect by others. While the regulatory framework and recognition of the problem of elder abuse and neglect is improving, many challenges remain. In addition to regulation there is a need for greater awareness raising, particularly among primary care teams including, GPs, community nurses and other healthcare staff who are key points of contact for older people.

Given the extent to which neglect and abuse can remain hidden, it is important that different agencies, local communities and the VCS all work together to recognise, prevent and treat the risk, and cases, of abuse and neglect. When considering the types of project to fund, BIG should recognise the nature and dimensions of neglect in the round and seek to strategically support initiatives

[13] For example, Nottinghamshire.

which raise awareness, identify, reach, prevent and treat neglect in its various forms.

# 4. Older people and the role of BIG

- The statutory sector increasingly faces resource challenges leading to the rationing of care and considerable unmet need.
- Social support in particular remains underfunded and is, in practice, a low priority. BIG can therefore benefit older people most effectively by funding a highly diverse range of day support activities, low level services and outreach activities to identify neglect and the most socially excluded.
- Initiatives and volunteers to assist older people access mainstream facilities and simply get out of the house are in notably short supply.
- Examples of good practice can be found around the country, these tend to include outreach activities and are holistic in nature. The needs of carers and cared for are recognised, as are the diverse range of preferences and aspirations among older members of the community.
- Effective groups are often also user led, run by older people for older people. Self-help, mutually supportive groups meet the preferences of older people to both give and receive help and represent a sustainable model of provision.

BIG has a dual funding approach. Many programmes reflect strategic thinking and are geared to specific outcomes. Others are demand led, with communities setting their own agenda and identifying local needs. This mix of funding - small grants, open funding and targeted strategic investments remain central to BIG's strategic framework (BIG, 2009). A range of initiatives to benefit older people have been supported since BIG was set up in June 2004. Few specific programmes have targeted older people, but the Community Fund treated older people as a priority group and the New Opportunities Fund also ran a number of strategic programmes reflecting the needs of older people, including; Healthy Living Centres, Veterans and Community Access to Lifelong Learning. In addition, the Awards for All England and Reaching Communities programmes devoted a large number of grants to causes and projects benefiting older people.

## 4.1 BIG activities targeting older people

The Community Fund's grant awards were informed by a number of key goals; to reduce isolation, promote independent living, minimise the impact of failing

health and mitigate the effects of low income. In this way, beneficiaries from projects would be better placed to contribute to and participate in society more fully. The Community Fund is now closed but some projects continued to be funded until 2010. Analyses by Barnes et al (2007) indicate that most of the money distributed by the Community Fund for older groups supported projects within the following broad themes: Social, Recreational, Educational, Health, Advice and Transport. At least one fifth of grants supported social activities, community centres or events. Much Community Fund funding was about social interaction, active ageing and companionship, whether dancing, bowling, day trips or just coming together in a village hall to reminisce. These initiatives, supporting social, recreational and physical activities, featured more prominently than projects and schemes devoted explicitly to 'problems' such as poverty, isolation, loneliness and social exclusion. Although the wide range of 'social' funding does of course function to combat social exclusion, it is possible that much of the social and recreational funding was received by non-marginalised older people. The hard-to-reach socially excluded were only explicitly referred to in a minority of cases. Broadly speaking, therefore, the orientation of Community Fund support was preventative in nature.

Whereas the Community Fund responded to local community goals allowing communities to set their own agenda for support within broad parameters, the New Opportunities Fund established several clear cut objectives in terms of strategic outcomes and established programmes of funding accordingly. Three key themes structured the New Opportunities Fund programme; Health, Education and the Environment.

Excluding the health programmes, such as Cancer Care or Heart Failure Support Networks, of the 44 main strategic New Opportunities Fund programmes the following were of benefit to older people, either exclusively, or as part of the wider community:

- Active Lifestyles
- Community Access to lifelong Learning
- Veterans: Home Front Recall and Heroes Return
- Healthy Living Centres
- New Opportunities for Health
- Peoples Network
- Information and Communication Technology
- Transforming Our Space

Barnes et al (2007) conducted a beneficiaries age analysis of New Opportunities Fund projects. The incidence of funding allocated toward people in the age ranges 16-64, 35-64, 65-74 or 75 plus were found to be in a distinct

minority compared to projects directed toward the under 16s or those aged 16-35. Dodds (2003) also raised lack of funding for older people as an issue, noting that a great deal of BIG's funding was devoted to young people and children.

More recently, a range of programmes have been developed under the strategic themes of Community Learning and Creating Opportunity; Community Safety and Cohesion; Promoting Well Being.

A brief review of projects funded under the Awards for All programme over the past few years (2008-2010) indicates a wide variety of projects oriented toward the needs of older people. Within the classification above, which differentiates between abusive neglect, self-neglect and social neglect, BIG funding appears to have been focussed almost exclusively on the latter. Indeed, when searching through the Merlin database for examples of projects BIG has funded which address the needs of older people, the term 'neglect' does not arise in any project descriptions, whereas tackling social isolation or exclusion is a fairly commonly cited goal. Where neglect is defined as a form of elder abuse, the problem requires intervention by statutory social services and/or police services. It is perhaps not surprising therefore to find an emphasis on the social dimensions of neglect among VCS provision.

Projects designed to improve the quality of life of older people by means of exercise, activities, social or learning opportunities are most common and include the following;

- Befriending services to combat isolation and loneliness (Age Concern)
- Premises funded to hold a variety classes and session for older people to socialise
- Subsidised taxi schemes to promote mobility, inclusion and access to services and facilities
- Television and DVDs purchased for an elderly residents movie night (Tenants Association)
- Dance and social clubs awarded funds for new equipment
- Funding for day trips and shopping trips
- Healthy living (several)
- Dance and exercise classes
- Bowling clubs (many)
- Luncheon clubs
- Materials for craft activities in a club setting
- Access to Arts trips and courses
- ICT training (several) and a purpose built online forum
- Home support out-reach services

- Award for a venue in a relaxed cafe style to encourage befriending and networking. The project included funds to train older people to provide the support services, and share their skills in IT
- Award to train a team of volunteers and cover their expenses to help isolated older people in the community (a few projects have been funded which recruit, train and cover the basic expenses of volunteers)

A review of Reaching Communities (RC) and People and Places Wales (PPW) funding for older people between 2008 and 2010 indicates a similar array of projects as funded under the Awards for All programme in terms of scope, although the scale is typically larger. Many projects are focussed on social inclusion by means of social activities, befriending, transportation, IT training, advocacy and signposting toward social services. The key difference arises in relation to staff costs. Many RC and PPW funded projects have used grants for project worker salaries and volunteer expenses.

Within Wales, people over the age of 50 are being supported by a new £20 million programme – AdvantAGE. This programme, which distributed funds in 2010 is designed to help older people face new challenges and key life changes by means of befriending or advocacy services.

## 4.2 Addressing Neglect – good practice examples

Examples of projects, provided below, indicate the type of scheme that might effectively be funded by BIG in the future. Two projects that are particularly focussed on the prevention of and responses to neglect, funded under the Reaching Communities programme, include;

- **Age Concern Hereford** - received funding to promote befriending and advisory services, with a focus on rural isolation. An outreach team travels to the homes of older people to conduct an initial assessment, on the basis of which individuals are then signposted to relevant agencies. The team continue a relationship with the older person by matching them with a volunteer who will maintain contact. Age Concern Hereford actively seek volunteers and have a dedicated web page[14] which describes a wide variety of volunteering opportunities – outreach work, telephone support services, falls prevention services, footcare scheme, administration, transportation, gardening circles and IT training. The mutual benefits to those helped and the volunteers are emphasised. Full training is offered and any expenses incurred are covered.

[14] http://www.achw.org.uk/web/Volunteering

- **Harrow Carers** - has secured funding to support older carers aged 75+. Recognising that the well being of older people is often dependent on the health and support of their carers, Harrow Carers seek out and support carers identified as unpaid, isolated, vulnerable and at risk of social exclusion. One case study on the Harrow Carers website[15] highlights a broad ranging package of support which benefits both carers and cared for, preventing further deterioration of health and welfare. One 76 year old man who cares for his housebound wife has responsibilities which have started to take a toll on his health, stress levels and back pain. An older carers support worker has been assigned to the man. As a consequence they have now successfully applied for Attendance Allowance for his wife, which has led to extra support at home. The support worker also involved the social services who have provided a variety of home adaptations and an emergency pendant. The carer also now attends coffee mornings which has enabled him to meet other carers and ensure he takes care of his health. A regular newsletter provides information and advice about carer services and latest news and government policies.

Several case studies of projects funded by BIG which support older people are presented in Barnes et al (2007). Many of these were good practice projects, providing a holistic approach to the multiple needs of older people, including the need for social contact, befriending and emotional support. One such project is summarised below;

- **Oasis Centre – Good Neighbour Project -** The Good Neighbour Project in East Belfast started in autumn 2005 with BIG support for three years. It was recognised that some older residents were experiencing isolation that was exacerbated by recent changes brought on by regeneration (e.g. uprooted residents and altered surroundings). The Good Neighbour Project provides intensive support and works in partnership with statutory agencies which have invested interest in the project. It reaches people in their homes and addresses practical and emotional needs to help improve older residents' quality of life. BIG funds a full-time development worker who matches clients with volunteer befrienders who visit their clients once or twice weekly and build a relationship of trust and friendship over time. To alleviate loneliness clients are encouraged to become socially active and befrienders accompany them to community activities.

Good practice projects have also been funded by the DWP as part of the **LinkAge Plus initiative.** The DWP invested £10 million in eight pilot areas from 2007-2009 to promote a holistic approach to older people service delivery. Initiatives to reduce social isolation were a key feature of the programme which set out to involve older people in service design and delivery, forge partnerships

[15] www.harrowcarers.org/projects/older-carers-project/case-studies/

between Local Authorities and other organisations, take a preventative approach and ensure a focus on the 'whole person' to include health, social care, independence and well being needs. A full evaluation has been conducted which concluded that the early intervention and 'little bit of help' approach of LinkAge Plus is cost effective and can avoid more expensive interventions later in life (Davis and Ritters, 2009). One project was set up in Gloucestershire - a rural county with a dispersed population and a higher proportion of people aged 50+ than the national average;

- **Village Wardens Project -** Research suggested that far fewer older people in rural areas were likely to pick up the telephone and ask for help and advice but they would be happy approaching someone they knew and trusted within the community for help and advice rather than 'officials'. In response the concept of the Village Agent was developed i.e. a locally based person who is able to provide face to face information and support which enables older people to make informed choices about their future needs**.** 30 Village Agents were recruited and trained. After 2 years the following outcomes were observed; a 50% increase in referrals to the Adult Helpdesk for social care support demonstrating that the Agents were contacting older people who were previously isolated and even though there was a need were not in contact with the appropriate agency; older people, especially those with mobility difficulties are now more visible; social networks have been supported and promoted including library clubs, social/lunch clubs, an internet café in the Village Hall; fortnightly outings by minibus, quiz nights and Bingo. Transport issues have also been resolved with several bus stops relocated, so they are now in locations which older people find easier to use.

Given the projected growth in the numbers of carers in the UK and in the incidence of dementia, associated with an ageing population, this is a priority area for central and local government in terms of social and health care. They are also a key concern in terms of neglect and social isolation. In the UK around 6 million people perform a caring role, which, according to a Centre for Social Justice report ***The Forgotten Age*** (CSJ, 2010) subsidises the public purse to the tune of around £90 billion a year. The CSJ report also observes that family breakdown, which has increased over recent decades, has led to a decline in the willingness of family members to provide care. As a consequence, the workload of primary carers has increased significantly, with more than a fifth now providing 50 hours or more care a week. This intensity of care can leave carers socially marginalised. A large proportion of informal care is provided by older people. By 2037, it is estimated by Carers UK that the number of carers could have increased to nine million[16]. Indeed, it is suggested that eldercare may become *the* work and family issue of the 21st century (Smith, 2004;

[16] See http://www.carersuk.org/Aboutus/Whoarecarers/Tenfactsaboutcaring

Ghosheh et al, 2006). Alzheimers cafes are a popular service to prevent neglect and re-integrate carers and those with dementia back into social settings;

- **Alzheimers Cafés for carers and cared -** There are 5 Alzheimers Cafes in the UK. The cafés host monthly gatherings where those with dementia and their family and friends can be together in a safe, welcoming environment, in the company of other carers, volunteers and health care professionals. These settings provide emotional support, education and are a source of social interaction. They are a forum for carers and the cared for to exchange experiences and learn more about the illness with guest speakers, entertainment and other activities. Advice and support is also available from visiting professionals and community psychiatric nurses who regularly attend the evenings. The most recent café opened in Staffordshire in 2008 - developed by the Carers Association Southern Staffordshire (CASS) and funding for three years has been received from Staffordshire County Council and South Staffordshire and Shropshire Healthcare NHS Foundation Trust

Housing is a key area where good practice examples have emerged. Living in an environment which is safe and enabling promotes well being, health and social inclusion. Two examples of positive care home settings are cited in Blood (2010):

- **Merevale Residential Home –** based in Warwickshire, this is a specialist home for people with dementia. "All members of staff view themselves as activity workers and seek to connect with and involve residents in every aspect of the home's life. The approach, which is about attitude rather than extra cost, has resulted in 'excellent' ratings and national awards" (Blood, 2010: 8).

- **Nas na Riogh Housing Association –** based in the Republic of Ireland, the Housing Association has converted a disused convent to develop self-contained sheltered accommodation. This approach is described as innovative as the site is in the middle of town and the old convent is used also for other purposes, generating a vibrant intergenerational community. Additional facilities, which are staffed by volunteers, include an arts venue, a soundproof rehearsal space, meeting and activity rooms, counselling rooms and a community coffee shop. Residing in a multipurpose building prevents older people being segregated away from the rest of the community.

There are a number of examples of schemes and settings, across the UK, where people who have 'support needs' actually support each other by means of telephone and internet support groups, collectives, care co-ops and communes. These approaches to meeting needs tend to be "fluid, negotiable, non-stigmatising and based round real relationships rather than on set tasks or

time slots.” (Hare, 2010). Mutual-support type schemes are gaining ground as a means of meeting needs without incurring excessive costs

For many older frail people, one-to-one support is needed to facilitate access to the outside world. But for the majority of older people, this degree of assistance is not necessary and mutual support groups can improve quality of life. It is increasingly recognised that given budget restraints and an aversion among some older people to accept formalised public service care, self-help solutions can be a good long term and self sustaining alternative. Southwark Circle, is one such self help group:

- **Southwark Circle** is a self-help group designed to support older people who may be lonely, often live alone and who “sometimes go days without having a proper conversation with someone”. Southwark Council have invested in the group which aims to become a self-sustaining social enterprise, combining paid-for services with unpaid mutual self-help. The group was launched in 2009 by going door-to-door to recruit people who would both contribute time and effort to help others and receive services in return. £30 a quarter for membership pays for a central volunteer run telephone service which forms the hub from which a variety of mutual support activities are created by putting older people and neighbourhood helpers in touch with each other. Members help each other in a wide variety of ways such as teaching language skills, providing ICT support, helping with odd jobs around the home and social networking. The self-help nature of the group provides the kind of support that many older people need by expanding their opportunities to contribute and to connect. A sense of purpose is thereby engendered. The project reflects a re-focus away from public services and toward the social economy.

In this final example of a good practice charitable organization, the focus is on responses to neglect and abuse rather than social engagement as prevention;

- **Action on Elder Abuse (AEA),** is a specialist organisation that operates across the UK (www.elderabuse.org.uk/About%20AEA/about_us.htm). AEA is a charity which focuses exclusively on the issue of elder abuse and addresses abuse within people's own homes, within sheltered housing, and within care homes and hospitals. AEA operates a helpline, which provides information, advice and support to victims and others who are concerned about or have witnessed abuse. AEA also provides a special advice service for the advocacy sector. These helplines provide information on the nature, circumstances and dynamics of elder abuse.

For a list of other good practice schemes which target different aspects of older peoples’ lives see CPA (2011).

## 4.3 Good practice characteristics

An overview of the good practice examples highlights a number of common characteristics. Many of the organisations and schemes adopt holistic approaches to fourth age needs, recognising their multiplicity. Problems are often not in isolation. A number of factors can trigger a shift in well being or ability to cope later in life, such as the death of a partner or the onset or deterioration of physical and mental capacity. In turn, these circumstances can then lead to increasing isolation, particularly as causal circumstances are often interconnected. Losing a partner, for example, may also mean the loss of a carer and/or the loss of income (CSJ, 2010)

Good practice ‘one-stop’ services will provide the comfort of a welcoming place to visit and/or a friendly face to talk to, combined with financial advice or assistance and signposting to caring provision if needed, among other services. Multiple service provision may include befriending, learning opportunities and a variety of stimulating activities.

Importantly, good practice will also include the identification of older people in need who have not necessarily come forward to ask for help. Outreach activities are therefore central to any strategy which seeks to root out and eradicate neglect, abuse and isolation. Reaching people in their homes is achieved most effectively at very local levels such as Housing Association groups with a knowledge of and interest in their local communities and housing estates. Age UK, with 330 branches across the country also have a strong local presence which has, over the years, developed into a trusted brand which people know they can turn to for help or advice. Other local groups, often based on principles of mutuality, may also form organically.

Good practice provision fosters the development of ongoing relationships and face-to-face contact where possible, nurturing volunteers with training and support.

Each of the good practice examples also put into practice the principles of promoting independence and treating older people with dignity, as individuals with a future who hold distinct aspirations and preferences. They also recognise that many older people in their fourth age wish to continue making a contribution to their communities, perhaps by volunteering, and are not to be treated simply as vulnerable, passive recipients of services. User led services are therefore recognised as ideal models of support.

Finally, organisations and projects which also focus on carers are an important component of holistic support packages for older people. Recognising the needs of carers is an important element of the preventative agenda, preventing carers from encountering the same neglect, exclusion and ill health which some older people risk as their capacities diminish.

## 4.4 Gaps in provision

There is considerable potential for BIG programmes of funding to make a difference to older people. Despite an increased orientation toward the needs of older people, adult social and health care services face significant challenges in a context of changing demographics, heightened expectations and increasingly stringent financial restrictions.

The range of statutory support is fairly comprehensive in principle, seeking to meet the social support, personal care and health needs of older people. In practice, however, access is severely restricted and for those who do secure state support, as resources are increasingly restricted, provision becomes focused on personal care services rather than social support and costs can be prohibitive. Social support therefore represents a key gap within the overall provision of statutory support for older people. There are indications that local authorities may cut support for people with moderate needs even further, increase charges and reduce care provision (CPA, 2011). There will therefore continue to be both acute needs and lower level needs for care, befriending and day-to-day services (Young Foundation, 2009: 231) but, as discussed above, it remains unclear how or who will pay for these services and what mix of formal and informal service provision will emerge.

In considering the type of organisations and projects that could be supported within a funding programme focussed on neglect, it may be helpful to break down the range of needs into six discrete stages of identification, support and prevention;

- Outreach activities are paramount to identify older people in need, whether experiencing or at risk of neglect, isolation or abuse. Self neglect cases are also a challenge to detect as older people often do not recognise their circumstances as potentially harmful.
- To promote understanding of neglect and abuse, education and training of frontline carers and key older people contacts has been required and further awareness raising initiatives among the wider population to recognise signs of neglect would help.

- Campaigns, both nationwide and highly local, can help older people to recognise and respond to neglect and mistreatment by highlighting where they can go for help and emphasising that support can be discrete, confidential and sensitive to specific living arrangements and ongoing relationships.
- More help is needed for carers who may be both neglectful (whether deliberately or not) but also isolated and possibly abused themselves.
- Post abuse services also play a role in a full package of support.
- There is considerable demand for a wide range of social support services to prevent neglect recurring or arising.

Smeaton (2009) conducted a review of the needs of older people in the fourth age and identified a range of gaps in provision relating to problems of neglect, social exclusion and crisis. Summarising the findings, gaps were identified as follows;

***Daycentre provision*** - Of particular value is support for schemes that provide multiple services, for example social/recreational activities, befriending schemes, advisory /information services and, of particular importance in identifying incidences of neglect – outreach work. VCS organisations struggle financially to provide a core service and therefore find it difficult to meet the demand for a diverse range of additional activities and opportunities. There is a clear need for different models of social support and variety within Day Care settings, to reflect heterogeneity of personalities, health and preferences. BIG can promote such diversity by supporting a large number of different project and organisational types which are dispersed geographically and which, collectively, provide a wide range of options. Without day care, admission into residential care would be the only option for many people, yet, day care is severely rationed by local authorities (Smeaton, 2009, CSJ, 2010)

***Access to mainstream facilities*** - More support for groups and projects which help older people to leave their homes and participate in everyday activities and leisure pursuits is needed.

***Befriending*** - There remains considerable unmet demand for social networking and befriending support. Interviews with VCS staff suggest that demand for Befriending services in a variety of forms is high with considerable geographic variation in provision. It should also be noted that living in care home settings does not preclude the possibility of loneliness and abusive relationships can and do exist in these 'protected' environments. Befriending and advocacy of care home residents is also a key gap in provision.

***Gardening support*** – Gardens can be very important to older people but can be difficult to manage thereby causing distress. Shabby gardens can also be a magnet to con-men and alert the unscrupulous to the presence of vulnerable older people who may then become a target for criminal activity. Gardening oriented projects represent a key gap in provision which BIG could support to improve quality of life.

***Little bit of help*** - Concern has been expressed about the focus of support for older people at home on those whose needs are intensive (including bathing, lifting, and dressing), at the expense of those with lower-level preventative needs (cooking, help around the home, transport) despite claims that a preventative agenda is a priority. Gaps in the provision of social care and support inevitably arise following these rules of eligibility, gaps which tend to be filled by friends, family and the third sector or, for some groups, remain unmet, leading to neglect and deteriorating living conditions.

***Transport*** - A survey of charity workers revealed that the costs of purchasing, running and maintaining transport facilities were a significant barrier to service provision. Charities require considerable support to continue providing this critical service. For many older people, adequate and affordable transportation is a prerequisite for access to community life.

***Digital inclusion*** - ICT can be invaluable for the less mobile who can use email to keep in touch with friends and family around the world, can shop online and can use technology for learning, entertainment and information purposes. Provided support is also available to help older more fragile people to leave their home on a regular basis, ICT can promote social inclusion.

***Information, advice and advocacy* -** Information, advice and advocacy are essential for older people to be in control of their lives and to access the services and support they need. As local authorities and statutory provision is further rationed, advice and support from the VCS is increasingly needed to fill the gaps.

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***Crisis Services*** - There is a general lack of crisis services during evenings, weekends and national holidays, and there is a need for services which can help older people with key transition periods associated with later life, such as bereavement, moving house, the onset of ill-health, moving out of hospital, or moving into residential care. Previous research has demonstrated the value of support services during such transitions (Parry et al, 2004; Hill et al, 2007). Bereavement support is particularly important among the 80 plus for whom the impact can be more devastating;

***Dementia support*** **-** Currently one in five of the population aged over 80 is suffering from dementia (around 700,000 people) (Knapp & Prince, 2007). This figure is predicted to reach 1 million by 2025 and 1.7 million by 2050 (ADASS, 2008). Projected service needs for people with dementia are therefore a primary area of concern.

Issues of isolation and loneliness of older people, especially those with dementia, were raised in a study of the support needs of older people (Bell and Bowes, 2006). Individuals with dementia and their carers described the difficulties they faced in getting out and about with a perception that people with dementia are 'sometimes shunned by others, as a stigma was attached to the condition' (Bell and Bowes, 2006).

The needs of dementia sufferers are broad and resource intensive and are largely the responsibility of the statutory sector. Nonetheless, BIG may have a role to play in supporting carers, and in making services accessible to people with dementia. One innovative approach to supporting those with dementia and their carers are Alzheimers cafes which have been set up around the UK.

One older people 'expert' interviewed in Smeaton (2009) suggested that support for dementia sufferers and their carers should in fact be prioritised by BIG, as funding for VCS provision in this area is in very short supply and has the potential to make a significant difference to those with dementia and their families;

> "*There's a huge need on dementia, we've got the national dementia strategy, we're trying to implement that at a local level from the development of a memory clinic through to providing support to carers and dementia sufferers to have social engagement with pop in through a number of cafes we have here. The funding for those cafes for social interaction is very difficult. If there was one specific area for the 80+ I would say, the dementia strategy is all very well but there are no resources to fund it … any money to support dementia cafes, that would be hugely useful …that's going to be one of the biggest areas of growing demand. We've got two, the poppy café and the sunflower café (but) they only open on a Saturday morning .. it's a funding issue*" (Assistant Director for Older people, London borough council)

***Informal Carers*** **-** More generally, carers are at greater risk of poverty, ill health, social exclusion and injury (Carers UK, 2008). In 2001 there were 5.2 million carers, primarily women, providing varying degrees and types of support. It is estimated that the number of carers could increase to nine million by 2030

and  over 3 in 5 people in the UK will become carers at some time in their lives[17].

The care of older people in their homes has traditionally been carried out by friends, family, neighbours and the voluntary and community sectors (Dodds, 2003). Many carers however face isolation, poverty, discrimination and ill-health - informal carers of older people therefore need considerable support to help them help the cared for. One in five carers is forced to give up work but Carer's Allowance  is just £53 a week while those over 65 or sick are ineligible for carers' benefits (http://www.carersuk.org/Aboutus /Howwehelp /Campaigning forchange).

A large proportion of informal care is provided by older people. Although women are associated with family care giving throughout life, more older men than older women are informal carers and this gap widens after age 74. This holds implications for carer respite services and support networks designed to enhance the quality of life for older carers.

Although family carers are favoured by older people in many situations, for personal care, non-family carers are sometimes preferred. In interviews with older people, Bell and Bowles (2006) found that the nature of relationship between a parent and child may be altered if the child started to perform intimate personal tasks for the parent, and some older people wished to avoid this shift. The free personal care provided in Scotland was of particular benefit to informal carers in this regard as a division of caring labour could be established whereby carers could provide social support and professional carers some personal care tasks. As carers had support, older people were able to remain in their homes for longer and some caring relationships were prolonged.

The range and intensity of support required by carers across the country is diverse and largely unmet. BIG can make a significant contribution toward supporting carers who may be in need of networking, emotional and respite support. Without this support, the quality of care of older people may be compromised and the risk of older people being moved into care homes against their preferences may be heightened. Projects such as the Alzheimers Cafes could be replicated across the country to good effect and modified to meet the needs of all older people and their carers.

[17] See http://www.carersuk.org/Aboutus/Whoarecarers/Tenfactsaboutcaring

***Older sub-populations* -** Sub-groups identified as needing more focussed funding and support include; people with mental health problems, people living in rural areas, informal carers and men. Minority ethnic groups also have distinct needs although reservations have been voiced about funding further ethnic divisions and separatism, emphasising instead the need to promote integration and unified provision.

## 4.5 Priority Areas

Given that the proposed programme of support to be introduced by BIG has an explicit focus on neglect, from the list of gaps above, it may be advisable to prioritise the following;

***Outreach activities*** – Given that so much neglect and exclusion is hidden, a key task is to identify the large number of older people whose needs are not being met and who are either experiencing, or at risk of, neglect of the various types defined above. A system of provision able to respond to transitional points in the lives of older people would be particularly beneficial in preventing downward spirals into neglect. Contact with older people should be made automatically upon bereavement, hospitalisation or at other transitional points in life such as moving into care homes. These are critical points at which neglect becomes a risk factor. Many of the most acute needs identified by the Young Foundation (2009) are associated with difficult transitions, and this, the report observes, 'is where many current policies and institutions visibly fail'.

***Transport*** – Much exclusion at older ages is associated with frailty and mobility difficulties. Costs and availability of transport and volunteers to provide transport are key obstacles to inclusion. Funding should therefore be directed toward either volunteers or schemes that can provide subsidised, suitable, transport facilities.

***Volunteers*** – A shortage and decline in the numbers of volunteers are causing problems where older people's facilities do exist. Where possible, funding should target initiatives which effectively encourage, support, train and uplift communities of volunteers. With more volunteers the burden of time commitments can be shared more evenly. Particularly where older people are volunteers, volunteering should be supported and encouraged by social events and mutually supportive environments which seek to meet the needs of both carers, cared for and volunteers. Volunteers are critical for many of the gaps identified above – befriending, transportation, outreach and staffing the

organisation of social activities. Volunteers are also needed in care home settings.

***Carer support*** – Neglect often arises when carers are in crisis. To prevent situations from deteriorating, respite and community support schemes should be encouraged, thereby protecting the well being of carers and cared for.

***Social Activity groups*** – Organisations such as Age Concern and other one stop shops able to provide comprehensive provision of services, advice, outreach and/ or signposting are of critical importance. At older ages individuals need clear, concentrated support which is made easy. As noted by the Young Foundation report (2009: 10), "we need more institutions, advisers and access points which are holistic, rather than function specific. Many of the people and families that most need help are the least likely to take it up, sometimes because of chaotic lifestyles but also for reasons of stigma, distrust and disengagement. It is not enough to provide something useful: how it is provided also needs to build trust and confidence". In addition, a wide range of support services based, for example, on mutuality and co-operation are likely to emerge and need funding as statutory support shrinks further. Given the heterogeneity of older people, a diversity of projects and initiatives should be funded, reflecting diversity of need and preference.

## 4.6 Prevention or cure in a context of budget limitations

The JRF report on a 'little bit of help' (2005) and evaluations such as the LinkAge Plus (Davis and Ritters, 2009), emphasise the benefits both to the public purse and the quality of life of older people, of early interventions and a preventative approach. In practice, resources are increasingly targeted at those with the greatest need and "this is despite emerging evidence from the Partnerships for Older People Projects (POPPs) and other studies and trials that indicate that earlier interventions before people reach high levels of need may be more cost effective for the social care system and provide better outcomes for individuals" (ADASS, 2008). The preventative approach should therefore inform any older people programme of funding. Within this model a little money can go a long way.

Preventative services are also a key gap in provision. Age Concern England (2007) expresses doubts that preventative policy objectives are being adequately resourced with ongoing, unresolved tensions between funding preventative support and the obligation to respond to immediate need**.** Age

Concern England (2007) also warns that increasing reliance on locally sourced care holds unrealistic expectations for budget stretched local authorities. The Wanless Review (Wanless, 2006) similarly questioned the extent to which the goal of a system of preventative and home based support is being put into practice. It has also been observed that widespread tightening of eligibility criteria is leading to heavy rationing of social care.[18]

The preventative approach should not, however, be to the exclusion of projects which aim to conduct outreach activities to find older people suffering from various forms of neglect, nor projects which are designed to provide, for example, post-abuse support. In terms of gaps, BIG already funds a large number of projects designed to promote social engagement among older people. There is less evidence of funding to support older carers who are struggling to meet the needs of partners and other older relatives, or outreach activity to identify 'invisible' older people who may be neglected by themselves or others. As discussed above, self-neglect and abusive neglect is the responsibility of statutory services, but as new models of care increasingly emerge at the local level, the role of the VCS within a broader framework of care will change, giving rise to a shift in the profile of projects which BIG may wish to support.

In some cases, the prevention/cure dichotomy may be inappropriate. A number of schemes are holistic in nature, encouraging community participation, mutual support and volunteering among older people. When older people volunteer to help others who are isolated and neglected, the latter are helped while the former also benefit from meaningful activity, social inclusion and an increased awareness of the factors that may lead to neglect. So prevention and cure are often found together, helping a wide range of older people in terms of age and need.

## 4.7 How can BIG deliver funding

A wide range of joined up services are necessary to ensure the well being and welfare of older people including all aspects of their physical and mental health. Services have been delivered by a variety of organisations including: Health

[18] Adult care services white paper (Independence, Health and Well-being) one year on (http://www.communitycare.co.uk /Articles/2007/01/ 18/1028 18/adult-care-services-white-paper-independence-health-and-well-being-one-year.html?key=NO%20 SEARCH %20TERM% 20SPECIFIED) Posted: 18 January 2007.

Trusts, Housing Associations, LAs, the VCS and private sector. Regardless of the precise welfare mix and funding levels of the future, safeguarding older people and service delivery is likely to continue in partnership form with collaborations between public and private sectors, the VCS and private individuals.

Given the reluctance of older people to discuss abuse and their reluctance to approach formal or ‘official’ avenues of help, funding directed toward VCS organisations that are known and trusted and are more locally based, are likely to be more effective for older people at risk of, or experiencing, neglect and mistreatment.

The DWP LinkAge pilots and research into elder abuse have highlighted the value of partnership working in meeting the needs of the older people. Mowlam et al (2007) suggest that older people are happier using voluntary sector ‘first port of call’ services but highlight the importance of forging close links with Safeguarding Adults and Crime and Disorder Reduction partnerships. The DWP LinkAge projects were regarded as successful often because of the partnerships which were formed between Local Authorities and other organisations, producing seamless service delivery with a focus on the ‘whole person’ including health, social care, independence and well being needs (Davis and Ritters, 2009).

Effective schemes are therefore likely to involve a number of organisations working in tandem with possible sub-contracting relationships, but evidence suggests that community based organisations, often small in scale, are regarded as best placed to develop long term trust-based relationships, identify local needs, deliver flexible services with a capacity to innovate and have knowledge of how to access and include vulnerable and hard to reach people (OTS, 2008). Grants are therefore best directed toward VCS groups in the first instance, who in turn are likely to, or may be encouraged to, forge relationships with other sectors whether private or statutory.

This model is in keeping with BIGs strategic framework;

> “While the VCS will remain the main recipient of our funding, many organisations outside the sector will be significant in the delivery of our outcomes. We will not force partnerships, but we will encourage links to be made between organisations who are working to deliver the same ends. The majority of our funding delivered through non-VCS bodies will be in partnership with the VCS, or of direct benefit to a stronger civil society.” (BIG, 2009)

In recognition that some VCS groups and enterprises who provide ‘that bit of help’ may struggle to survive the next year, a CPA (2011) report similarly recommends consideration of a range of locally based options, including; “collective solutions, small grants or seed-funding for self-help groups, and developing local markets to provide support people want and value”.

## 4.8 BIG investment timing

Given the scale of reform likely to emerge following the comprehensive spending review, potentially leading to the wholesale restructuring of care delivery, it is appropriate to ask at what point amidst all this change should funders time their investments to achieve strategic goals? It remains unclear exactly who will be delivering services, who will be paying for them and, therefore, where funding should be targeted.

We can be confident that the VCS will continue to play a central role in protecting the interests and well being of older people at risk of neglect and abuse. But given the scale and growth in support needed, the drive toward efficiency and, perhaps, economies of scale, it is possible that a smaller number of large VCS organisations will become key players in the field. BIG will therefore need to consider future-proofing their investments to ensure sustainable, long term, positive outcomes for older people in local communities.

Some VCS organisations may disappear, especially those which have depended on funding from LAs. As a temporary measure, a £100m Transition Fund has been made available to help charities, voluntary groups and social enterprises which deliver public services to survive and be in a position to take advantage of future opportunities. Whether the Fund is adequate to protect organisations from closing during the transition to a different funding environment is uncertain.

BIG may wish to wait until the service delivery and funding shake-up is resolved, when a clearer picture will have emerged of the funding needs and role of the VCS and which VCS organizations have proved resilient with a continued presence in the delivery of services for older people.

An alternative option is for BIG to act quickly, to provide funding assistance during this transitionary period, supporting organisations in their efforts to change their funding base, perhaps moving to social enterprise models or relying increasingly on volunteers rather than paid members of staff. Organisations may need funding to develop new strategic business plans and seed money to initiate organizational change. The sooner such funding

becomes available the better, as change can take time to be introduced, tested and eventually bed down.

## 4.9 Activating volunteers

The VCS is dependent upon the available time and goodwill of volunteers but demand for volunteers has been rising at the same time as supply has been shrinking in some areas (Smeaton, 2009). A particular gap in volunteering arises in care home settings. Care home managers have identified low levels of volunteering in British care homes where there is a significant unmet need for volunteers to form one-on-one relationships with care home residents (CSJ, 2010).

As noted by CSJ (2010), there is a need to further encourage "neighbouring and neighbourliness, often neglected in social policy", as a means of tackling problems of neglect and social isolation. The CSJ report identified four key barriers to volunteering faced by older people who represent two thirds of the volunteer workforce:

- a lack of confidence
- a lack of awareness about available volunteering options
- a lack of access to safe transport and money
- risk averseness, bureaucracy and perceived restrictions from insurance policies

BIG can improve engagement of older volunteers by funding charitable schemes such as Volunteering England,[19] or by providing funds to increase awareness of such initiatives. Volunteering organisations can provide a central repository of information, signpost to opportunities and, in principle, could run courses to promote confidence and, perhaps, opportunity specific skills.

The self-help, mutually supportive approach of schemes such as Southwark Circle goes some way to alleviate problems associated with finding and keeping adequate numbers of volunteers. The benefits of social participation for volunteers and cared for are emphasized.

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[19] Volunteering England has a network of Volunteer Centres across the country. Volunteer Centres are local organisations that provide support and expertise within the local community, to potential volunteers, existing volunteers and organisations that involve volunteers. (www.volunteering.org.uk/)

BIG has also supported many projects which promote volunteering, and there are a number of examples of projects that have received funding not only for advisory services and social activities etc. but also for the recruitment, training and expenses of volunteers. This would seem to be the best approach to encouraging voluntary activity. With funding, local VCS organisations can formalise the search for volunteers with resources to recruit, train, provide support and encourage social engagements within the volunteering community. Good practice projects ensure the experience is 'fun' and sociable, including social events for the volunteers (see Age Concern Hereford, p26 above).

## 4.10 In summary

BIG performs a much welcomed and important role in supporting a wide range of needs among older people. Initiatives to benefit older people have been funded under a number of themes including: health, learning, information/advice, veterans and community support. Within the latter, the most commonly funded projects were designed to promote social activities such as walking, dancing and bowls or support social centres and events such as D-Day celebrations. Given the extent to which social support remains underfunded in the statutory sector the role of BIG remains critical in supporting the VCS to meet gaps in such provision.

Large numbers of older people aged 80 plus across the UK are in need of support to remain socially included, with widespread isolation in both cities and rural locations. To promote social participation and prevent neglect, a variety of stimulating activities and regular contact with peer groups are required. For the less mobile, opportunities to leave the home which currently can be few and far between, are in great demand. For the frail who live alone, opportunities to have visitors, telephone based friendships or internet communications are also critically important to prevent neglect and the associated adverse mental and physical health consequences.

The scope for BIG to promote this agenda and improve the well being and quality of life of older people is considerable. BIG can benefit older people most effectively by supporting the VCS and funding a highly diverse range of day support activities, low level services, transport, and outreach activities to identify the most socially excluded.

Initiatives and volunteers to assist older people access mainstream facilities and simply get out of the house are in notably short supply. Of particular value would be support for schemes that provide multiple services and one-stop-shops attending to social, advisory, advocacy, care and health needs. 'One

stop' approaches may involve multiple agency working with closer relationships between social care, health care, police and VCS teams at a local level. In this way older people in need are less likely to fall through the gaps of responsibility. VCS organisations, supported by BIG, among other sources of revenue, can play an important linking role, ensuring that older people are treated as whole people with all their often interconnected needs met in full. The 'linking' role of VCS groups is in keeping with coalition government policy which aims to promote partnership working and increasingly devolve responsibility for care to the local authority and community levels.

In terms of social support, diversity of provision is key, reflecting the heterogeneity of older people, some of whom prefer access to dedicated facilities for their age group while others favour mainstream, age diverse activities. Rather than being treated as passive recipients of social support however, most older people wish to and do remain active and socially engaged into their 80s and beyond, many involved in a wide range of voluntary activities. Self-help, mutually supportive groups meet the preferences of older people to both give and receive help and represent a sustainable model of provision worth further support.

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