

Homelessness, Ageing and Dying

Exploratory research looking at the needs of older people who are homeless as they age, and are faced with the issues of serious ill-health and dying.

FOR THE SIMON COMMUNITIES OF IRELAND

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SECTION 1

Introduction

1.1 Who are the Simon Communities?

The Simon Communities throughout Ireland provide care, accommodation and support for people experiencing homelessness and those at risk. Together, with people who are homeless, Simon seeks to tackle the root causes, promote innovative responses and urge the government to fulfil their commitments. Simon delivers support and service to between 4,500 and 5,000 individuals and families who experience – or are at risk of – homelessness on an annual basis.

The Simon Communities of Ireland is an affiliation of local Communities in Cork, Dublin, Dundalk, Galway, the Midlands, the Mid West, the North West and the South East.

1.2 The background to the research

There is a lack of definitive information about the exact number of people who are homeless and the nature of the homelessness at any one point in Ireland. There is also a lack of definitive information on the physical and mental health needs (inclusive of problematic drug and alcohol use) of people who are homeless and particularly amongst older people who are homeless, or formerly homeless. In an effort to address this deficit the Simon Communities of Ireland made a funding application to the Age and Opportunity *Get Vocal Programme* to undertake research looking at this issue. This application was ultimately successful and following a competitive tendering process Dr Kathy Walsh was appointed to undertake this research.

The discrepancy between the *Housing Need Assessment* figures and the ‘Counted In’ figures and experiences of other bodies and organisations that are seeing a growing demand for services can be seen to stem back to the way homelessness is defined. *Housing Need Assessment* figures exclude certain groups of people (e.g. those not on the local authority housing lists, people using emergency accommodation, transitional accommodation, residential supported units, etc.). It is also the case that people who are homeless move from place to place or indeed move in and out of homelessness, making it difficult to get an accurate point in time count of the total homeless population.²

1.3 The research aim and objectives

The overall aim of this study was to influence policy and practice responses to the needs of older people who are homeless as they age and are faced with the issues of serious ill health, dying and death.

The project objectives were to:

- a. Identify a solid evidence base for campaigning and advocacy work at a local, regional and national level for better policy and practice responses to the needs of older people who are

1 The ‘Counted In’ survey is a survey of homeless services users. Its purpose to monitor the extent of homelessness and to identify the needs of people who are currently using homeless services. It includes all those (including those not on the local authority housing lists and people in transitional housing, residential supported units etc.) using homeless services a particular time in a particular place.

2 <http://www.focusireland.ie/index.php/press-release-archive/2009/210-17th-august-2009housing-needs-assessment-underestimates-homelessness>

- homeless/have experience of homelessness as they age, become sick and face dying and death.
- b. Identify innovative policy and practice responses to address these issues as they impact on older people who are homeless/have experience of homelessness.
 - c. Facilitate the empowerment of older people who use Simon services by enabling them to develop the knowledge, skills and attitudes to deal more effectively with these issues as they arise in their lifecycles.
 - d. Facilitate staff, service users and volunteers across the individual Simon communities to develop the knowledge, skills and attitudes that will enable them to advocate more effectively on these issues both with and for people who are using Simon services around the country.
 - e. Integrate the research findings and recommendations into the campaigning and advocacy work carried out by the Simon Communities of Ireland at a national level.
 - f. Support and facilitate policy and decision makers to become more informed about the needs of older people who are homeless or who have experience of homelessness and to make it easier for them to respond effectively to these issues.
 - g. To contribute to the body of knowledge available. Specifically, it is hoped that other organisations working with people who are homeless/have experience of homelessness and organisations working with older people will become aware of these findings and integrate them into their work.

1.4 The research process

The research process can be broken down into a number of different elements.

The first stage in the process was the establishment of a Research Advisory Group, made up of individuals with a particular interest/expertise in the area of homelessness and/or ill health and/or dying. See Appendix 1 for details of the membership of this group. The purpose of this group was to oversee the research and this group met regularly throughout the research process to oversee progress and to provide support where it was required.

The second part of the research was the literature review. This included a review of all relevant literature, including similar studies undertaken elsewhere. The third stage of the research was the primary data collection phase. This can be divided into two parts. The first part involved detailed one to one interviews with older people who were homeless or who had some previous experience of homelessness and who used the services of the Simon Communities around the country. (This meant that not all of the interviewees were homeless at the time of their participation in this study, some lived in local authority 'accommodation' and 'others' in their own home). The purpose of these interviews was to identify the needs and experiences of these individuals. A total of sixteen individuals were interviewed in eight locations around the country. (See Section 3 for details of the findings of these interviews). The second part of the data collection phase included interviews with experts, policy makers, academics and others working in this area. See Appendix 2 for details for the external stakeholders interviewed.

The findings that emerged from the consultations with older people who are homeless or who have recent experience of homelessness and the interviews with key external stakeholders also formed the basis of a focus group discussion with the Simon Involvement and Action Group³. A seminar will be held at the end of the research process. Its purpose will be to share the research findings and the key learning arising from the study with key individuals and stakeholders, thus ensuring the findings from the study will be shared as widely as possible.

³ This is a group of people who use/have used Simon services.

1.5 A definition of older people

According to the CSO⁴, average life expectancy is currently 76.8 for men and 81.6 for women. In that context numerous definitions of 'older people' exist at government and statistical level. Historically, the term was applied to persons of pensionable age. The Department of Social Protection, for example, have introduced 55 as the age cut-off point between unemployment benefits and 'pre-retirement' (you could no longer be unemployed at 56). Programmes run by older people's non-governmental organisations (e.g. Active Retirement) increasingly attract participants under 60 (though generally nearer 60 than 50).

Definitions of age status for people who are homeless/have experience of homelessness vary from study to study, given that individuals who have experience of homelessness over a sustained period/s have generally been found to have a lower life expectancy than other groups. The interim findings of a recent University of Sheffield study⁵ investigating homeless mortality in England found the average age of death of a man who is homeless is 47 years old. It is even lower for women at just 43⁶. This study is particularly interesting because it looks at the mortality of single people who are homeless and includes those who are sleeping rough, in hostels and in other hidden homeless situations.

Problematic drug and alcohol use were found to have accounted for just over a third of all deaths, while people who were homeless were over 9 times more likely to die by suicide than the general population. In addition, deaths as a result of traffic accidents were 3 times as likely, infections twice as likely and falling over 3 times as likely among this group. The growing consensus is that persons aged 50 and over have lower life expectancies and mortality rates higher than the general population and should therefore be included in the "older homeless" category⁷.

1.6 Ethics

This study was undertaken according to the Social Policy Association guidelines on research ethics⁸ which require that research participants '*participate in the research on the basis of freely given consent and that their participation does not expose them to avoidable harm*'. Key strategies put in place in this study to ensure the application of these guidelines included:

- Strategies to protect the research participants' rights, interests, sensitivities, privacy and maintenance of confidentiality included the use of pseudonyms and the removal of all information that could be used to identify a particular individual or indeed their location.
- Informed consent – participation in this research required the individuals involved to give informed and written consent.

Initial contact with potential research participants was initiated by Simon staff. Where a particular individual expressed an interest in considering involvement in the study the Simon staff member provided them with more details of the study (in terms of what their participation in the research would involve, who is funding the research and the likely use that will be made of the research findings). Based on that information the potential interviewees were asked to make a decision about whether they wanted to consider participation or not. If they decided they were still interested, the Simon staff member contacted the researcher to arrange a time and location for the interview. The choice of venue for the interview was the decision of the research participant. The research participant also had a choice about whether they wanted

4 http://www.cso.ie/Quicktables/GetQuickTables.aspx?FileName=VSA30.asp&TableName=Life+Expectancy&StatisticalProduct=DB_VS

5 Crisis (2011) Homelessness: A silent killer: A research briefing on mortality amongst homeless people

6 Research has also found that people who have serious mental illness like schizophrenia or bipolar disorder can have a life expectancy 10 to 15 years lower than the UK average according to research undertaken by the Biomedical Research Centre for Mental health at Maudsley Hospital in London in 2011 (Chang et al.)

7 National Coalition for the Homeless (NCH) Factsheet No. 15 (2007) Homelessness among Elderly Persons, USA. <http://www.nationalhomeless.org/publications/facts/elderly.html>

8 SRA Social Policy Association Guidelines on Research Ethics

another person to be present for the interview (six of the sixteen chose to have someone else attend the interview. Again, the choice of who the interviewee wanted to attend the interview with them was theirs. (In two cases it was a Simon staff member, in four cases it was a Simon volunteer).

The actual interview began with the researcher explaining the purpose of the research and the format of the interview. She also explained how the anonymity of the interviewee would be protected, how the data collected would be stored, who would have access to it and on what terms and about the confidentiality of information provided by participants in the course of the interview. The interviewee was encouraged to ask questions and to not participate if they were not happy with the answers they received. They were also advised that they could choose to terminate the interview at any point and were free to skip any questions they were not comfortable answering. Assuming the interviewees were happy to proceed, they were asked to verbally confirm this and to sign a written consent form (to be seen and held exclusively by the researcher). Nineteen individuals signed the consent form and agreed to proceed with the interview. As the interview proceeded with three of these individuals, it became apparent that their capacity to sustain a conversation and the narrative of their lives appeared to have been adversely affected by chronic problematic alcohol use. These interviews were ultimately not included in the study because of concerns in relation to their reliability and coherence.

The researcher kept detailed notes of the interviews and sought permission as part of the consent process to record the interviews (for her exclusive use) to ensure a full record of the interviews.

- Provision of information about support services – participation in the interview process brought up difficult issues for some participants. Where this was the case interviewees were asked whether a) they wanted to terminate/take a break from the interview (all declined) and b) they wanted/needed to be referred to relevant support services. A small number requested that the researcher would advise a relevant Simon staff member that they had been upset.

1.7 Limitations of the Research

This study has a number of key limitations, as follows:

Small Sample Size

The available budget, together with the time consuming and qualitative nature of the research methodologies used and difficulties with the recruitment of research participants capable of /interested in sustaining a meaningful conversation about their experiences, meant that the total research sample size is small (16 individuals).

Discussions of Death

The original study objectives were to explore attitudes to ill health, dying and death. The reality was that while research participants were prepared to discuss issues associated with dying, they were far less comfortable with discussions of death. This is a sensitive area that would require more time than was available to open up the discussion in any depth. As a result, the conversations with the study participants clearly focus more on attitudes to dying than attitudes to death.

Participation limited to Simon services users

The available budget and associated time constraints meant that participation in the study was limited to Simon Service users. The consequences of this are that all of the participants, because of their connection to Simon, are also linked into a variety of support and health services.

It is also the case that while the focus of this study was on Simon service users ideally, had resources allowed, it would also have included Simon staff and volunteers.

Routes used to recruit research participants

Research participants were initially identified and recruited by Simon staff and volunteers. These individuals were all known to the research participants and it remains unclear to what extent research participants decision to participate in the study was motivated by wanting to be supportive of Simon staff. It is also not known to what extent individuals who might have fitted the profile were excluded and for what reasons they might have been excluded.

Mix of research participants

The fact that the research participants (reflecting the breadth of Simon client types) came from a range of accommodation types including emergency accommodation, local authority housing, etc. clearly made generalisation of the research findings difficult.



SECTION 2

Literature Review

2.1 A definition of homelessness

The 1988 Housing Act defines a homeless person as somebody who has no reasonable accommodation to live in or lives in a hospital, institution or night shelter and cannot provide accommodation from their own resources because of a lack of home. This definition, while widely used, is not without its critics particularly in the voluntary sector who believe it is too narrowly focused, developed as a response to the need *'to be able to draw clear boundaries and make distinctions around who is entitled to what share of state-provided goods and services, rather than recognising the realities and complex needs of people who are homeless or at risk of homelessness'* (Harvey, In Downey (eds.) 2008: p59).

The European Federation of National Organisations Working with the Homeless (FEANTSA) define homelessness as *'the absence of a personal, permanent, adequate dwelling. They identify people who are homeless as being 'unable to access a personal, permanent, adequate dwelling or to maintain such a dwelling due to financial constraints and other social barriers and those people who are unable to access and maintain such a dwelling because they are unable to lead a fully independent life and need care and support but not institutionalisation'*. FEANTSA has developed the ETHOS typology of homelessness and housing exclusion based on the conceptual understanding that there are three domains which constitute a "home", the absence of which can be taken to delineate homelessness. Having a home is defined within the typology as having an adequate dwelling (or space) over which a person and his/her family can exercise exclusive possession (*physical domain*); being able to maintain privacy and enjoy relations (*social domain*) and having a legal title to occupation (*legal domain*). See Table 2.1 for details of this typology. The typology classifies people who are homeless according to their living situation:

- *rooflessness* (without a shelter of any kind, sleeping rough)
- *houselessness* (with a place to sleep but temporary, in institutions or shelter)
- living in *insecure housing* (threatened with severe exclusion due to insecure tenancies, eviction, domestic violence)
- living in *inadequate housing* (in caravans on illegal campsites, in unfit housing, in extreme overcrowding).

Figure 2.1 FEANTSA ETHOS Typology of Homelessness

	Operational Category	Living Situation	Generic Definition
ROOFLESS	1. People living Rough	1.1 Public space or external space	Living in the streets or public spaces, without a shelter that can be defined as living quarters
	2. People in emergency accommodation	2.1 Night shelter	People with no usual place of residence who make use of overnight shelter, low threshold shelter
HOUSELESS	3. People in accommodation for the homeless	3.1 Homeless hostel 3.2 Temporary Accommodation 3.3 Transitional supported accommodation	Where the period of stay is intended to be short term
	4. People in Women's shelter	4.1 Women's shelter accommodation	Women accommodated due to experience of domestic violence and where the period of stay is intended to be short term
	5. People in accommodation for immigrants	5.1 Temporary accommodation/reception centres 5.2 Migrant workers accommodation	Immigrants in reception or short term accommodation due to their immigrant status
	6. People due to be released from institutions	6.1 Penal Institutions 6.2 Medical Institutions (*) 6.3 Children's Institutions/homes	No housing available prior to release Stay longer than needed due to lack of housing No housing identified (e.g. by 18 th birthday)
	7. People receiving longer-term support (due to homelessness)	7.1 Residential care for older homeless people 7.2 Supported accommodation for formerly homeless people	Long stay accommodation with care for formerly homeless people (normally more than one year)
INSECURE	8. People living in insecure accommodation	8.1 Temporarily with family/friends 8.2 No legal (sub) tenancy 8.3 Illegal occupation of land	Living in conventional housing but not the usual or place of residence due to lack of housing Occupation of dwelling with no legal tenancy illegal occupation of a dwelling Occupation of land with no legal rights
	9. People living under threat of eviction	9.1 Legal orders enforced (rented) 9.2 Re-possession orders (owned)	Where orders for eviction are operative Where mortgagee has legal order to re-possess
	10. People living under threat of violence	10.1 Police recorded incidents	Where police action is taken to ensure place of safety for victims of domestic
INADEQUATE	11. People living in temporary/non-conventional structures	11.1 Mobile homes 11.2 Non-conventional building 11.3 Temporary structure	Not intended as place of usual residence Makeshift shelter, shack or shanty Semi-permanent structure hut or cabin
	12. People living in unfit housing	12.1 Occupied dwellings unfit for habitation	Defined as unfit for habitation by national legislation or building regulations
	13. People living in extreme over-crowding	13.1 Highest national norm of overcrowding	Defined as exceeding national density standard for floor-space or useable rooms

(*) includes drug rehabilitation institutions, psychiatric hospitals etc.

Note: Short stay is defined as normally less than one year; Long stay is defined as more than one year.

This definition is compatible with Census definitions as recommended by the UNECE/EUROSTAT report (2006)

2.2 Types of homelessness

Homelessness can be visible and hidden. Visible homelessness is where people who are homeless are on the streets, sleeping rough and in shelters; while hidden homelessness includes people who are homeless living in temporary, insecure, low quality or overcrowded housing with relatives or friends, living in bed and breakfast accommodation and squatting. There is also an additional category of people at risk of homelessness. People who fall into this category may have housing but run the risk of becoming homeless because of economic difficulties, previous experience of homelessness and/or the threat of violence. Homelessness can indeed be quite a dynamic process with people moving in and out of it relatively quickly. *O'Connor* (in Downey (eds.), 2008, pp-58-63) identified three categories of homelessness:

- Rough sleepers/long term users of emergency accommodation and shelters
- Episodic bouts of homelessness
- Temporary homelessness which is exited quickly and the person does not return to homelessness.

2.3 Factors that contribute to Homelessness

Many factors can contribute to homelessness including poverty, poor educational achievement, poor quality jobs or unemployment, high cost of buying or renting a home, difficult relationships at home, leaving institutional care, inadequate community support services, ill-health (including physical and mental health), physical, sexual and mental abuse, disability, problematic drug and/or alcohol use, crime and leaving institutions e.g. prison. The link between homelessness and poverty and social exclusion is widely acknowledged, nationally and internationally. It is often when the systems and structures in society fail that people become homeless. For many individuals it can be a complex mix of a number of these factors and experiences which result in housing insecurity and ultimately homelessness, very often on several, separate occasions. Some of these factors can be linked to structural inequalities while others are related to the circumstances faced by a particular individual.

- Structural causes including poverty, unemployment and housing issues.
- Institutional causes including those living in foster, prison, mental health institutions, and the armed forces.
- Relationship causes including abusive relationships and family breakdown (death or separation).
- Personal causes including mental illness, learning difficulties and drug and/or alcohol use.

In addition, research has recently begun to highlight the existence of an 'important gender dimension to homelessness'⁹.

2.4 Nature and Extent of Homelessness in Ireland

Counting the number of people who are homeless is difficult for a number of reasons and this is a challenge experienced in most jurisdictions.

The recent CSO Special Report on Homelessness¹⁰ identified 3,808 people on census night as located in accommodation providing shelter for people who are homeless (including emergency, long term and

9 Mayock, P. & Sheridan, S. (2012) Women's 'Journeys' to Homelessness: Key Findings from a Biographical Study of Homeless Women in Ireland. Women and Homelessness in Ireland, Research Paper 1. Dublin: School of Social Work and Social Policy and Children's Research Centre, Trinity College Dublin.

10 CSO (2012) Special Report on Homelessness

transitional accommodation) or sleeping rough. The largest number of people who were homeless was in the Dublin region (62.4%), while 92% (59 individuals) of people sleeping rough were also in the Dublin region.

Irish local authorities also make an assessment of the numbers in housing need in their area, including people who are homeless, every three years as part of the Department of Environment, Community and Local Government's *Assessment of Housing Need*. The most recent assessment of need was undertaken on the 31st March 2011¹¹ where 98,318 households were found to be in need of social housing. Older persons (2,266 households) and homeless households (2,348 households) account for just over 2 per cent of need respectively. The number of households identified as homeless in the 2011 Assessment was significantly higher than the 2008 Assessment (2,348 in 2011 compared with 1,394 in 2008).

Some of the differences in the 2011 and 2008 figures relate to changes in the methodology used to collect the 2011 data. Notwithstanding the significant increase in the number of households identified as homeless between the 2008 and 2011 assessments, the 2011 housing assessment figures for homelessness continue to raise questions given that the 2008 Homeless Agency '*Counted In*' survey of homelessness found 2,144 households using homeless services in the Dublin region alone, while similar '*Counted In*' studies in Cork, Limerick and Galway cities in 2008 found 767 households that were homeless. The key difference between the '*Counted In*' Survey and the *Housing Needs Assessment* is that the '*Counted In*' survey specifically focuses on counting the number of persons using homeless services at a particular point in time at a particular location, while the *Housing Needs Assessment* includes only those on the local authority housing list thereby excluding those in transitional housing, residential supported units etc.

The discrepancy between the *Housing Need Assessment* figures and the '*Counted In*' figures and experiences of other bodies and organisations that are seeing a growing demand for services would appear to stem back to the way homelessness is defined and the methodologies used. Official statistics for example exclude certain groups of people (e.g. those not on the local authority housing lists, people using emergency accommodation, transitional accommodation, residential supported units, etc.). It is also the case that people who are homeless move from place to place or indeed move in and out of homelessness making it difficult to get an accurate point in time count of the total homeless population.¹²

The majority of people who are homeless are single adults - the Homeless Agency's 2008 survey found that in Dublin alone there were 1,439 single people who are homeless - the majority of whom are men, who tend to be homeless for longer periods than women. There are a smaller number of homeless families (The Homeless Agency's 2008 survey found that in Dublin there were 249 adults with children under 18 years- 576 children in total). The majority of these families are housed in emergency bed & breakfast accommodation.

The 2008 '*Counted In*' survey of people who are homeless found the average age of homeless service users in Dublin was 39 (the average age of the 2011 Simon National Health Snapshot¹³ female participants was 40 and male participants was 44.5 years) while more than a fifth of adults attending homeless services were aged 50 or over (24% of female participants in the Simon National Health Snapshot 2011 were aged over 50 (with 4.1% of these aged over 65) while 37% of the male respondents were aged over 50 (with 6.7 % of these aged over 65). No similar figures are available officially, making it difficult to quantify and understand the extent and nature of homelessness that exists across the country.

11 Housing Agency (2011) Housing Needs Assessment 2011

12 www.focusireland.ie/index.php/press-release-archive/2009/210-17th-august-2009housing-needs-assessment-underestimates-homelessness

13 Simon Communities of Ireland (2011) Simon National Health Snapshot - 2011

2.5 Homelessness among older people

Pillinger (2008)¹⁴ identified three age related pathways into homelessness; youth, adult and later life. People who become homeless can enter and re-enter at any of these different stages, depending on the extent to which their various personal, housing and social support needs are not been adequately met. These include personal supports in meeting everyday health and care needs for example, older people and people with physical or learning disabilities are likely to have support needs; that are enduring and/or permanent.” (Edgar *et al.* 1999¹⁵). Generally speaking, it has been found that anyone over 50 who has had a prolonged experience/s of homelessness is vulnerable to many of the physical health problems associated with older age.

Life expectancy

There is currently no definitive information on the average life expectancy of a person who is homeless in an Irish context. What is clear from a variety of studies is that people who are homeless in Ireland (are no different to other locations) have a higher risk of illness and have earlier mortality rates than the general population¹⁶. International research has found the most glaring discrepancies in mortality ratios between younger and middle-aged groups from 18 to 34 years and from 35 to 54 years of age. While older people who are homeless also have a greater risk of dying than their housed counterparts, the standard mortality ratios, while higher, are not as dramatically high as for the younger age groups. International literature estimates that people who are homeless and rough sleeping have mortality rates which are 3.5-4 times greater than the general population¹⁷. A study of women using a homeless shelter in Toronto¹⁸ concluded that “*Homeless women 18-44 years of age were 10 times more likely to die than women in the general population of Toronto*”. It noted that the mortality rates for older women (over 45 years) were lower than that for older men who were homeless suggesting that older women who are homeless retain their usual female survival advantage over their male counterparts.

Another Canadian study¹⁹ found that (using data from the 1991-2001 Canadian census, to track 15,000 homeless and marginally housed people across Canada for 11 years) ‘Homeless and marginally housed people had much higher mortality and shorter life expectancy than could be expected on the basis of low income alone. The study found that the probability of survival to age 75 was 32% for men and 60% for women compared to 51% and 72% among men and women in the lowest income group in the general population. The study’s authors attributed a large part of this premature mortality to alcohol and smoking-related diseases and to violence and injuries, much of which might have been related to problematic alcohol and/or drug use.

2.6 National policy responses to homelessness

The Way Home is the National Strategy to address Adult Homelessness in Ireland (2008 – 2013). It has three core objectives:

- eliminating long-term occupation of emergency homeless facilities;
- eliminating the need to sleep rough and
- preventing the occurrence of homelessness as far as possible.

14 Downey, Daithi (ed.) (2008) *Perspectives on Irish Homelessness: Past, Present and Future*. The Homeless Agency, Dublin.

15 Pp. 66

16 O’Connell, James J. (2005) *Premature Mortality in Homeless Populations: A Review of the Literature*. National Health Care for the Homeless Council, Inc., Nashville:

17 Hwang, S. et, al. (2009) Mortality rates among residents of shelters, rooming houses and hotels in Canada: 11 year follow up study, *BMJ* 2009;339:b4036 doi:10.1136/bmj.b4036

18 Cheung, Angela, M. & Stephen W. Hwang Risk of death among homeless women: a cohort study and review of the literature in *Canadian Medical Association Journal*, April 13, 2004: 170 (8) Pp. 1243-1247.

19 Anon (2009) Study reveals high death rates and short life expectancy among the homeless and marginally housed. <http://esciencenews.com/articles/2009/10/26/study.reveals.high.death.rates.and.short.life.expectancy.among.homeless.&marginally.housed>

Local authorities also have *Homeless Action Plans* which 'in the past' have varied from authority to authority. These Plans were jointly reviewed²⁰ in 2002 by Simon Communities of Ireland, Society of St Vincent de Paul, Threshold and Focus Ireland who concluded that 'while the plans were a welcome development' they did little for groups priced out of the housing market, with insufficient attention given to the provision of help for people to move into permanent accommodation. The plans did acknowledge the need for health and social facilities for people who are homeless but lacked specific proposals for their development.

New legislative provisions in the Housing (Miscellaneous Provisions) Act 2009 came into force on 1 February 2010 that put Homelessness Fora and Homelessness Action Plans on a statutory basis at regional or local level. The purpose of these Fora is 'according to the legislation' "*to provide information, views, advice or reports in relation to homelessness and in relation to the provisions of the draft homelessness action plans and the operation and implementation of the action plans*".

Homelessness is not a standalone issue and therefore other policies and strategies can have an impact including the National Health Strategy and the interim National Drugs Strategy, in place until the publication of the National Substance Misuse Strategy and "Vision for Change", The National Mental Health Strategy.

The National Health Strategy identifies a number of initiatives to improve the health and well-being of people who are homeless that include elements of *Homelessness – An Integrated Strategy* (2000) and the *Youth Homelessness Strategy* (2001) as well as the provision of medical cards for people who are homeless.

The (interim) National Drugs Strategy 2009-2016 identifies the fact that a significant number of people who are homeless require access to treatment and rehabilitation services and advocates for increases in expenditure on homeless services specifically in relation to accommodation and on support services generally. The Strategy recognises that gaps in services persist, particularly in regard to attracting (and retaining) drug users with complex needs who are homeless into treatment. The Strategy also makes specific reference to the problems associated with people who present with dual diagnosis (i.e mental health and problematic drug and /or alcohol use). Research by the National Advisory Committee on Drugs in 2005 (Lawless & Corr) found that there was no systematic provision of care services for this group of people and that many services operate criteria that can exclude individuals from accessing services. While the prevalence of dual diagnosis is not known, as it is not recorded by service providers, the NACD study reported previous research in Ireland that indicated it could be relatively high. In addition, the NACD found that people who are homeless are more likely than the general population to experience mental health and problematic drug and/or alcohol use problems due to environmental factors, particularly the lack of supported housing.

One of the central principles of a "*Vision for Change*" is that mental health services should be provided to an individual in the catchment area in which they normally reside. This presents difficulties, when people become homeless and move, often into the city areas. For this reason, and because the largest proportion of people who are homeless are in Dublin, the Strategy proposed the establishment of two multidisciplinary, community-based teams for the Dublin area.

20 *Housing Access for All?* (2002) Analysis of Housing Strategies and Homeless Action Plans undertaken by Simon Community, Threshold, Focus Ireland and SVdeP.

2.7 The relationship between homelessness and health

Health is defined by the WHO as ‘a state of complete physical, mental and social well being and not merely the absence of disease or infirmity’.²¹

A person's home (or the absence of it) clearly plays a central role in shaping their physical health and their feelings of wellbeing and general ability to cope with everyday life. 33% of the individuals identified as homeless in the CSO special report on homelessness indicated that their health was ‘fair’, ‘bad’ or ‘very bad’ (compared with 10% for the wider general population). The relationship between health and homelessness is however a complex one. What is clear is that people who are homeless have higher than average mortality rates linked to higher levels of physical and mental illness and problematic drug and/or alcohol use, inadequate access to health care and often severe poverty. Holohan²² (1997) found that 66% of the people he studied who were homeless experienced at least one physical or psychiatric problem. Further research conducted in 2005 by O'Reilly & O'Carroll (2005), which compared the health status of the people who are homeless with the findings of the 1997 Holohan study, found that the physical and mental health of people who are homeless had not improved; in fact, levels of illicit drug use and blood borne diseases, including HIV and hepatitis, had risen significantly²³. O'Connell *et al* 2004 identified older people who are homeless as a ‘particularly vulnerable group who have both high mortality rates and high levels of cognitive impairment and mental illness’ (Pp.124) than the general population. It is interesting in this context that the London based homeless charity St. Mungos has developed its first Health Strategy (2008-2011)²⁴ for its hostel dwellers that seeks to facilitate health delivery in its hostels; integrate into a single document its vision of service delivery across physical health, mental health, drugs and alcohol; and address priority areas for promoting positive health and well-being.

Physical Health Issues

The links between homelessness and poor physical health are well established and often linked to exposure to the elements and lack of a safe protected shelter. Rough sleepers, for example, tend to suffer injury and fall victim to violence, while exposure and inadequate conditions in night shelters and hostels can lead to high levels of certain infectious diseases, such as tuberculosis and hepatitis. “*People who are homeless have higher morbidity from physical conditions that are common as well as conditions that are rarely found in the general population such as HIV, Hepatitis and Tuberculosis*”²⁵. The on-going University of Sheffield study²⁶ found that whilst disease is the cause of the vast majority of deaths amongst the general population, people who are homeless are more likely to die from external causes with higher incidences of deaths as a result of traffic accidents, infections and falls.

Holohan *et al*²⁷ identified that people who are homeless are more likely than their housed counterparts to suffer from arthritis, leg ulcers, oedema, problems with bones and joints (caused by long hours standing in public places or walking around the streets), heart disease, tuberculosis, eye & ear complaints, epilepsy, skin problems as well as injuries from accidents and assaults. Condon also found that 98% of the people who were homeless that she examined needed dental treatment suggesting that this type of care is particularly difficult to access for people who are homeless. These findings are reinforced by the

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- 21 Preamble to the Constitution of the World Health Organization adopted by the International Health Conference June, 1946,
 22 Holohan, T. (1997) Health Status, Health Service Utilisation and Barriers to Health Service Utilisation among the Adult Homeless Population of Dublin. Eastern Health Board
 23 Pp. 124
 24 St Mungos (2008) St Mungo's Health Strategy for Homeless People (2008 – 2011)
 25 SafetyNet (2009) Service Activity Report, SafetyNet: Primary Care Network for Homeless Health Services, Pp. 5
 26 Crisis (2011) Homelessness: A silent killer: A research briefing on mortality amongst homeless people
 27 Feeney, A., H. McGee, T. Holohan, & Shannon W. (2000) Health of Hostel-Dwelling Men in Dublin. Dublin: Royal College of Surgeons in Ireland and Eastern Health Board.
 Condon, M. (ed.) (2001) The Health and Dental Needs of Homeless People in Dublin. Northern Area Health Board
 Lawless, M & C. Corr (2005) Drug Use Amongst the Homeless Population in Ireland. National Advisory Committee on Drugs
 Merchants Quay Ireland (2009) Older People's Experiences of Housing Exclusion: An Exploratory Study on behalf of NCAOP

more recent findings of the 2010 and 2011 Simon Health Snapshot Studies²⁸ which found that 56% of respondents in 2010 and 65% of respondents in 2011 had been diagnosed with at least one physical health condition, while Simon staff reported that 36% in 2010 and 29% respondents in 2011 had at least one undiagnosed health condition.

Multi-drug resistant TB is becoming a particular problem associated with rough sleeping given that it is difficult to follow the rigorous daily treatment regime for the six months as required if a person is homeless. Certain severe and contagious diseases are found to a higher degree among the homeless population than among the general population, for reasons related to inadequate access to healthcare, malnutrition, unsanitary conditions and lifestyle factors such as drug and /or alcohol use. These include hepatitis B and C, HIV, and diabetes.

Smoking is also common among people who are homeless and along with poor conditions in hostels and poor nutrition, serves to predispose many people who are homeless to pneumonia, influenza and minor upper respiratory infections²⁹. It is interesting to note that many of the studies on the physical health of people who are homeless have concentrated on people living in hostel type situations, with significantly less known about the physical health of individuals who (using the ETHOS typology) are living in houseless, insecure and inadequate accommodation.

Mental Health Issues

Worry over possible housing loss and lack of control over one's accommodation situation can lead to mental health issues including depression, stress, insomnia and anxiety. Housing that is overcrowded and of bad quality can also impact on mental health³⁰. As indeed can housing that is located in areas that are perceived to be undesirable and which lead to feelings of low self-esteem and/or insecurity, loneliness and depression. Feeney et al (2000) found that 37% of the people who were homeless had no close friends and 47% had no close relatives they could approach when they need support. For some individuals homelessness can be a major contributory factor in relation to mental health issues, while for others mental health issues can be a route into homelessness.

It is not surprising therefore to find that rates of mental ill-health are higher among the homeless population than among the population in general (Hourigan & Evans, 2003). Researchers³¹ estimate that between 25% and 50% of people who are homeless in Ireland experience mental health problems. These estimates are confirmed by a variety of more local studies including a study³² of hostel dwellers in inner city Dublin, which found that 52% suffered from depression, 50% from anxiety and 4% from other mental health problems. This survey also found that 72% of homeless men in hostels, who met criteria for serious mental health problems, were not in receipt of care. The 2011 Simon National Health Snapshot found that over 47% respondents had been diagnosed with at least one mental health condition (the 2010 Simon National Health Snapshot identified 52% respondents with at least one diagnosed mental health condition). Again depression was the most commonly occurring diagnosed mental health condition.

Symptoms of poor mental health experienced include stress, anxiety and feelings of isolation, along with incidences of depression and a higher risk of suicide. Cleary and Prizeman (1998)³³ found that 68% of people who were homeless and attending a day centre had attempted suicide. Mental health and homelessness often relate to each other in a negative cycle with mental health problems contributing to

28 The 2010 and 2011 Simon Snapshot studies are point in time surveys that provide details of the health status of a sample of Simon Service Users.

29 WHO-Europe Health Evidence Network: How can health care systems effectively deal with the major health care needs of homeless people

30 World Health Organisation 2004: "Review of Evidence on Housing and Health" Fourth Ministerial Conference on Housing and Health, background document, pg 4.

31 Amnesty International (2003) Mental Illness-The Neglected Quarter-Homelessness. Amnesty International All Ireland Section. McKeown, K (1999) Mentally Ill and Homeless in Ireland: Facing the Reality, Finding the Solutions. Disability Federation of Ireland. Homeless Agency (2004) Making it Home: An Action Plan on Homelessness in Dublin 2004-2006. Homeless

32 ERHA & RCSI (2000) The Health of Hostel-Dwelling Men in Dublin: perceived health status, lifestyle and healthcare utilisation of homeless men in south inner city Dublin hostels.

33 Cleary, A & G. Prizeman (1998) Homelessness and Mental Health. Social Science Research Centre

the breakdown of social relationships, to unemployment and to eventual homelessness, which in turn may lead to worsening mental health, as well as complicating factors such as problematic drug and /or alcohol use. Mental illness frequently presents as schizophrenia, depression and other affective disorders, psychoses (including drug-related psychosis), anxiety states or personality disorder.³⁴ Among rough sleepers, the prevalence of severe and enduring mental health problems is particularly high, with problems such as depression, anxiety and learning difficulties extremely widespread.³⁵

Many people who are homeless with mental ill-health issues are also often problematic drug and/or alcohol users which in turn may aggravate existing mental health problems. Research indicates that experience of trauma (sexual and/or physical abuse) is very high among people who are homeless, particularly among those suffering from dual diagnosis. This has major implications for their state of mental health and well being. It can lead to mental vulnerability and play a role in tenancy breakdown.³⁶ Recent research from the US³⁷ postulates that trauma rates are high enough among this part of the homeless population to warrant the inclusion of trauma and counselling services in the care packages available. This type of support is seen as an important part of treating mental problems and helping the individual overcome drug and or alcohol related issues.

2.8 Problematic alcohol and drug use and dual diagnosis

Holohan (1997)³⁸ estimated that the prevalence of use of alcohol amongst people who are homeless ranges from 29% to over 50% while other studies suggest it could be as high as 70%. Chronic alcohol use takes its toll on the cardiovascular system and greatly weakens a person's overall state of health over time. It causes severe damage to the liver and can lead to cirrhosis. Over 50% of 2011 Simon National Health Snapshot survey respondents indicated that they were current alcohol users, while alcohol had generated health issues for about 28% survey respondents.

A problem drug user has been defined by the UK Advisory Council on the Misuse of Drugs as "any person who experiences social, psychological, physical or legal problems related to intoxication and/or regular excessive consumption and dependence as a consequence of his or her use of drugs or other chemical substances". Research³⁹ has found problematic drug use more prevalent among younger age groups with heroin the most frequently used drug amongst survey respondents. Cannabis was the second most commonly used drug with growing numbers using benzodiazepines. The majority of intravenous drug users report problems related to scarring and bruising, infections and accidental overdose. Many drug users are also hepatitis C positive (See also, *Drugscope*, 2000).

Problematic drug and alcohol use may contribute to homelessness and to health problems; but it may also be that problematic drug and alcohol use are a consequence of a person's homelessness. 20% of the people who were homeless involved in the 2011 Simon National Health Snapshot study cited personal alcohol use as the most common reason for becoming homeless while 13% reported personal drug use as one of the two key reasons for becoming homeless. Over 50% of respondents in the most recent Simon National Health Snapshot in 2011 reported that they were drug users, while 31% identified themselves as current drug users⁴⁰. The on-going University of Sheffield study⁴¹ on mortality among people who are homeless has identified drugs and alcohol as major causes of death amongst people who are homeless.

34 World Health Organisation 2004: "Review of Evidence on Housing and Health" Fourth Ministerial Conference on Housing and Health, background document, pg 11.

35 C. Frankish, S. Hwang and D. Quantz: "Homelessness and Health in Canada: Research Lessons and Priorities", Canadian Journal of Public Health, Ottawa, Marc/Apr 2005. Vol. 96, pg 27

36 AHURI Research and Policy Bulletin: "Cycles of Homelessness" Issue 39 March 2004, www.ahuri.edu.au

37 R. Christensen, C. Hodgkins, L. Garces, K. Estlund et al: "Homeless, Mentally Ill and Addicted: The Need for Abuse and Trauma Services" Journal of Health for the Poor and Underserved, Nashville: Nov 2005, Vol 16, Iss 4 pg 620

38 Holohan, T. (1997) Health status, health service utilisation and barriers to health service utilisation among the adult homeless population of Dublin. Dublin: EHB

39 The 2010 and 2011 Simon Health Snapshot's

40 Simon Communities of Ireland(2011) Simon Health Snapshot 2011

41 Crisis (2011) Homelessness: A silent killer: A research briefing on mortality amongst homeless people

Problematic drug and alcohol use are both a mental and physical health issue. One research study went as far as attributing 30% to 70% of the deaths of their study participants to alcohol related causes.⁴² Alcohol use is identified in 'A Vision for Change' (2006) as the single most prevalent health problem for people who are homeless with frequency of consumption varying by gender and age.

2.9 Complex Needs

Turning Point⁴³ defines people with 'complex needs' as individuals with multiple interconnecting needs that span medical and social issues. Individuals with 'complex needs' may have mental health issues, combined with substance misuse problems, and learning disability. At the same time they may experience social exclusion, such as living in poor housing, with few opportunities for meaningful activities and leisure".

There are also significant numbers of people who are homeless that experience the coexistence of mental health issues and physical health issues which may or may not be complicated by problematic drug and/or alcohol use. The term "complex/multiple needs" refers to the fact that people who are homeless will have 'and will often present to services with' more than one serious problem. These multiple and complex needs often aggravate each other. A useful extract from a definition of complex/multiple needs 'developed by NGOs in the UK' is where a person who is/was homeless 'presents with three or more of the following':

- *mental health problems;*
- *misuses various substances;*
- *personality disorders;*
- *offending behaviour;*
- *borderline learning difficulties;*
- *disability; physical health problems;*
- *challenging behaviours;*
- *vulnerability because of age.*

'If one of these needs were to be resolved, the others would still give cause for concern.'⁴⁴

A more detailed discussion on meeting complex needs within a general social care setting can be found in Rankin & Regan, 2004.

2.10 Barriers to Accessing Health Care

Among the key barriers for people who are homeless to accessing the medical and health care services⁴⁵ and supports they need, is that meeting basic needs in relation to food, shelter, employment and safety are often perceived as of higher importance than healthcare. Competing needs is a term used to describe

42 Larimer, Mary, E. PhD. et. al, Health Care & Public Service Use & Costs Before & After Provision of Housing for Chronically Homeless Persons with Severe Alcohol Problems in Journal of American Medical Association, April 1, 2009. Vol. 301, No. 13, Pp. 1349-1357

43 Rankin, J. & Regan. S. (2004) Meeting Complex Needs: The Future of Social Care. Turning Point & The Institute of Public Policy Research: London.

44 Multiple Needs Briefing, Bevan P, Homeless Link 2002

45 The 2008-2012 Adult Homeless Strategy indicated that the following health services were in place for saults who are homeless: multidisciplinary teams in Dublin, Cork, Limerick and Waterford (These were all resourced at different levels with some subsequently subsumed into Primary Care Teams (eg. Dublin Inner City), GP clinics in hostels and day centres; funding to NGOs to employ nurses, chiropodists and counsellors; improvements in access to medical cards for homeless people; an outreach mental health team in Dublin; a dedicated alcohol detoxification and rehabilitation service; dental surgery in a day centre for homeless people; an outreach needle-exchange service; protocols developed with both acute and mental health hospitals to prevent inappropriate discharges into homelessness, (communication with the HSE Suggests that these protocols are due to be reviewed in 2012 as part of the National Service Plan), as well as SafetNet services in Dublin. The reality is now that funding and support particularly for the NGO sector has because of the current economic climate been cut, thus reducing the levels of services available generally.

the necessity of prioritisation of needs by people who are homeless, given the limited resources at their disposal⁴⁶. A Study of Homeless Adults in Los Angeles found 'for example' that 31% of the survey respondents had gone without needing medical care in the previous 12 months because other needs were prioritised above access to health services. In this study, authors argued that the high rates of hospitalisation among adults who are homeless are often as a result of neglected illnesses that could have been "prevented or treated in ambulatory care settings if identified earlier." They also noted that "Any attempt to address the healthcare needs of the homeless must take into consideration their unmet needs for food, clothing, shelter and bathroom facilities. Locating walk-in clinics where the homeless congregate to receive subsistence services would help to reduce the role of time and scheduling constraints as barriers to care."

Other barriers to people who are homeless accessing the primary health care in particular include⁴⁷:

- Stigma: people who are homeless report encountering negative reactions when they try to access healthcare services. They identify trying to deal with administrative personnel as particularly difficult;
- Discrimination: people who are homeless find it harder to register with a General Practitioner than members of the general public. Requests for a permanent address and other details can constitute a real or a psychological barrier;
- No continuity of care: the lifestyle of people who are homeless tends to be a mobile one, but there is frequently no flexibility in the healthcare system in this regard. A move from one area to another may mean that a person who is homeless finds himself or herself outside the system again;
- Difficulty accessing drug and alcohol services: services may be insufficient and often have very long waiting times, but they are crucial for the health of people who are homeless.
- Lack of knowledge about entitlements: some people who are homeless don't know what they are entitled to in the line of healthcare and services. If they were better informed they would be more confident about trying to access them;
- Financial obstacles: in many countries there may be costs associated to accessing healthcare that makes it inaccessible to people who are homeless. O'Carroll and O'Reilly found that over 40% of people who are homeless (44% in 2008 and 45% in 1997) did not have a medical card despite the introduction of a range of initiatives to increase uptake of free entitlements to primary care.

Added to this list as barriers to accessing Irish health services must be the absence of a medical card and previous negative experience of accessing health services.⁴⁸ Recent changes⁴⁹ in the way the medical card scheme has been administered have posed challenges but strategies have now been put in place by the HSE to prioritise the processing of medical cards for people who are homeless⁵⁰. The findings of a recent study⁵¹ on the survivors of abuse are also very relevant in this context, suggesting that experience of abuse has contributed to an anxiety regarding the possibility of receiving nursing care later in life. It is not clear exactly how many people who are homeless have experience of abuse. Given that time in care is generally accepted as a route into homelessness and that a charity, consulted⁵² by the Commission to Inquire into Child Abuse, providing accommodation to people with experience of

46 M. Kushel, R. Gupta, L. Gee, J. Saas: "Housing Instability and Food Insecurity as Barriers to Health Care Among Low-Income Americans." *Populations at Risk*, JGIM 2005, pg 76

47 "Listening to Homeless People: Involving Homeless people in Evaluating the Health Services" Groundswell UK, Healthlink, 2003 <http://www.health-link.org.uk/publications/fileupload/index2.php>

48 Simon Communities of Ireland (2011) *Simon Health Snapshot 2011*

49 The system has recently been centralised, leading to long delays in processing applications. Although communication with the HSE suggest that it is still possible to 'fast track' certain categories of applicants (including people who are homeless) through contact with a dedicated person in the central office.

50 Personal Communication Maurice Hoare (HSE) 5th April 2012

51 Higgins, M (2010) *Developing a profile of survivors of abuse in Irish religious institutions*. St. Stephens Green Trust

52 Commission to Inquire into Child Abuse (2009). *Report of the Commission to Inquire into Child Abuse*: Dublin

homelessness aged in their 40's and 50's estimated that between 50% and 70% of residents had experienced institutional abuse, it is likely that the numbers could be high. This poses a very particular challenge for these individuals accessing care in all its forms. The Charity consulted as part of the Commission also identified the group of individuals who had had experiences of abuse as tending to be part of the longer term population of people who are homeless with mental health, alcohol abuse and challenging behaviour issues. This population is not typical of people who are homeless generally but is representative of a proportion of the population.

Interestingly, while people who are homeless face significant barriers when accessing health care, research has found that they tend to use acute care services at higher rates than other vulnerable groups.⁵³ The 2011 Simon National Health Snapshot found that 55% of respondents had used accident and emergency services in the previous month. (The London Pathways model, introduced to support people who are homeless through the hospital system, has demonstrated that, through a programme of early and sustained intervention, it is possible to significantly reduce the number and the length of admissions of people who are homeless. In the case of the London Pathways model they have managed to reduce the number of bed days by 1000, representing a saving in real terms of approximately STG £300,000 (approx. €360,868) a year⁵⁴).

2.11 Dying and Death in Ireland

Almost 30,000 people die each year in Ireland. The National Council of the Forum on End of Life estimate that 25% of people die at home, over 48% in acute hospitals, 4% in hospices, 3% in road traffic accidents, 3% die by suicide and 20% in long stay care (These figures are estimates based on the death statistics from 2004, 2006 and 2007, and are drawn from a variety of sources. Just over three quarters of deaths annually are drawn from those aged 65 years and over. Forty percent of these older deaths occur in acute hospital settings (See Table 2.1 for details). The most recent (2009) data available from the CSO suggest that a further 20% (4,000) older people die at home, while 15% die in private nursing homes, while the remaining 25% die in other settings, mainly public long-stay care facilities⁵⁵ (O'Shea et. al, 2008: 29).

Table 2.1: Total No of Deaths in Acute Hospitals for People Aged 65 Years and Over

Age Group	Total Deaths	Deaths in Acute Hospitals
65-74 years	5,280	2,453
75-84 years	9,412	4,079
85+ years	7,382	2,286
Total	22,074	8,818

Source: National Audit of End-of-Life Care in Hospitals in Ireland Hospice Friendly Hospital Programme's 2008/09

53 Larimer, Mary, E. PhD. et. al, Health Care and Public Service Use and Costs Before and After Provision of Housing for Chronically Homeless Persons with Severe Alcohol Problems in Journal of American Medical Association, April 1, 2009. Vol. 301, No. 13, Pp. 1349-1357

54 Personal communication with Dr. Nigel Hewitt clinical lead for the homeless team at UCLH and Medical Director of the London Pathway on 15th February 2012

55 Public long-stay care facilities can include non-acute hospitals, convalescent homes or homes for people with physical/intellectual disabilities, long stay institutions, or community residences where nursing or medical care is provided.

2.12 End of life care⁵⁶

The concept of end of life care is *'broader in scope than palliative care and allows a longer lead time to death'*. End-of-life care is intimately bound-up with quality of life issues and therefore needs to be flexible and responsive to the needs of older people living in acute and long-stay care settings, given that this is where the majority of older people die in Ireland.⁵⁷ *"The need for end-of-life care can arise far away from actual death, depending on the physical, mental and emotional state of the individuals and their families."* (p. 21). There is no agreement about when end of life should begin.

End of life care for older people generally includes a mix of gerontological care and palliative care in order to address Froggatt's (2004) three stages of end of life care in long stay settings:

- The living and losses experienced in the care home
- The actual dying and death
- The bereavement that follows.

There are various dimensions to the provision of appropriate support and care to older people faced with the issues of serious ill health, death & dying including: the quality of care received; the location of the care and where relevant the acknowledgement or recognition of the approaching death on the part of the individual, their family and their medical team; individual choice; respect for the older person's dignity; and appropriate responses to their vulnerability at this life stage⁵⁸. Research shows that over two-thirds of Irish people expressed a wish to die at home, if at all possible, but the reality is that the majority die in acute hospitals or long-stay residential settings (Irish Hospice Foundation, 2004).

People tend to die in acute general hospitals where there is an absence of dedicated end of life services. Facilities for end of life care in many acute hospitals are not always suitable and recent research found that more than half of people who died in acute hospitals or psychiatric hospitals died in multi-bedded rooms (O'Shea 2008). Where services are better developed, it is no surprise to find an increased incidence of death in a special in-patient unit (hospice) or home-care setting (IHF/HSE Baseline Study 2005).

Key good practices identified by O'Shea for end of life care include consideration of the person's wishes at all stages of the care process (including any advance directive made prior to the onset of incapacity). He argues that there is a role for an independent advocate in assisting the person to make a decision about their care and treatment. While there is currently no legislation at present to underpin advance directives, either formal or informal, they are a means of ensuring an individual's wishes are clear and can be respected. He also makes the case for the development of written policies/guidelines on advance directives on end of life care for ethnic minorities in residential settings according to the researchers. [It is likely that similarly dedicated guidelines could be developed for older people who are homeless].

Challenges and barriers to the provision of quality end of life care include staff shortages, lack of privacy, resource constraints, capacity problems, infrastructural weaknesses, education deficiencies and poor attitudes and expectations in relation to quality of life for older people at end-of-life. O'Shea in his work argues that ageism within society generally and within the health and social care system in particular makes it difficult to sanction investment in end-of-life care for older people, with little engagement with quality of life issues for older people in long-stay setting (p. 20). There is also a small but growing body of research that argues that the dying and death of individuals in what is termed 'the fourth age' 'defined as 85 years and older' may have a different experience to younger individuals. Nicholson & Hockley⁵⁹ argue that 'this group are more likely to experience repeated hospital admissions, lack of preventative planning,

56 A decision was made for the purposes of this study to use the definitions provided and applied by the Irish Hospice Foundation. It should be noted that specialist palliative care uses a different terms' palliative care needs' which is not time bound.

57 O'Shea, Eamonn, Murphy, Kathy, et. al (2008) *End of Life Care for Older People in Acute and Long Stay Care Settings in Ireland*. Hospice Friendly Hospitals Programme and National Council on Ageing and Older People.

58 The New Ageing Agenda, The Ageing Well Network website <http://www.ageingwellnetwork.com/The-New-Ageing-Agenda/health>

59 Nicholson, C & Hockley, J (2011) Dying and death in Older People. pp. 101-109 in *Death Dying and Social Differences* (2nd Ed) (Ed Oliviere, D, Monroe, B and Payne, S. Oxford University Press.

social isolation and economic hardship and are less likely to access palliative care than their younger counterparts' (p 101). Harris⁶⁰ (1990) indeed describes this group as the '*disadvantaged dying*'.

The Irish Hospice Foundation has developed or funded a range of training programmes to help facilitate and connect key care and medical staff with end of life care and their local hospice. These programmes include a 'Link Nurse Initiative', a pilot programme in which local hospice education centres train nurses working in nursing homes/community hospitals in order to enhance their own skill and to help them to connect and make linkages between their patients and the local hospice/s. A second initiative is a staff development programme called 'Final Journeys', which helps examine attitudes and understanding of end of life, originally in the hospital setting, but which could be adapted for use with a variety of care staff (including staff in homeless agencies). The Foundation also provides a range of bereavement and loss education inputs and this includes linking problematic drug/alcohol use and loss issues.

2.13 Experiences/attitudes towards dying and death among older people who are homeless

There are no specific health services targeting older people who are homeless. So it is not surprising to find that there is little 'if any' information available or indeed work done on the experiences and attitudes towards dying and death among older people who are homeless in an Irish context. Neither is there any information available on the mortality rates and causes among people who are homeless, making it difficult to quantify and qualify both the extent or the problem and the nature of the issues involved.

Some work has been from the perspective of homeless sector workers and how they deal with death. The study, which was undertaken in 2009⁶¹, involved homeless sector workers from around Dublin. The study explored how these workers dealt with death and described the processes that enabled them to deal with the experience in a way that enabled them to maintain a positive view of their work and service users. A series of very useful resources⁶² designed to support homeless sector workers were developed as a result of this work and these provide a useful source of training and support materials for homeless sector workers. Interestingly, some work has also been done in an Irish context on Traveller's and gypsies' attitudes to dying and death.^{63 64}

There are very few international studies that have explored the experiences and attitudes of people who are homeless toward dying and death. One of the few studies on the subject 'undertaken in the US' found that many participants were of the view that deaths—particularly early ones—may have contributed to their present homelessness. (i.e. the death of a parent/care giver early in the participants lives). The study also found that many of the study participants had lost a loved one or caregiver early in life (this was especially the case for older people who were homeless). Others had lost loved ones or friends who were also living on the streets.

Study participants were generally found to be quite fearful and concerned about death, dying and end of life care, given that death on the streets can be more traumatic and demeaning than deaths that domiciled people may experience. They were able to site numerous brutal experiences with/of dying and death. They had developed a variety of coping strategies to deal with these fears, including a sense of fatalism or isolation and emotional detachment and/or the use of humour. Some had even employed risk management techniques as a means of dealing with death including advance care planning and documentation which 'for some' involved discussion with significant others and/or appointment of a proxy while for others it meant some form of documentation of wishes or contact information.

60 Harris, L (1990) Continuing Care: The disadvantaged dying. *Nursing Times*, 86(22): 26-9

61 Lakeman R. (2010) How Homeless Sector Workers Deal with the Death of Service Users: A Grounded Theory Study. *Journal of Death Studies*.

62 These can be assessed at <http://www.working4recovery.com/death/>

63 McQuillan, R & Van Doorsaler, O. (2007) Indigenous ethnic minorities and palliative care: Exploring the views of Irish Travellers and palliative care staff. *Palliative Medicine*, 21 (7): 365-41

64 McQuillan, R (2011) Traveller's and gypsies' dying and death pp 159-165. In *Death Dying and Social Differences* (ed Oliviere, D, Monroe, B and Payne, S) Oxford University Press

The study found that death related experiences associated with health care providers were generally negative. The majority believed professionals were not concerned for their health because they were homeless and were deemed less worthy of treatment than citizens from the general population. The author suggests that these negative experiences with health care providers and institutions should be researched further as a possible contributor to continued homelessness. The attitudes toward death among people who are homeless may also shed light on high risk behaviours and risk management strategies employed.

It is not clear whether the learning arising from studies done with other vulnerable population groups is relevant to people who are homeless, given that people who are homeless/have experience of homelessness may have a number of very distinct and unique characteristics⁶⁵ including the following:

- A lack of access to stable and safe accommodation which underlines the fragility of life.
- Limited access to the services which contribute to good health and wellbeing & high levels of poor health.
- Exclusion from institutions providing health care often due to poor treatment by health care providers.
- Complex needs (that include multiple and interconnecting physical and mental health and social needs).

2.14 End of life care for people who are homeless

The absence of a formal national system for recording the number, cause and nature of death and tenancy type of people who are homeless in Ireland means that significant gaps exist in our understanding of the experience of dying and death for people who are homeless. This is compounded by that fact that we do not know how many, 'if any', people who are homeless present for hospice care. The UK experience suggests that few if any people who are homeless tend to present for hospice care because of a high level of non-engagement with services and the prevalence of perceived problematic behaviour.⁶⁶ A working group has recently been formed in the UK to bring together homeless support organisations to begin the process of recording deaths.

Delivering high quality end of life care for people living in hostels or on the streets presents particular challenges for housing and healthcare for a number of 'reasons' including the fact that the average age of death is lower (47 for men and 43 for women according to the most recent study).^{67 68} It is also the case the admissions among this group tend to be crises admissions which require longer stays and which sometimes result in the individuals being discharged and sent back to the hostel. This in turn can be problematic because the individuals may as a result of their illness have additional care needs. The intermediary care model⁶⁹ (proposed in an Irish context by Dr. Austin O'Carroll and others) offers a potential solution to this problem if some of the beds provided in this type of facility could be provided for individuals with palliative care needs. It is also the case that a small number of palliative care (level II) beds may be available in community hospitals around the country.⁷⁰ The exact number of beds available is 'unclear' as is the capacity of these hospitals to deal with individuals who may present with both complex needs and challenging behaviour. The willingness of individuals who are homeless to present to these hospitals is also something of an unknown.

65 Song, John, *et al.* (2007) *Experiences with and Attitudes Toward Dying and death among Homeless persons* J Gen Intern Med. 2007 April; 22(4): 427–434. Published online 2007 January 18.

66 Interview with Peter Kennedy, Palliative Care Coordinator St. Mungos 27 January 2012

67 Crisis (2011) Homelessness: A silent killer: A research briefing on mortality amongst homeless people

68 This is significantly less than the life expectancies identified for the Traveller population (another often cited vulnerable group). The average life expectancy of a male Traveller was found to be on average 10 years less than settled men and 12 years less for a Traveller women according to the National Intercultural Health Strategy 2007 – 2012.

69 O'Carroll, A. O'Reilly, F. Corbett, M & Quinn, L (2006) Homelessness, Health and the case for an Intermediate Care Centre Report by Mountjoy Street Family Practice

70 Communication (29/3/2012) Caroline Lynch, Communications/Advocacy Manager, The Irish Hospice Foundation

Liver failure is frequently a contributing factor, which brings a number of complications, including memory loss and, as it is often caused by problematic drinking and drug use, people are often less willing to engage with health professionals in the first place. It is also the case that staff who work with people who are homeless who have moved into hostel accommodation may not encounter it often, making it much harder to predict or prepare for. Marie Curie Cancer Care, in partnership with the Homeless Charity St Mungo's, recently produced a report⁷¹ on supporting people who are homeless with advanced liver disease approach end of life. The purpose of this study was to help identify the issues and signals used to detect when end of life is approaching, and facilitate staff to offer the best possible palliative care and advice for friends, family and other staff. Getting end of life care right is clearly important not only for those who die, but for other residents, staff and the wider homeless community⁷². Another interesting element of the services provided at St Mungos has been the appointment of the first ever Palliative Care Co-ordinator whose role was to help in the identification of individuals nearing end of life⁷³ and to raise staff awareness of the signs of end of life and thereafter to train and support staff to identify and provide best possible care and support for individuals at the end of their lives and in their care. In this context the publication (drawing on the experiences of St Mungo's) by the NHS of a guide⁷⁴ entitled 'End of Life Care: Achieving quality in hostels and for people who are homeless- a route to success' is a welcome development (See Appendix 3 for details).

2.15 Other Supports for people who are homeless with serious ill health

2.15.1 Nationally

The Primary Care Safety Net Initiative launched in 2007 aims to provide a dedicated, cohesive and comprehensive primary health care service for people who are homeless in Dublin, Dundalk, Galway and Cork⁷⁵. The Primary Care Safety Initiative is a coordinating partnership which includes the Health Service Executive, General Practitioners and the Voluntary Sector. It *provides specialised health care services targeting the homeless population in settings that they use on a regular basis such as hostels and community based support services (SafetyNet, 2009:5)*. In addition, SafetyNet supports medical practitioners, who might otherwise experience isolation, and promotes best practice clinical standards among SafetyNet members.

One of the additional services the providers of the SafetyNet Initiative would like to see developed is the provision of "an intermediate care facility designed for people who are homeless who have been discharged from hospital but who are too sick to return to their homeless accommodation or to the streets". This facility would be similar to that proposed by O'Carroll⁷⁶ and would be particularly relevant to people who are homeless and who have been diagnosed in primary care with health conditions of such severity that homeless accommodation is unsuitable but hospitalisation is unnecessary⁷⁷.

71 Marie Curie Palliative Care Research (2011) Supporting homeless people with advanced liver disease approaching the end of life. University of London & St Mungos

72 Puckett, Katie, Dignity in Death article in e-magazine Inside Housing printed on 28th January 2011 <http://www.insidehousing.co.uk/analysis/best-practice/dignity-in-death/6513430.article>

73 Interview with Peter Kennedy, Palliative Care Coordinator St. Mungos 27 January 2012

74 NHS (2010) 'End of Life Care: Achieving quality in hostels and for homeless people -a route to success. This guide identifies six key steps for end of life care for people who are homeless

75 Downey, Daithi (ed.) (2008) *Perspectives on Irish Homelessness: Past, Present and Future*. The Homeless Agency, Dublin.

76 O'Carroll, A. O'Reilly, F. Corbett, M & Quinn, L (2006) Homelessness, Health and the case for an Intermediate Care Centre Report by Mountjoy Street Family Practice

77 Downey, Daithi (ed.) (2008) *Perspectives on Irish Homelessness: Past, Present and Future*. The Homeless Agency, Dublin 8.

2.15.2 Internationally

The introduction in the US of the Pathway Housing First Model (PHF)⁷⁸, linked to a housing and case management program (Larimer, et. al, 2009) (which facilitated the participant's housing placement and co-ordinated appropriate medical care, with substance abuse and mental health treatment referrals as needed), for chronically ill adults who are homeless had the effect of reducing hospitalisation and emergency department visits. While it led to an improvement in physical functioning and mental health of the men it did not 'ultimately' improve their mortality rates.

Another interesting health initiative is the London Pathway Integrated Healthcare initiative⁷⁹ for hospitalised rough sleepers and single people who are homeless and attending hospital. The initiative seeks to engage with and treat all aspects of the health of people who are homeless, including their long-term underlying problems as well as the immediate problems that led them to be in/to attend hospital. For the most unwell and chronically sick patients, Pathways staff convene weekly paper-based ward rounds which bring together people from a range of professional disciplines to coordinate and integrate the patients' care plans. This makes sure that the sickest patients get the most attention. London Pathway medical staff follow a strict discharge protocol to ensure that the patient who is homeless moves on/is moved to the most appropriate location in a coordinated and supported way.⁸⁰

2.16 In Summary

The CSO Special Report on Homelessness identified 3,808 individuals (67% male and 33% female) as located in either accommodation providing shelter for people who are homeless or sleeping rough. 62.4% of these individuals were located in the Dublin Region.

The causes of homelessness vary. They can be structural (e.g. related to poverty, unemployment and housing), institutional (as a result of leaving institutions including foster care, prison, mental health institutions and the armed forces), related to relationships (including abusive relationships and family breakdown (death or separation), and for personal reasons (including mental illness, learning difficulties and drug and/or alcohol use).

Average Irish life expectancy is currently 76.8 for men and 81.6 for women. According to the UK research, the average age of death of a person who is homeless is 47 for men and 43 for women. This is because people who have a long term history of homelessness have higher levels of physical and mental illness, problematic drug and/or alcohol use and higher death rates than the general population.

Anyone over 50 who has had a prolonged experience/s of homelessness is generally thought to be vulnerable to many of the physical health problems associated with older age which also often present with high levels of cognitive impairment and mental illness. For this reason individuals who are aged 50 and homeless are included in the "older homeless" category.

Individuals who are homeless often have 'complex needs' which may include physical and mental health issues, combined with problematic drug and/or alcohol use, and learning disability. Experience of trauma (sexual and/or physical abuse) is also often very high among people who are homeless, while alcohol use is the single most prevalent health problem.

78 Housing First is a housing model developed in the US as a response to chronic homelessness. Housing First programs provide direct access to housing. Unlike housing programs that have specific conditions that need to be met in order to become a tenant, the goal is to re-house the person regardless of past or current behaviours. In Housing First projects, we don't, for example, require mental health treatment plans, addiction recovery, or other forms of compliancy prior to moving in. Once a person is housed, staff support and work with the tenants to solve any issues that create problems in housing. This approach can greatly reduce the amount of time people spend homeless. <http://heretohelp.bc.ca/publications/visions/housing-homelessness/alt/4>

79 See Standards for Commissioners and Service Providers, The Faculty for Homeless Health (May, 2011) http://www.londonpathway.org.uk/uploads/homeless_health_standards.pdf

80 www.londonpathway.org.uk

Dedicated supports for people who are homeless in an Irish context include the Primary Care SafetyNet Initiative which operates in Dublin, Dundalk, Galway and Cork.

The majority of older people (over 65 years) die in acute and/or long-stay care settings in Ireland. Good practices for end of life care include consideration of the person's wishes at all stages of the care process (including any advance directives made prior to the onset of incapacity). There may also be a role for an independent advocate in assisting the person to make decisions about their care.

The absence of a formal national system for recording the number, cause, nature of death and tenancy type of people who are homeless in Ireland means that significant gaps exist in our understanding of the experience of dying and death for people who are homeless.

This is compounded by that fact that we do not know how many, if any, people who are homeless present for hospice care.

International studies exploring the experiences and attitudes of people who are homeless toward death found individuals fearful and concerned about death, dying and end of life care. The UK experience suggests that few people who are homeless present for hospice care because of a high level of non-engagement with services and the prevalence of problematic behaviour.

Delivering high quality end of life care for people living in hostels or on the streets presents particular challenges for housing and healthcare.

Liver failure (often caused by problematic drinking and drug use) is frequently a contributing factor to early mortality.

Some interesting initiatives developed in the UK to address the end of life needs of people who are homeless includes a) the appointment of Palliative Care Co-ordinator whose role it is to help in the identification of individuals nearing end of life and to train and support staff to identify and provide best possible care and support for such individuals; b) the publication by the NHS of an End of Life Care: guide for people who are homeless-and living in hostels and c) the London Pathway Integrated Healthcare initiative designed to support hospitalised rough sleepers and single people who are homeless and attending hospital.

SECTION 3

Findings

3.1 Profile of interviewees (who are homeless/have experience of homelessness)

3.1.1 Overview

Interviews were conducted with sixteen individuals, three women and thirteen men in eight⁸¹ locations. The average age of the interviewees was sixty-one. Thirteen of the interviewees lived in urban locations, while three lived in rural locations. All were in regular contact with a Simon Community and had a key worker. Five interviewees were living independently, three in houses rented from various local authorities, one in a Simon Apartment and one in his home⁸². Eleven interviewees were living in communal accommodation, serviced by Simon staff and volunteers. See Table 3.1 for an overview of these interviewees.

Table 3.1 A Profile of the Interviewees

Pseudonyms ⁸³	Current Living Arrangements	Age
Dominic	Lives in an emergency Simon hostel that caters for all age groups	73
Dara	Lives in an emergency Simon hostel that caters for all age groups	51
Kate	Lives in an emergency Simon hostel that caters for all age groups	66
Derek	Lives in Simon medium support communal accommodation	66
Dan	Lives in Simon medium support communal accommodation	Late 60s
Ciaran	Lives in Simon high support communal accommodation (that caters for an older age group)	55
Con	Lives in Simon high support communal accommodation (that caters for an older age group)	Mid 50s
Cillian	Lives in Simon high support communal accommodation (that caters for an older age group)	69
Ciara	Lives in Simon high support communal accommodation (that caters for an older age group)	53
Garret	Lives in Simon high support communal accommodation (that caters for an older age group)	67
Graham	Lives in Simon high support communal accommodation (that caters for an older age group)	55
Peter	Lives in local authority housing at the edge of a market town, with support provided by Simon	55
Sean	Lives in a local authority housing in a small rural village, with support provided by Simon	60
Kevin	Lives in local authority housing in a large town, with support provided by Simon	66
Liam	Lives in Simon housing, with support provided by Simon	61
Leo	Lives in own home (which is very poor condition), with support provided by Simon	64

81 Dublin, Cork, Galway, Dundalk, Longford, Sligo, Leitrim and Limerick.

82 This house (Leo's house) is in very poor condition and efforts had been made to get Leo to re-locate to a nearby town. He moved for a short period but within a few months moved back his home, preferring as he described it 'to be in my own corner'.

83 Names and identifying have been changed to protect the identity of the interviews and their families

Two of the interviewees (Kevin and Dara) were born in the United Kingdom. Kevin came to Ireland when he was a child of ten, while Dara moved to Ireland in her thirties in search of a quieter life. Half of the interviewees spent a considerable part (generally 15-20 years) of their adult working life outside of Ireland, mainly in the United Kingdom. Ben was unusual in that he moved when he was young to England and emigrated from there to Australia, returning to Ireland in his fifties, while Kevin was stationed in various locations around the globe as part of army life. 10 interviewees had been married; often for quite considerable periods of time, while a number of interviewees had been involved in long term relationships. 10 interviewees (seven men and three women) had children, while some also had grandchildren. Only five of these ten interviewees had any contact with their children and grandchildren. This was a source of considerable regret, particularly for the three female interviewees.

DAN



Dan is in his late sixties. He was born in Cork, but brought up in London, from where he emigrated to Australia in his early twenties. He is now in his late sixties. Dan lived in Australia for more than 25 years living in a variety of different places doing a range of different, mainly warehousing jobs. Dan lost touch with his Irish roots but decided to return to Ireland in the mid-nineties. He hoped to be able to find work but believes now that his age was against him. Initially he lived in a bed and breakfast but was unable to afford this in the longer term and moved into a hostel. Since then he has moved between hostels. He has been living in the current hostel for over five years and is happy there as it is quiet and central enough. Dan is active and likes to get out and go for a walk every day. He reads a lot and is very self-contained. Dan has struggled with his moods and when he was younger says he found it hard to accept things. He believes that as he has got older he has become able to accept things more, be more rational. He tries not to think too much about anything including dying and death, but does believe in god and an afterlife and for him that makes life easier.

DEREK



Derek was born in Galway and given up for adoption by his mother who was a single parent. He left school at 14 to go to work. He had a variety of jobs in and around Dublin before he moved to London, where he met his wife. They had three children together and were married for over 25 years. One of the most unusual jobs Derek had in London was working as a gravedigger for about four years. Derek later returned to Ireland and went onto work for the same employer for 20 years. When Derek's marriage broke up he moved out of the family home and into private rented accommodation. His poor mental health meant that he was unable to sustain the tenancy and he became homeless. He ended up sleeping rough for a number of years. More recently he found his way to Simon Services and life became easier. A few years ago Derek's physical health began to deteriorate and he developed emphysema as a result of a life time of smoking. More recently Derek was diagnosed with a serious degenerative condition which affects his balance and increasingly his mobility and his speech. There is currently no cure for this condition. Derek is able to navigate the space he is living in and hopes to be able to live and die where he is. Over the last number of years Derek has re-established contact with his family and particularly his children and grandchildren. Derek is very aware of the degenerative nature of his condition and has decided to take control of his death. He has made his will and knows where he wants to be buried. Derek lost his faith a number of years ago and this absence of faith was very difficult when he got sick. He does not go to church but believes and hopes there is an afterlife.

DOMINIC



Dominic grew up in Dublin leaving school at 13 to find work. Dominic has had a variety of jobs since frequently losing his job as a result of his drinking. Dominic moved to Birmingham in his twenties where he worked for over twenty years. His memory is poor because of alcohol and he is frequently confused and can at times suffer from paranoia. Dominic continues to this day to be a heavy drinker and smoker, and has regularly slept rough and stayed in hostels. He thinks he may be in his current hostel 5-6 years but is not sure. He is generally content and likes the staff and volunteers. He does worry about things being stolen from his room and has developed a complex system for managing his money and avoiding it getting stolen. Dominic says he is not ready to die yet and that he would like to go to heaven but thinks he will have to spend some time in purgatory first. He says alcohol helps him not to worry. He thinks he is lucky because he believes in god and goes to mass and that should help when he dies. Dominic would like to continue living where he is for his lifetime.

3.1.2 Types of Homelessness

Four or five interviewees had periods of homelessness throughout their adult life. These periods of homelessness were often linked to heavy and sustained periods of drinking, linked in turn with periods of depression. For Kate, her first experience of homelessness was as a result of domestic violence. Three interviewees who had been diagnosed with schizophrenia spoke about how that had left them struggling with life. It was often only when they were older that they had been formally diagnosed and received the treatment they needed. Seven interviewees (Derek, Dara, Garret, Cillian, Ciara, Kate, Kevin) had spent long periods of time sleeping rough. None of the interviewees were currently sleeping rough; indeed most of them believed that they would not be able to survive with their current health conditions on the street.

Interestingly over half of the interviewee's first experience of homelessness occurred in their early fifties. For many it was the death of a partner or a breakdown⁸⁴ of long term relationship (closely followed by a court order requiring them to vacate the family home) that had provided the trigger for their first period of homelessness, often linked to alcohol abuse and ill health (for example Liam had a stroke very shortly after he left his family home). Some interviewees moved from the family home to bed and breakfasts but were not able to sustain the costs of this as a long term option and moved onto hostels or rough sleeping. For others (Sean and Leo) 'particularly in a rural context' it was long term neglect and deterioration of their respective family homes (caused by a combination of mental health issues and alcoholism respectively) that led to them finding themselves living in almost uninhabitable accommodation). Ben in contrast found himself effectively homeless when he returned to Dublin from Australia and was unable to find work.

84 The causes of these relationship breakdowns included marital infidelities, depression, alcoholism and gambling

CIARAN

Ciaran had a difficult family life because of a violent father. He got into trouble with the law and was sent to an Industrial School and from there to rehab where he met his wife with whom he has three children, two boys and a girl. Ciaran's children are now in their late teens and early twenties. As Ciaran's family grew so did his drinking problems. He believes now that his drinking was his effort to forget earlier childhood traumas. His marriage eventually broke down after 18 years and he left the family home. After leaving the family home Ciaran moved in to a flat. That did not last long however because at the time he was drinking heavily. He moved out of the flat and stayed with friends and in hostels. He found hostel life difficult. He was eventually referred to a 6 month alcohol treatment programme which worked well for him. When he finished the programme he was keen not to return to the hostels so with support from the treatment centre went to a half-way house for a time. One day in the company of his son however he fell off the wagon again. This particular drinking binge had serious consequences for him in that he could no longer return to the halfway house but it had even more serious consequences for his son who was ultimately convicted of a very serious crime, committed that evening. Ciaran really struggled following his son being sent to gaol. Round that time Ciaran got a flat, but living alone he started drinking heavily again. His family were supportive and visited every week bringing food with them, but the drinking got worse. He attempted suicide on a number of occasions. After his last attempt he was hospitalised for a while. Following his discharge from hospital he started drinking again and was eventually referred to a unit that provides a higher level of support than a regular hostel. He is happy with this because it has been decided that he will be here for up to three years and that gives him security, he is also clear that he needs to eat and that he does not cope well on his own. He likes where he lives but sometimes feels that he is treated as a child, when he is herded into activities that he does not want to do. Ciaran occasionally worries about dying and death but worries more about his family and particularly one of his sons.

CON

Con is in his fifties. When he was younger Con worked in hotels in Ireland, London and Brighton. He met his wife in England and they married in 1971. They had two daughters together; one is now in her early 20's and the other in her thirties. The marriage broke up because of Con's alcohol use and he left the family as a result of a court order. When Con left home he initially stayed in B&B's but that was too expensive as a long term option. So he found his way to a hostel and stayed there for a while. He was eventually referred to Simon, who sorted him out with an apartment in the city centre. He was there for about 12 months. He liked the apartment and liked living independently but a decision was made by Simon to move him because they said he was drinking too much and not taking care of himself. Con was initially moved somewhere for a few days before being moved to his current shared accommodation. He likes where he is but does not want to be there, he does not think he needs it. He does not know how long he will be in his current location for and is not sure how he would adapt to another change. Con is physically well generally but mentally he says he lives in turmoil. He believes his catering background has kept him interested in eating and food and that in turn has been a help in terms of keeping him physically well. Con tends to live more on a day to day basis than he did in the past. He does not really think about dying for himself but he thinks about it for his mum. She is 84 and he adores her, Con and his mum meet every week, do her shopping and have a pint. He is not sure what he would do without her.

3.2 Health Issues

3.2.1 The Relationship between Homelessness and Health

Some interviewees identified low mood, depression and schizophrenia as both a contributory factor and a consequence of their periods of homelessness, for others it was problematic alcohol use. The interviewees who had spent long periods of time sleeping rough believed that these experiences had a very negative impact on their health. For the majority however it was a complex combination of factors that included problematic alcohol use, mental health issues, stress, leading to mental health issues as well as physical health problems.

KATE



Kate was brought up in south west of England. She left school at 15 to go to work. Kate married in her mid-twenties and had two children a boy and a girl. This was a happy time in her life. Kate's husband left the family some time later. Kate remained in the family home to rear her two children. It was during this time Kate's nerves began to give her trouble and she was ultimately diagnosed with schizophrenia. After the children had left home Kate slept rough for a time in London often in a British Telecom's van. When her nerves improved she began to sign on and stay in hostels. Kate eventually decided to move to Ireland (her dad had Irish roots) for a better, quieter life. When she first arrived she stayed in a convent for a while. Kate moved from the convent into Simon services and has lived in a variety of types of accommodation since. She has lived in the current hostel for years and years. She can no longer remember exactly how long she is there. She says she is sometimes happy there and sometimes not. It is the noise and the comings and goings of other residents that bother her most. She would love a house of her own. Kate receives regular medication for her schizophrenia. Her mobility has also been affected by a broken ankle that never healed properly as well as arthritis and rheumatism. Kate also has a number of serious chest complaints. Kate has used both alcohol and drugs over the years to help her cope with life. She no longer uses drugs but she continues to drink. Kate watches a lot of TV and listens to the radio to block out the noise. She used to read but has not been able to find her glasses for some time now. Kate says she used to feel scared about dying and death, but has gradually got more used to the idea of going to sleep and not waking up. Kate is very clear she would not want to go into a nursing home. She worked in a home for a while when she was younger and saw older people treated badly. She is clear that if she were ill she would rather go to hospital and die there than anywhere else.

3.2.1 Physical and Mental Health issues

The interviewees were living with serious physical and mental health conditions. Six interviewees had mobility issues, while four interviewees were unable to get around unaided.⁸⁵ Others had more serious life threatening conditions. Derek 'for example' has a very serious degenerative condition that affects both his mobility and his speech, while Liam had a number of strokes, a tumour and a brain haemorrhage.

Many interviewees have emphysema and other serious chest complaints as well as a variety of heart complaints, several interviewees have had heart attacks and a significant number had cirrhosis of the liver and diabetes. Dental issues were a concern for a number of interviewees, which in turn limited what they were able to eat. Type II diabetes was also an issue for a number of interviewees who struggled to manage their condition, particularly when they continued to use alcohol.

85 These interviewees used walking frames and rollators to get about

At least four interviewees had been diagnosed with schizophrenia and had regular injections to help manage their condition. Interviewees also reported having had nervous breakdowns and having to deal with depression on an on-going basis. Quite a few interviewees had been hospitalised as a result of these conditions and a number spoke about some unsuccessful suicide attempts.

Most interviewees were on a variety of medication for a range of physical and mental health conditions. In some cases the medication was dispensed by staff, while in other cases staff simply held the medication and provided it as requested. One or two individuals spoke about how, if they had access to their medication, they would again attempt suicide through an overdose.

SEAN



Sean is just sixty. Sean finished school at 14 when he started attending hospital on a very regular basis for epilepsy. Sean has had various jobs throughout his life loading and delivering turf. Sean has always been a loner and is happy in his own company. Sean lived most of his life in the house he grew up in in the country. When this house eventually became uninhabitable, Sean moved to his current accommodation: a small Council house in a nearby village. Sean is on a cocktail of medication for his epilepsy and for various chest related complaints. He continues to be a heavy smoker. Sean prefers to talk about the past than the present. He speaks a lot about how the village and its hinterland have changed and about how he no longer knows people in the local pub.

Transport is a problem for Sean and he often walks long distances to visit the nearby larger towns for a change of scenery. Sean says he would love to be working as he finds the day long with nothing to do. He occupies his time listening to the radio; he is not a good reader. He says his is a lonely life at times but that he has to bear it. Sean never thought about getting older and says he does not often worry about dying. Although he says someone did tell him he should make a will. What does worry Sean deeply is the thought that he might die and not be found for some weeks.

3.2.3 Problematic Drug and Alcohol use and dual diagnosis

Almost all of the interviewees engaged in problematic alcohol use. Three interviewees had not had a drink for a number of years, while the majority continued to have issues with alcohol. One interviewee described alcohol as the '*mild anaesthetic*' that helps him cope with life. Only one of the interviewees had been involved in sustained drug use and deterioration in her health and mobility had seen her abandon her drug habit. The vast majority of interviewees had smoked (three had quit in the last couple of years) and the majority continued to smoke between 20 and 40 a day and some considerably more, particularly at the weekends.

CIARA



Ciara got married to a local man when she was 22. They had three children together, two daughters and a son (they are all now in their twenties). Her only contact with her children currently is writing. Ciara started drinking when she was about 14 or 15 and her drinking has got worse as she got older. Her marriage broke up in her thirties because of her drinking and her ex-husband subsequently reared their children and re-married. When Ciara left the family home she moved out of the city to a small village for a while where she spent a lot of time in the local day centre and the pub. Ciara has lived in a variety of different flats and houses but was unable to sustain the tenancies when she was drinking. Ciara was eventually offered a place in a house where she was for about a year. She liked it because it was in the middle of town with plenty going on around her. She got an offer to move her current accommodation a few months ago and is still settling in. She says the staff and the place are very nice but it is in a part of the city that she does not know. She does not think she would want to go back to her previous accommodation as it was a lot noisier with a lot more younger people, she likes the quiet of the new place but would like to get out more. Ciara is very unsteady on her feet and needs the support of a walking frame to get about. Her limited mobility means that she has to use the bus to go into town and now needs someone to accompany her when she is out and about. Staff shortages to date have meant that no one has yet been able to go with her. She is hoping this will change soon. Ciara continues to drink and is sometimes confused. She says she has lost whole stretches of time because of her alcohol consumption. Because she is unable to get out unaided Ciara finds time heavy on her hands and says she is often bored. Ciara says she did not expect her life to turn out like this. She has a great fear of death and where she will go when she dies. Her wish (like many others) would be to go to sleep and just not wake up.

3.2.4 Complex Needs

The vast majority of the interviewees can be described as having 'complex needs' in that they have multiple and interconnecting needs that span physical and mental health and social issues. Some have mental health needs combined with problem alcohol use. Several interviewees also made reference to traumatic incidents in their past (which included domestic violence as well as incidents of physical and sexual abuse) but did not talk about them in any detail.

Many interviewees (even those living in hostels and particularly those living in rural areas) were quite isolated, with limited opportunities for meaningful activities. Travel and access to transport was a particular issue for a number of interviewees. For some it was access to/the absence of public transport that was the issue, for others with limited mobility it was that they were not able to get out and about without the support of another person.

DARA



Dara ran away from home when she was 14. By the age of 18 she had two children, she is now 51. Dara married the father of her third child but it was a difficult relationship as he was violent. She eventually left him and moved to England where she had two more children. Dara's children are now adults and live in and around Dublin. She does not currently have contact with them. On her return to Ireland Dara began a relationship with a man twenty years her senior. That relationship lasted for 21 years until his death from cancer. In the beginning they were both sleeping rough but a number of years before he died they had managed to get a flat and a dog together and life was better. Dara has slept rough for long periods much of which seems to have disappeared in a haze of alcohol, with large gaps in her memory. As her health disimproved she started to use various hostels. Dara had her first nervous breakdown after the birth of her second child. She has a number of others since. Dara also has serious arthritis (she believes this is as a result of sleeping rough). Dara was a heavy drinker and often combined her drinking with aspirin. Dara has not had a drink for three years. Dara suffers from low moods, and pains in her legs and chest. She has as yet not checked out what is the cause of these pains as going to hospital for her just takes too long with too much sitting around. Dara is often bored given that she spends a lot of time in her room as her mobility is restricted and she has collapsed on previous occasions, making her nervous about going out and about. Dara worries both that she will be moved to a nursing home and that she could be put out of the hostel. Dara lives from day to day and tries not to think that much about what lies ahead. She thinks about death at times and is afraid of dying. She would like to make her peace with her children before she dies.

3.2.5 Barriers to Accessing Health Care

All of the interviewees had a GP that the vast majority got on well with. Physically getting to the GP outside of regular appointments appeared to be an issue for some interviewees (given that getting to their GP often involved significant organisation as the location of the clinic is often some distance away. It was also the case that some interviewees were so unsteady on their feet that they needed a companion with them and that was not always easily organised). Some interviewees, particularly those with chronic conditions also had regular contact with a public health nurse. In some instances the nurse called to them to do regular checks ups on on-going chronic conditions and/or to administer injections. Worryingly, some interviewees spoke about having symptoms that they had as yet not presented to have assessed. The reasons given for not presenting for hospital appointments and/or A&E included long waiting time, a fear of being admitted to hospital and not being able to get alcohol and/or a fear of being admitted to hospital, getting bad news and being unable to return to their current accommodation and 'worst of all' having to move to a nursing home.

Helping people who are homeless access health services must be a priority. The London Pathway project 'based at University College Hospital in London' is an example of a project established to support people who are homeless access enhanced levels of healthcare within the hospital system. The project, which is staffed by dedicated homelessness nurses and a GP, involves the identification of people who are homeless and accessing hospital services at an early stage. It involves regular GP lead ward rounds (three per week), weekly multiagency meetings and work with Care Navigators to develop care plans for and with people who are homeless to help them more easily navigate their way through the health care service. Anecdotally, the project has generated a lot of goodwill and good outcomes for people who are homeless, it has also improved the attitudes of staff working across the hospital. At a more practical level, the project has managed to reduce both the number of admissions and the length of admissions by a

thousand bed days. This represents a saving in real terms of approximately STG £300,000 (approx. €360,868)⁸⁶ a year. This service is targeted at all aged groups of people who are homeless and is not specifically targeted at those requiring end of life care. Dublin based GP Austin O'Carroll⁸⁷ has 'for some time' been making the case for the establishment of a dedicated intermediary health care service for people who are homeless in the capital. This service would target individuals who are too sick for hostels but not sick enough for hospitals. This service 'were it to be developed' could make a useful contribution to meeting the needs of people who are homeless and approaching end of life but who do not yet require intensive medical care.

LEO



Leo left school at 14 to work on the home farm and has lived in the family home since that time. Leo has always liked a drink and generally underplays his consumption levels to people who do not know him. Leo worked the family farm till a few years ago when it was sold. Since the farm was sold Leo has a lot less to do. Over time Leo's home (which is on a country lane about a mile and a half from the main road), fell into very poor condition and was very damp, making Leo's various health complaints worse. Leo was given the option to move into accommodation in the nearby town. He moved but within three or four months moved back to his original home. He said he preferred his original home where he could have a fire, neighbours who know him and were kind to him and he had more to do. Following Leo's return to his family home, work has been done to make his home more comfortable, Leo spends a lot of time reading (he gets his books from the local library) watching videos and doing sticks for the fire. He is also currently fit enough to walk the 1.5 miles out to the road to get a lift or the bus into town. Despite all these activities Leo is not as busy and he would like. He says he would like to be doing more and speaks often and fondly of the satisfaction and the contacts he had made working on a local Community Employment (CE) scheme. Leo has lived alone for the majority of his life but for the last 14 years has shared his home with his dog. He worries that he would not be able to live alone without her. Leo has found getting old hard especially at Christmas when he can feel really down. Leo has a variety of alcohol related health issues as well as issues with his heart. He says he is generally a self-contained and contented person who tried to take every day as it comes. He tries not to think about dying and death and hopes he might slip away quietly in the night, he says he is lucky that he believes there is something on the other side and prays to his parents to ease his journey to the other side. Leo wants to die at home and hopes that this will be possible when his time comes.

3.3 Attitudes to Dying and Death

3.3.1 Experiences/attitudes towards dying and death

Many interviewees attitudes to death were clearly coloured by the deaths (or in one case the thought of the death of a family member)⁸⁸ of friends and families. Among the interviewees who had slept rough many spoke of having friends whom they lived with on the streets die 'often suddenly' and how hard that had been to deal with. These individuals were very pleased not to have to face the prospect of dying on the streets. Some interviewees had the experience of an unexpected death in a hostel they were staying

86 Personal communication with Dr. Nigel Hewitt clinical lead for the homeless team at UCLH and Medical Director of the London Pathway on 15th February 2012

87 O'Carroll, A. O'Reilly, F. Corbett, M & Quinn, L (2006) Homelessness, Health and the case for an Intermediate Care Centre Report by Mountjoy Street Family Practice

88 Con was very upset at the thought of his mother dying. *'I don't really think about dying for myself but I think about it for my mum. She is 84 and I adore her, we meet every week and do her shopping and have a pint. I'm not sure what I would do without her'.*

in. In some cases the interviewees said the death had been treated as a major disaster, almost an assumption of failure and that this had been the cause of high levels of stress and anxiety for hostel staff and residents. In reality 'according to the interviewees' everything that could have been done was and the person had just died. *'It was no one's fault; sometimes death just happens'* was how one interviewee described it.

Many of the interviewees, particularly those that were drinking heavily, said that they just lived on a day to day basis and tried not to think too much about anything at all.

All of the interviewees had, because of their health and 'lifestyle' thought about their death. Most either did not want to die or were afraid of dying. A small number said they were happy to die and 'were the opportunity to present itself' they would consider suicide.

The thought of their dying and death kept some individuals awake 'or indeed woke them' in the night. Where that happened, many coped by turning on the radio and trying not to think about it. Some of the interviewees spoke about how 'when they were sleeping rough' they wondered whether they would ever wake up. Others spoke about failed suicide attempts and how they had accepted death as part of that process but then struggled with living thereafter. For some interviewees they worried less about their death and more about leaving their families at a time when they believed some of their children and grandchildren needed their help. Kevin for example was particularly concerned that his grandchildren might take drugs and wanted to be around to warn them of the dangers of drug taking. Other interviewees spoke about how they had 'over time' got used to the idea of going to sleep and not waking up and that it no longer really bothered them, for some because they had made their peace and their plans and for others, because they did not think they would be missed.

The majority of interviewees had a belief in the existence of a higher power. For some this was God, for others Jesus Christ and for others simply a spiritual or higher being and for them this made the idea of dying easier. Some interviewees spoke about how they had lost their faith and that made the thought of dying 'difficult' although most still hoped that there might be an afterlife. Some interviews spoke at length about heaven, hell and purgatory and mused about where they might go when they died.

'I don't believe death is the end. I don't believe I will be born again. I think it is more of a recycling process'

Peter

'I would like to think I will go to heaven but I think I will have to spend time in purgatory before that'

Dominic

'I don't really believe in an afterlife but would not be surprised if there is a spiritual being. I find myself a frequent attendee at religious services so I guess I am hoping there is something out there.'

Graham

A few interviewees were regular mass goers, while for one man his move to a location where he was able to get communion on a regular basis was a welcome development.

Only one interviewee, Derek, had actively made preparations for his death. His argument was that, having worked as an undertaker for a number of years, he wanted to be in control of what happened to him. He also wanted to ensure that whatever money he had went to his grandchildren. Derek's active preparations may also have been spurred on by the knowledge that he has a degenerative condition that ultimately

means that he will lose his power of speech. Things a number of interviewees said they would like before they died included *'making peace with their children'*, *'making contact with their family'*, *'meeting/getting to know their grandchildren'* and *'cooking a meal for themselves and others'*.

The majority of interviewees had not spoken about death or dying to anyone. A few said that they had tried to bring the subject up with others and with the staff around them to get their views but that other peoples response generally was to change the subject and to tell them *'not to be so maudlin'*. One of the things the vast majority of interviewees were concerned about was where they might die. Most expressed a very strong desire to die where they were living and failing that, in hospital. Some interviewees had hoped *'when they were younger'* that their siblings might have been able to care for them if they were dying; all had now realised that just as they had aged so had their siblings and they were no longer in a position to take on that role.

Transfer to a nursing home was *'for many interviewees'* the thing they feared most. Some spoke about how they had been in institutions when they were young and how they could not bear to be sent to one at the end of their lives. Others had worked in nursing homes and institutions and had observed older people not being treated very well when they had no one to speak up for them.

GARRET



Garret grew up in the west of Ireland speaking Irish so when his family moved to the north of England he had to do a crash course in English. Garret left school at 15 and got a job as a machinist. With money in his pocket for the first time this was when he began drinking. When he was 17 Garrett moved to London and lived with his sister. He always had work. Often the work was tough, laying tarmac or pipes and his relaxation was watching sports, drinking and a few bets. Garrett was sometimes lucky with his gambling and would win enough money to be able to afford not to work for a while. It was during one of these breaks from work that he met the woman he described as the love of his life. Meeting her led to him settling down but it did not last very long as she died of cancer only a few years later. He was devastated, eventually returning to Ireland to try and move on. Garret eventually found his way to his current location where he slept rough for a while. With the help of a local man he got into a Simon house in the city which he liked. When Garret's health was better he used to go to the football, the dogs and even the cinema with friends, many of whom are now dead. He also used to walk a lot to go to mass, the coffee shop and the betting shop. Heavy drinking from a young age has taken its toll on Garret's heart. He is now on a lot of medication and has had at least one heart attack and three strokes; he also has cirrhosis of the liver and is unsteady on his feet. He worries that he will have to move out of where he lives because the stairs are getting difficult and he has already fallen. Garret thinks about dying particularly when he is not well... but he says it does not worry him too much as he knows there is an afterlife.

Interviewees generally wanted to die in their sleep, they did not want to die alone. For those who were estranged from their family, they wondered who would be there when they were dying; most interviewees in this situation hoped they would *'go to sleep and not wake up'*. A particular concern for the interviewees who lived alone was that they would die alone and their body not be found for weeks.

Things that gave the interviewees comfort when they thought about their death included the thought that they might meet their deceased family and partners, prayer (some interviewees had strong devotions to particular saints) and the presence of religious icons (e.g. pictures of the sacred heart). Some people *'when they spoke of dying and death'* brought up the subject of their next of kin. For most interviewees their next of kin was generally a sibling, for a small number their next of kin was a son or daughter.

CILLIAN



Cillian went to England when he was 14 to escape his violent alcoholic father. He enjoyed his life there, returning home about 7 years later only to be diagnosed with TB. When he was released from the hospital Cillian returned to his family home where he stayed there for a while before moving to a bed sit. Cillian was not always clear about his life and did not want to discuss many aspects of his life. Cillian had four children two boys and two girls. Two of his sons are dead and he does not have contact with his daughters. Cillian has stayed in a variety of different types of accommodation. He has frequently had to move because of alcohol related issues. He has also had long spells of sleeping rough. His longest spell was for four years. He moved from Dublin 17 years ago to another city as the drug problem in the capital grew and he felt less safe. He was attacked by another resident in one facility and that made life more difficult. When he was fifty he was able to move into accommodation targeted at the over 50's and believes that has made a real difference to his quality of life in terms of reducing his stress levels. He is happy to have a safe bed at night.

Cillian has a variety of health problems including lung disease and liver damage. He also suffers from depression and is on high doses of medication. He attributes his depression to a difficult early family life. He is in regular contact with a brother. Cillian is not very mobile and cannot manage steps. He can read but as it is an effort he tends to spend more time watching television and listening to the radio. Cillian likes the fact that he is able to get communion in his current accommodation. Cillian has a poor sleep pattern and says that made the day long. He says he would be happy to die and has attempted suicide on a few occasions. He says that if he could get his hands on enough tablets he would take them. He described himself as a sad man, who has lived a hard life and that he would like to end it if he could.

3.4 Other Issues

3.4.1 Boredom⁸⁹

Boredom occurs in many institutional settings. Its many and varied causes include a lack of companionship, feelings of helplessness, no opportunity to care for others, ill health, a lack of variety of activities, etc.). Research has indeed found that boredom for some individuals living in institutional settings may be as significant a challenge as physical and functional problems⁹⁰. An earlier Joseph Rowntree study (1996) found high levels of isolation and boredom among the single homeless people living in hostels. It also found that boredom was an issue for some single people who were previously homeless living in permanent accommodation. It was not surprising therefore to find that boredom was an issue for all the interviewees living in hostel type accommodation. This was less of an issue for the interviewees who were able bodied and could get out and about. For those that had limited mobility this was the thing they struggled most with. Most watched television/video and DVD's and listened to the radio but 'as they commented' *'there is only so much of that you can do'*. Some interviewees read extensively, others did not read at all either because their reading skills were poor or because they had misplaced their glasses some time before and had not got round to replacing them. Members of the Simon Involvement and Action Group were of the opinion that the issue of boredom was a more general one affecting many people who were homeless regardless of their age, but it was clearly exacerbated for individuals whose mobility was restricted.

89 The problems of aging and boredom are well known, especially for the frail elderly. It affects people regardless of where they live, in nursing homes or their own homes. It's a struggle and a worry for many caregivers and as boredom can often translate into depression.

90 Slama CA, Bergman-Evans B. (2000) A troubling triangle. An exploration of loneliness, helplessness, and boredom of residents of a veterans home. *Journal Psychosocial Nursing Mental Health Service*;38(12):36-43.

Where interviewees were able bodied and living in the hostels they often undertook simple jobs, they were also more able to become involved in activities organised within and from the hostel. Many of them enjoyed walking and 'where they had a travel pass' they used it. Some of the hostels organised a number of activities including art classes, walks and occasional trips. Several interviewees were very interested in music; a number played the guitar and used their music as an escape from day to day realities. Pool was a popular pastime for some interviewees.

Interviewees who lived more independently were generally able bodied and active although even they were '*not as busy as I would like*'. Day to day living and pets (two of the four interviewees who lived alone had dogs and another dog sat for a neighbour) required them to get out and about. Two of the hostels also provided its residents with access to pets (a cat in one location and dogs in the other) and the interviewees living in these locations enjoyed the company of the cat and being able to walk the dogs respectively. Two of these interviewees attended day centres at least a couple of days a week, where they were able to get a hot meal in company. One of the interviewees who had been in prison preferred to eat with other people and rarely ate alone.

Few of the interviewees were interested in bingo and said in many of the centres they attended that was the only activity on offer. More interviewees and particularly those from more rural background were interested in cards but found the opportunities to play cards were very limited. Many of the interviewees living in more communal accommodation spoke about how they would like to have the opportunity to cook a meal for themselves occasionally. They missed being in control of what they ate and frequently remembered enjoying cooking at an earlier stage in their life.

Security was an issue for interviewees living in hostels that catered for all ages. Interviewees were fearful about leaving money, cigarettes or indeed anything valuable in their rooms for fear of it being stolen. This did not appear to be an issue for interviewees living in longer accommodation that catered more specifically for older age groups. Where the interviewees had family that they were in contact with, they enjoyed spending time with them and feeling part of a family. Money management was an issue for a number of the interviewees and some had developed complex systems (using regular weekly deposits and daily withdrawals from the post office) to help them manage their money.

The absence of public transport options was an issue for several of the interviewees living in more rural locations. They generally walked (often significant distances; Leo 'for example' regularly walks the 1.5 miles to get to the main road, where he hitches a lift into town) to access public transport or got a lift from neighbours. Quite a number of the interviewees had been involved in Community Employment Schemes. All who had been involved in these schemes enjoyed them and were very sorry when their time on the scheme came to an end. Few if any of the interviewees ventured out after dark as they were nervous that they might be attacked.

The issue of meaningful activity was identified as a cross cutting issue in the three year UK Homeless Link Project on Addressing the Needs of the Older population and a report⁹¹ identifying the learning from four projects funded by Help the Aged was produced. This report provides some useful ideas on the types of activities that can be used with older people who are homeless. Other cross cutting issues identified as part of that project included personalisation, institutionalisation, service user involvement, engagement and empowerment and community integration. The majority of these issues were not explicitly explored as part of this study, although it was a number of the interviewees living in the more hostel type accommodation that made indirect reference to their institutionalisation as a result of having lived in their current accommodation over an extended period.

91 Homeless Link (2009) Meaningful Activity and Older Homeless People – A Report on the Learning from Four Projects Funded by Help the Aged. The report can be accessed on line at <http://homeless.org.uk/sites/default/files/FINAL%20Meaningful%20Activity%20report%20.pdf>

GRAHAM



Graham is 55 and a native Irish speaker. He grew up on a farm and left school early to help on the farm. He also did a bit of mackerel and herring fishing and plastering as he was always good with his hands. A combination of mental health issues and drinking led Graham to leave home and eventually to sleep rough. He was referred to various hostels before eventually coming to live in his current accommodation where he has been for a number of years. Graham likes where he lives, he says it suits him. He also likes that his keyworker is also a native Irish speaker...he says it makes life easier. Graham used to drink heavily but gave up alcohol 15 years ago. More recently Graham got involved in a health programme and is feeling a lot better. He has lost weight, is eating better and getting more exercise. This helps him to reduce his stress levels and worry less about things. Graham watches a good bit of TV and listens to radio in Irish. He says watching TV and listening to the radio helps him keep his mind occupied and reduce his worry levels. He also sometimes gets the bus out to where he used to live and meets up with friends in the local pub. Thinking about dying and death sometimes keep Graham awake at night but when that happens he turns on the radio and tries to stop thinking about it.

3.4.2 Tenancies

Current worries for a significant number of interviewees could be traced back to issues related to their tenancies. A number of those living in local authority accommodation worried what would happen to them if they were not able to sustain their tenancy. For those individuals, many of them made it their business to pay their rent as a priority. Other issues these interviewees struggled with in relation to their tenancies often related to keeping their place tidy and refuse disposal.

Many of those interviewed living in communal accommodation aspired to have their own place, the majority recognised that this was probably not an option for them (without significant additional home help input (this in turn was not seen as likely in the current economic climate)) given their current health status. The tenancy related issues for interviewees living in hostels/ houses can be divided into two; fears about exclusion from their current accommodation and fears about being moved (to a nursing home in particular). The three or four interviewees fears around exclusion tended to relate to what would happen to them if they, as they described '*went on a bender*'. A much larger number of interviewees were concerned that they could be moved to a nursing home, when they were content where they were. An interesting example of a successful relocation of three older men from a Simon House to a retirement home/nursing home was identified in Galway and this could perhaps provide a model that could be used in other locations when the needs of an individual increase to such a level that they require high levels of on-going personal care.

PETER



Peter left school early to support his mother and younger siblings. His father was an alcoholic and not a good provider for the family. Peter was married when he was 25 for a couple of years and has a daughter and now grandchildren. He has no contact with his daughter or grandchildren. After his marriage broke up Peter moved to England to work on the building sites. He was only there a few months when he started hearing voices. He returned to Ireland where he was admitted to hospital and diagnosed with schizophrenia. Thereafter he attended hospitals on a weekly basis for treatment and medication. As Peter's condition stabilised with medication so did his housing situation. He began to attend various courses which he loved, although they did not lead to full time work. When his father became unwell he moved back home to help his mother. Some little time after the death of his father, his mother found a new partner, and Peter moved out of the house and back to the hostels. Moving back to the hotels saw Peter's drinking increase significantly. Peter believes he would not have survived this life for too long but for the fact that he met an old girlfriend and her son. They were moving out of the city for work and a better life and he decided to join them.

Peter and Jane lived together for years working in various jobs. They split two years ago but have remained friends. They live near one another and Peter visits weekly generally for Sunday diner. Peter now lives alone in a small Council house which he loves at the edge of a market town. He recently acquired a dog and says that has been good for getting him out and about more. Peter doesn't have many visitors, but says his dog is both company and a good watch dog. Money management has always been an issue for Peter so his system is to collect his money and pay off things as quickly as possible. Peter says apart from money he does not worry about much. He does not believe that death is the end, nor does he believe that he will be born again; he thinks it is more about recycling and he is happy about that. He says because he believes there is an afterlife he does not worry so much about dying and death.

3.4.3 Staff

The interviewees were generally very complementary about Simon staff and volunteers and indeed the staff in other groups and organisations they had contact with, particularly their GP's and public health nurses. Simon Project workers were identified as an important source of information and support in terms of helping and supporting individuals to manage their health and access the health system when required.

The interviewees regretted that there was little time to chat particularly about times past but recognised that the staff and volunteers were busy. A few of the interviewees also commented that the volunteers 'who tended to be young' were not very comfortable if and when the interviewee brought up the conversation of mortality and thoughts of their death. Interestingly a number of the Simon services around the country were in the process of developing a visiting programme (with volunteers) for individuals accessing supports from Simon. At the time of the research a number of the interviewees had had visits from volunteers and were looking forward to the next visit. The members of the Simon Involvement and Action Group suggested that people who had previously accessed Simon services could provide a useful source of volunteers in the context, particularly give their experiences.

LIAM

Liam became politically active in his teenage years and this led him to involvement in the republican movement. Liam was ultimately convicted of a number of crimes and spent some years in gaol. His release from gaol saw him moving to a new area and finding different work. Shortly after that he met and married his wife. They had a son and daughter together who are now in their twenties. The marriage eventually broke up, although Liam and his wife have remained in contact.

The breakdown of his marriage saw Liam served with a court order to leave the family home; this in turn coincided with a stroke. So he found himself unwell and out of home. He ended up staying in hospitals with friends and in various hostels. When he was finally released from hospital to recuperate he stayed with his estranged wife until he was able to function independently. When he was well enough he began the process of trying to find a home for himself. It took him about 2-3 months to find his first home; he has moved on a number of occasions since then and now lives in a Simon apartment.

When Liam was younger he used to be very fit so drink or drugs were never for him. He is less fit now and was recently diagnosed with a tumour and has gone on to have two brain haemorrhages. He now also has epilepsy as a result of the early stroke and occasionally gets seizures. Liam is an avid reader. He also spends time with his daughter trying to support her. She has attempted suicide and has self-harm tendencies. Liam says he has had to think about dying because of all the things that have happened to him over the last number of years. He knows death is going to happen but is trying to maintain himself in order to long finger it for as long as he can. Liam does not really believe in an afterlife but says he would not be surprised if there is a spiritual being.

3.4.4 Provision for older people in homeless services

Over half of interviewees who were living independently were accessing day centre supports targeting older people, and were enjoying this interaction with their peers. Many of the houses/hostels interviewees lived in accommodation which appeared to have higher than average levels of older people and the interviewees were generally very happy about this. A small number of interviewees were living in hostel accommodation that was open to all. These interviewees frequently spoke about how they feared for their belongings and how noisy it could be at times.

KEVIN



Kevin was born in Edinburgh but returned to Ireland when he was 10. He left school at 14 and worked for a few years before joining the army. He got married when he was 21 and went on to have several children and now grandchildren. He travelled extensively in the army. He left the army before he was eligible for a pension because of the death of his wife. After his wife's death Kevin sold the family home and began to drink very heavily. He went on to live with another woman for about four years until the money from the sale of the house ran out. With no place to live and no money he started sleeping rough. He slept rough for about nine years. This upset his sister and daughter, but they stuck by him, washed his clothes and tried to help him. Kevin eventually got fed up of sleeping rough and presented to a local hostel, where he was told he would have to be sober. He later returned sober to the hostel and got to stay and so began his journey away from sleeping rough. Kevin eventually got a Council house where he now lives. Kevin's health has suffered because of his drinking and rough sleeping. He has had four strokes and at least three heart attacks to date. He also has problems with his stomach, and his blood pressure. Things can also get in on top of Kevin and he has had what he describes 'fits of depression'. The last of which led him to take an overdose. He is as a consequence no longer trusted with his medication and his nephew now helps him with this. Kevin attends Simon services for the company, a change of scenery and a hot meal. He says it gets him out. Kevin prays daily and especially at night, he says prayers help him a lot. He thinks about dying often but tries not to worry about it. He said if he was dying he would like to go to the place he goes to for respite but that he would ideally like a couple more years to see his niece and granddaughter get married.

3.5 In summary

The interviewees were all users of Simon services. They came from a variety of locations and lived in a variety of accommodation types. Interviewees who lived in communal accommodation which catered for all age groups found their accommodation noisy and more challenging than those who lived in communal accommodation which catered for higher than average levels of older people.

- Ten interviewees had been married, while a number had been involved in long term relationships.
- Ten had children and some also had grandchildren. Only five had contact with their children.
- Nine interviewees' first experience of homelessness occurred in their early fifties. For some it was the death of a partner or the breakdown of long term relationship (closely followed by a court order requiring them to vacate the family home) that had provided the trigger for their first period of homelessness, often linked to alcohol abuse and ill health. In contrast about a third of the interviewees had periods of homelessness throughout their adult life. Seven interviewees had spent long periods of time sleeping rough.
- More than ten interviewees were living with serious physical and mental health conditions. Others had more serious life threatening conditions while four interviewees were unable to get around unaided. At least four interviewees had been diagnosed with schizophrenia and had regular injections to help manage the condition. Interviewees also reported having had nervous breakdowns and having to deal with depression on an on-going basis. Quite a few interviewees had been hospitalised as a result of these conditions with a number of unsuccessful suicide attempts. Most interviewees were on a variety of medication for a range of physical and mental health conditions.
- Fourteen interviewees had engaged in problematic alcohol use.
- Fourteen interviewees (even those living in hostels and particularly those living in rural areas) reported feeling isolated with limited opportunities for meaningful activities.

- Travel and access to transport was a particular issue for eight interviewees' whether living in rural areas and/or with mobility issues.
 - Attending for hospital appointments and/or A&E was an issue for many interviewees who reported a reluctance to attend related to long waiting time, a fear of being admitted to hospital and not being able to get alcohol, getting bad news and being unable to return to their current accommodation and worst of all having to move to a nursing home.
 - All of the interviewees had thought about death and their death in particular. Most either did not want to die or were afraid of dying. A small number said they were happy to die and were the opportunity to present itself they would consider suicide.
 - Many interviewees, particularly those that were drinking heavily, said that they just lived on a day to day basis and tried not to think too much about anything at all. That said, the thought of dying and death kept some of these individuals awake at night.
 - The majority of interviewees had a belief in the existence of a higher power. For some this was God, for others Jesus Christ and for others simply a spiritual or higher being and for them this made the idea of dying easier.
 - The majority of interviewees had not spoken about death or dying to anyone. Only one interviewee had made preparations for his death.
 - The majority of interviewees were concerned about where they might die. Interviewees did not want to die alone; this was a particular issue for those individuals estranged from their family. Most expressed a very strong desire to die where they were living and failing that, in hospital. Transfer to a nursing home was what many interviewees feared most.
 - Boredom was a particular issue for interviewees living in hostel/communal accommodation.
 - Many interviewees worried about their tenancies and were fearful about having to move to a nursing home. Interviewees living in communal accommodation worried about what they would do if they were ever to be excluded from their accommodation.
 - The interviewees were complimentary about the staff and volunteers who they had contact with but regretted there was little time to chat with staff and volunteers because they were busy.
-

SECTION 4

Conclusions and Recommendations

4.1 An Overview

The purpose of this research was to identify and examine the needs of older people who are homeless or who have previously experienced homelessness as they age and are faced with the issues of serious ill health, dying and death. Among the key needs identified as a result of this research include the need for:

- Access to appropriate health care.
- Services which contribute to good health and well-being.
- End of life care.
- Suitable and stable accommodation and accommodation support.
- Information and research.

The provision of these services alone is not enough. The services need to be capable of addressing the complex (interconnecting physical and mental health and social) needs of older people who are homeless and dealing with poor health and issues related to dying and death.

The remainder of this section examines these under five thematic headings.

4.2 Appropriate health care

Research has shown that individuals who have a long term history of homelessness have higher levels of physical and mental illness, problematic drug and/or alcohol use and higher death rates than the general population. The average age of death for a person who is homeless is 47 for men and 43 for women.

This research found the majority of interviewees were living with serious physical and mental health conditions, including, chest and heart problems as well as advanced liver disease.

Across the country there are some specialist services available to people who are homeless particularly in urban centres (e.g. the Primary Care Safety Net Initiative which currently operates in Dublin, Galway and Cork) however there are none dealing specifically with older people who are homeless.

The interviewees involved in the research perhaps because they were connected to Simon services (and also known to wider services) all had a medical card and a GP (they generally liked) and some had regular contact with the health nurse in relation to on-going management of certain chronic conditions. Individuals living in hostels also had the benefit of hostel staff monitoring their health. Mobility issues (where people need to be accompanied to appointments) and access to transport (particularly for those living in rural areas) were obstacles for individuals in terms of their ability to access primary health services in particular.

Attending hospital appointments and/or A&E was however an issue for many interviewees who were fearful a) of being admitted to hospital, b) of not being able to get alcohol, c) of getting bad news, and/or d) being unable to return to their current accommodation and having to move to a nursing home. These fears were indeed clearly providing a significant barrier to individuals accessing the services they

needed. The HSE are committed to more accurate health needs assessment and have begun to pilot a scheme in Dublin, it is hoped that this scheme will identify both the barriers and the solutions to the barriers.

On a positive note the HSE is committed to ensuring that the healthcare needs of people who are homeless and elderly people who are homeless are clearly identified and met in a holistic manner using a care and case management approach and this is a very welcome development.

Health Care Recommendations

1. *Recognition of the particular health needs of people who are homeless and particularly the health needs of individuals aged 50 and over who are homeless*

There is a clear need for recognition and advocacy within the health services and within the application of the care and case management approach that people who are homeless (similar to the Traveller community) have particular health needs.⁹² Specifically there is a need for a recognition a) that individuals who are homeless have a reduced life expectancy and b) that individuals aged 50 and over who are/have a long history of homelessness have health needs more associated with the over 65 population and a mechanism needs to be found to support individuals who fall into the “older homeless” category access health and support services more generally designed for older people.

2. *Hospital Discharge Policies/Establishment of a Pathways Model*

Hospital discharge policies vary from location to location. It is important that the system is standardised to ensure that people who are homeless are not discharged into homelessness. In the short term the 2012 HSE Service Plan contains a commitment to review the effectiveness of current discharge protocols. This review of integrated discharge planning protocols will be undertaken by the National Review Group and will include consideration of all discharges including people who are homeless. This is a welcome development, important to ensuring that a) the needs of people who are homeless are taken into account and b) that organisations working with people who are homeless ‘such as Simon’ are consulted. The London Pathway project ‘based at University College Hospital in London’ has proved (with dedicated supports) it is possible to offer people who are homeless access to enhanced levels of healthcare within the hospital system and save money (approx. €300,000 a year).⁹³ In the longer term this is a model that could be adapted and applied in an Irish context, targeted at all aged groups of people who are homeless with a range of health needs.

3. *The Provision of Appropriate Accommodation with Healthcare Support’*

The case for the establishment of an intermediate care centre targeting individuals who are too sick for hostels and not sick enough for hospital, ideally with a number of beds dedicated to people who are terminally ill (proposed by Dublin based GP Austin O’Carroll in 2006) is one which requires further exploration in an Irish context particularly given that this model has demonstrated excellent results in other locations (e.g. St. Mungos in London).

92 Traveller health needs are for example addressed at national level by the National Traveller health Advisory Group, no similar national structure exists for homelessness.

93 Personal communication with Dr. Nigel Hewitt clinical lead for the homeless team at UCLH and Medical Director of the London Pathway on 15th February 2012

The implementation of these recommendations would meet some of the national policy objectives identified in the:

- National Drugs Strategy 2009-2016 -in relation to meeting the particular health needs of people who present with dual diagnosis (i.e. mental health and problematic drug and /or alcohol use).
- “Vision for Change” National Mental Health Strategy – which proposes the establishment of two multidisciplinary, community-based mental health teams for the Dublin area.
- The National Health Strategy – which identifies a number of initiatives to improve the health of people who are homeless.
- The Way Home: The National Homeless Strategy 2008-2013 Strategic Aim 5 – ensure effective services for people who are homeless identified health services as a vital component of services for people who are homeless.

4.3 Services which contribute to good health and well-being

The research found that many interviewees had lived outside of Ireland and had moved around quite a bit, which meant that they had often lost contact with other family and with friends from their younger days. Only a third of the interviewees had contact with their immediate families with many interviewees (including those living in communal accommodation and particularly those living in rural areas) feeling isolated.

Some interviewees availed of activities organised where/close to where they lived but this was more difficult for interviewees with mobility issues, for those that did not/or were not currently in a position to read. Access to transport was an issue for interviewees living in rural areas and/or with mobility issues who wanted to get involved in activities.

Boredom was an issue for many interviewees and was a particular issue for interviewees living in hostel type accommodation. Many interviewees noted that because of their health they had limited opportunities for meaningful activities. Interviewees were generally very complimentary about the staff and volunteers who they had contact with but regretted there was little time for general conversation because staff and volunteers were busy.

Religious belief/belief in the existence of a higher power were a source of comfort for many interviewees. The spiritual and religious needs of interviewees were addressed by staff in a small number of locations (for example, staff arranged for communion to be provided on an occasional basis in hostels).

Recommendations which contribute to good health and well-being

4. *Provide access to a range of activities to tackle the issue of boredom*

Older people who are homeless need to be provided with a range of activities to reduce their boredom levels and promote their general wellbeing, with particular thought to be given to the provision of activities for those whose mobility and/or vision may be impaired and for those who are less well able to read. Examples of the kinds of activities would include reminisces work, music therapy, gardening, etc. Occupational Therapy support can be useful in this context as indeed can the implementation of holistic needs assessment.

5. *Expand individuals social networks (using volunteers/former service users) and community mobilisation*

Some interviewees have benefited from visits from volunteers enlarging their social network. These volunteering initiatives need to be expanded to enable all those who would wish to avail of visits to volunteers to participate in the initiative. Former homeless service users could be particularly targeted to become involved in peer support networks.

6. *Raise awareness of the spiritual needs of older people who are homeless among staff*

Staff working with people who are homeless need to be made more aware of the spiritual needs of people who are homeless and of the supports that could be put in place to meet these needs. (The IHF workshops on spiritual care at the end of life could provide a useful source of material for this area).

The implementation of these recommendations would meet some of the national and policy objectives identified in the:

- Various regional Homeless Action Plans many of which recognised the need for social facilities for people who are homeless.
- “Vision for Change” Report of the Expert Group on Mental Health Policy – which highlights the importance of belonging and participating for people with mental health issues.
- The National Health Strategy – which identifies a number of initiatives to improve the well-being of people who are homeless.
- The Way Home: The National Homeless Strategy 2008-2013 Strategic Aim 5 – ensure effective services for homeless people links the provision of health services to the roll-out of primary and social care networks.

4.4 End of life care

The majority of older people (over 65 years) in Ireland die in acute and/or long-stay care settings. There is no definitive information on where older people who are homeless (over 50 years) die, neither do we know how many, if any, people who are homeless present for hospice care. Interviewee’s views and experiences (coupled with experience from the UK and international research) suggest that the majority probably die in acute hospital settings, given their levels of ill health and non-engagement with services, the prevalence of problematic behaviour and their aversion to nursing homes. Among the most common causes of death among people who are homeless are multiple organ and liver failure, which bring with them a number of complications including memory loss with problematic drinking, frequently a contributing factor to early mortality. Delivering high quality end of life care for people who are homeless clearly presents particular challenges for housing and healthcare.

International studies exploring the experiences and attitudes of people who are homeless toward death found a lot of fear and concern about death, dying and end of life care. Most interviewees in this research had, often because of poor health or difficult experiences (particularly when sleeping rough), thought about death and their death in particular. Some interviewees had had various suicide attempts. Most were fearful about death, the thought of dying kept some awake at night while others tried to keep the thoughts at bay with alcohol and/or prayer. Most either did not want to die or were afraid of dying. A small number said they were happy to die and ‘were the opportunity to present itself’ they would consider suicide.

Very few had thought about what they might want at the end of their lives and only one individual had made any preparations for his death. For those individuals that had thought about what they might want, they generally wanted to have family close or to make peace with their family and their children before they died. Many more had thought about what they did not want, the vast majority did not want to die alone, and if they did, they wanted to die in their sleep and be found quickly. This was a particular issue for those individuals estranged from their family. Transfer to a nursing home was what many feared most. The majority had not spoken about death or dying to anyone. Where individuals had tried to raise the issue of their death with people working with them, most people were found to be reluctant to engage in this type of conversation and quick to change the subject.

Recommendations in relation to end of life care

7. *Raise awareness at policy, statutory and NGO level of the importance of end of life care for people who are homeless and provide staff working with people who are homeless with end of life care training*

Use the findings of this research to raise awareness of the issue and the need for particular provision to be made within the health sector for end of life care for older people who are homeless. Under the current system these individuals (aged 50 and over) are not eligible to avail of services for older people and generally have a history of non-engagement with services.

Staff working in this sector needs to be more aware of role and purpose of end of life care and support (to include bereavement). They also need training and support in order to enable them to identify signals that the individuals need to be assessed in relation to the provision of end of life care. Two initiatives (developed by the Irish Hospice Foundation) offer very useful sources of training materials that could be adapted for use with staff working in the homeless sector. The 'think ahead' initiative promotes discussions on care planning (which would be beneficial for staff and ultimately for service users) while the 'final journeys' programmes is a model that could be adopted to raise awareness and improve staff members skills confidence in approaching 'and ultimately discussing' end of life care issues with service users. Another useful source of materials is the work done by Richard Lakeman in Dublin City University. Where staff are trained, sufficient time needs to be allocated within their schedules to engage with service users. As this research suggests staff currently working with people often have little time to spend in conversation.

8. *Enhance access to end of life care for people who are homeless through the appointment of a Palliative Care Coordinator*

Palliative and end of life care are very sensitive areas that need careful handling. The appointment of a Palliative Care Co-ordinator (shared between different services and organisations) would ensure the necessary skills are available to support and train staff to be able to deal with the issues.

9. *Ensure that Palliative Care beds are accessible to people who are homeless*

Palliative Care beds (Level 2) are available in a number of community hospitals around the country. Work needs to be done to determine to what extent these beds are currently accessible to people who are homeless and to identify what needs to be done to make these beds more accessible. Were an intermediate care centre/s to be developed (Recommendation 5), it would be important to ensure that some of the beds provided in the centre would be available for end of life care.

The implementation of these recommendations would meet some of the policy objectives identified in the:

- Various regional Homeless Action Plans which recognised the need for provision for people who are homeless.
- The National Health Strategy which identifies a number of initiatives to improve the well-being of people who are homeless.

4.5 Suitable and stable accommodation and accommodation support

The research found many interviewees (in a similar way to the general population) were deeply concerned that they might be moved to a nursing home if their health deteriorated. Their preference was to remain where they were for as long as possible and if they became very unwell to be moved to hospital. Their preferences are no different to those of the older people in general who are generally reluctant to consider this form of care because of loss of independence and general negative associations associated with this type of care. The differences between the general older population and the interviewees is age (the interviewees often have to consider the prospect of nursing home care at a much younger age than the general population because of poor health) and in some cases significantly more frequent occurrence of difficult experiences of living in institutions when younger and/or to having worked in nursing homes.

The ideal situation for many interviewees (since most consider where they live their home) would be for the primary care team (e.g. GP, Public Health Nurse, Occupational Therapist, Physiotherapist) and Social Care Team and when the time comes the Palliative Care Home Team to be involved in supporting the person to live independently in "their home" and in some cases this is what happens.

In other cases the reality is that the facilities and personal care services available within a particular accommodation facility (stairs, lack of disabled care facilities, lack of staff to provide personal care) can preclude the individual from continuing to live where they consider to be their 'home' on the basis of clinical need, as their health/mobility deteriorates, in turn precipitating what is often a difficult and rushed move that the individual believes they have no control over. This in turn highlights the importance of advance planning for individuals as their health needs increase.

Interviewees living in communal accommodation targeted at all age groups also have a lot of concerns in relation to noise levels, levels of anti-social behaviour, the security of their possessions and the general comfort of their location, while the interviewees living in communal accommodation targeted at older age groups reported appreciating the quietness and comfort of their surroundings suggesting there may be a case to be made for accommodating older people who are homeless in more age specific accommodation.

Recommendations in relation to suitable accommodation and accommodation support

10. *Ensure the provision of facilities for older people who are homeless*

Research has shown that older people's health and wellbeing generally tend to benefit from being in calm and comfortable surroundings. Where possible, older people who are homeless should have the option to be accommodated in dedicated longer terms facilities sheltered housing and housing (provided by approved housing bodies) designed to meet older people's needs for comfort and security. Where possible these facilities should be able to accommodate residents' pets.

11. *Ensure (where possible) accommodation facilities for people who are homeless are accessible for those with mobility issues*

Facilities for people who are homeless should be designed to ensure they are accessible for people with mobility issues. Where facilities are in place the necessary adaptations should be made to ensure the facility is capable of accommodating an individual with mobility issues.

The implementation of these recommendations would meet some of the policy objectives identified in the:

- National Housing Strategy for People with a Disability.

12. *Early intervention and negotiation by staff working with people who are homeless where there is prospect of increasing care needs necessitating an individual's move to residential care.*

Where it looks likely that an individual living in homeless accommodation facilities or precarious/ poor quality housing situations will require more personal care and clinical support, this needs to be identified and discussed with the individual as soon as possible. The individual should be encouraged by the staff working with them to articulate their fears and concerns about any potential move and be involved in the decision making in relation to the final choice of the facility. It must be recognised that this process can take a considerable amount of time but that this is necessary to ensure a smooth transition.^{94 95}

The implementation of these recommendations would meet some of the policy objectives identified in the:

- Various regional Homeless Action Plans.
- The National Health Strategy – which identifies a number of initiatives to improve the well-being of people who are homeless.
- National Housing Strategy for People with a Disability.

4.6 Information and research

This research challenges the stereotypical image of a person who is homeless. It introduces interviewees who have worked, been in relationships and had children and grandchildren, individuals no different to other people of their generation, except for the particular mix of life events and characteristics that led them to drift into a precarious housing situation/s. It shows the variety of accommodation types people who have been homeless find themselves in and highlights the fact that people who are homeless (again no different to the general population) regardless of their age or health continue to aspire to a home of their own.

Information and Research Recommendations

13. *Develop a better understanding of the causes of death*

Investigate the feasibility of collecting data on numbers and causes and locations of deaths as part of the health information to be collected using the PASS system. This information 'once collected' could provide useful information of the most frequently occurring cases of death in an Irish context.

14. *Develop a better understanding of the Older Peoples Pathways into and out of homelessness*

Undertake a longitudinal study of older people who are homeless (similar to the 2008 Study on Young People's Homeless Pathways) in order to provide a better understanding of the process of homelessness among the older generation, with a particular focus on movements into, through and out of homelessness. This information 'once collected' could then be used to develop more appropriate responses to older homelessness. The implementation of this recommendation would contribute to the achievement of two of the core objectives of 'The Way Home' the National Strategy to address Adult Homelessness in Ireland (2008 – 2013); elimination of the long-term occupation of emergency homeless facilities and the prevention of the homelessness respectively.

94 In an acute hospital setting this process is facilitated by the primary care social worker (community based) or medical social worker who organises and provides the psycho-social support for individuals referred to them where the clinical decision is made that residential care is required. Their role is to focus on ensuring the smooth transition for the individuals to long term residential care.

95 In Galway three individuals were very successfully relocated from various communal houses where they had been for some considerable time to preretirement facilities. The individuals in question were adamant they did not want to go to a nursing home. It should be noted that his move was facilitated by the existence of Fair Deal scheme, the future of which is currently uncertain.

15. *Undertake additional exploratory research on the health and wellbeing of people who are homeless*

This research has focused exclusively on the experiences of older Simon Service users. It would be useful if similar research could be done amongst people who are homeless at a national level.

4.7 Summary of the Recommendations.

This report has been compiled at a time of deep national recession which has precipitated a series of tough budgets and heralded the introduction of significant cuts in public spending. The current economic and financial situation means that there will almost certainly be further cuts in funding and makes it unlikely that any additional capital funding for the housing/homeless sector will be available in the short to medium term. This report 'recognising these constraints' has identified a series of relatively modest recommendations some of which have a small cost and others of which 'while they would require some modest investment' would ultimately result in cost savings to the exchequer. See Table 4.1 for details.

Table 4.1 Summary of Recommendations

Theme	Recommendation	Priority
Appropriate health care	1. Recognition of the particular health needs of people aged 50 and over who are homeless	High
	2. Hospital Discharge Policies/Establishment of a Pathways Model	High
	3. The Provision of Appropriate Accommodation with Healthcare Support ¹	High
Health and well-being	4. Provide access to a range of activities to tackle the issue of boredom	High
	5. Expand individuals social networks	High
	6. Raise awareness of the spiritual needs of older people who are homeless among staff	Medium
End of life care	7. Raise awareness of the importance of end of life care for people who are homeless and provide staff working with people who are homeless with end of life care training	High
	8. Enhance access to end of life care for people who are homeless through the appointment of a Palliative Care Coordinator	High
	9. Ensure that Palliative Care Beds are accessible to people who are homeless	High
Suitable accommodation & accommodation support	10. Ensure the provision of facilities for older people who are homeless	Medium
	11. Ensure (where possible) accommodation facilities for people who are homeless are accessible for those with mobility issues	High
	12. Early intervention and negotiation by staff working with homeless people where there is prospect of increasing care needs necessitating an individual's move to residential care	High
Information and research	13. Develop a better understanding of the numbers, causes and locations of death among older people who are homeless	Medium
	14. Develop a better understanding of the Older Peoples Pathways into and out of homelessness	Medium
	15. Undertake additional exploratory research on the health and wellbeing of people who are homeless	Medium

Appendices

Appendix 1. Membership of the Research Advisory Group

Age and Opportunity Research

Research Advisory Group Membership – May 2011

Organisation	Individual Name and Role
Simon Communities of Ireland (SCI)	Niamh Randall – National Research and Policy Manager Catri O’Kane – Best Practice Coordinator Jane Coyne – Communications Officer ⁹⁶
Simon Community Reps	Majella D’Arcy – Head of Specialist Services Dublin Simon Niall Mulligan – CEO, Dundalk Simon
UISCE	Ruadhri McAuliffe, Coordinator
Independent Researcher	Mary O’Shea Former Director Dublin Aids Alliance, Former Assistant Director Merchants Quay Ireland
Mental Health Reform (formerly Irish Mental Health Coalition)	Orla Barry Director
HSE	Eddie Matthews ⁹⁷ National Planning Specialist Integrated Services Directorate,
Dept. of Social Work and Social Policy, Trinity College Dublin	Dr Eoin O’Sullivan Senior Lecturer in Social Policy
Irish Hospice Foundation	Paul Murray ⁹⁸ (replaced by Caroline Lynch, Communications & Advocacy Manager in Feb 2012)

96 Jane Coyne left SCI in December 2011. Louise Lennon, Policy Assistant, SCI joined RAG in March 2012.

97 Eddie Matthews retired from HSE on 24th June 2011 and is no longer a member of RAG.

98 Paul Murray retired from the Irish Hospice Foundation on 25th January 2012. Caroline Lynch, Communications & Advocacy Manager with Irish Hospice Foundation replaced him as RAG member in Feb 2012

Appendix 2. Key External Consultees

Type of Consultee	Organisation	Individual	Type of Consultation	Date Undertaken
National Policy	Dept of Environment and Local Government	Mary Tully	In person	22/12/2011
	HSE (with a homeless brief)	Maurice Hoare	Phone In person	5/4/2012 6/7/12
Regional Policy	Dublin Region Homeless Executive	Daithi Downey	In person	10/1/2012
Palliative Care	Irish Hospice Foundation	Paul Murray	Phone	2/12/2011
	Irish Hospice Foundation	Orla Keegan	Phone	13/12/11
	The Forum on End of Life in Ireland	Mervyn Taylor	Phone	7/12/2011
	London Pathway	Prof Nigel Hewitt	Phone	15/2/2012
Research	St Mungos London	Peter Kennedy End of Life Co-ordinator	Phone	27/1/2012
	The Irish Centre for Social Gerontology in NUI Galway	Prof. Thomas Scharf Professor of Social Gerontology	Phone	7/12/2011
	School of Social Policy and Social Work/the Social Policy and Ageing Research Centre (SPARC) in TCD	Dr Eoin O'Sullivan	In person	2/2/2012
	Coalition on Older Homelessness Project (based in Homeless Link in the UK).	Sarah Gorton	Phone	5/1/2012
	CARDI Centre for Ageing Research and Development in Ireland),	Paul McGill	Phone	various
The Simon Involvement and Action Group	University of Sheffield	Dr. Maureen Crane Specialist researcher older homeless people	Phone	15/12/2011
		Focus Group		21/2/2012

Appendix 3. Six key steps for end of life care for people who are homeless

(From: End of Life Care: Achieving quality in hostels and for people who are homeless- a route to success (NHS))

1. *Discussions as the end of life approaches*

The only way to find out someone's wishes for end of life care is to ask them. But how do you begin that conversation? 'This is perhaps one of the most challenging steps,' says Tes Smith, the guide's author and social care lead within the NHS programme. 'People wonder if it's the right time, and if they are the right person. The answer is, why should it not be you?'

Ms Smith suggests that hostel workers ask themselves what they already know about the person and what the person knows about themselves. 'Do they know they are unwell and that they have a life-threatening illness? If they don't, you could ask generally about their health. If someone says, "I'm not feeling so well, but I don't know why", you can ask a simple question: "What can I do to help you find some answers?". But if someone says "I'm fine", you can't push that.'

As for spotting that someone is close to the end of their life, even health workers struggle with this. Ms Smith offers some general signs to look out for: 'When somebody is in the dying phase, they sleep more. They're less inclined to eat or drink or to engage either socially or generally in life. For example, if someone's habit has always been to go out at 9am and suddenly they stop, that could be a sign.'

2. *Assessment, care planning and review*

As a person approaches the end of their life, it is vital to establish their needs and wishes as early as possible and identify any areas of unmet need. The report recommends a care plan assessment should take into account all aspects of end of life care - social, emotional and spiritual, as well as physical.

But Ms Smith warns against becoming fixated with the process of assessment itself. 'A conversation can be an assessment,' she says. 'You don't have to sit in front of someone with loads of forms.'

3. *Care coordination*

As many clients not only suffer from chronic physical illnesses but have mental health and substance abuse issues, a coordinated approach to care is essential. But it can be very difficult for hostel staff to know who to turn to and what services are out there. At the simplest level, Ms Smith recommends getting in touch with social services and GPs, who will be an invaluable source of information.

4. *High-quality services in different settings*

Hostel residents are entitled to the same high level of care, no matter where they are dying, and they should be able to choose where that is. If they regard a hostel as their home, it is understandable that they would want to stay there. 'People who are homeless don't like being in hospital - that's why they have health problems,' says Peter Cockersell, director of health and recovery at St Mungo's. 'But they often end up dying in hospital by default. They spend their last days somewhere they would actively avoid.'

Whether or not a hostel is an appropriate place will depend on the services and space available - single rooms, for example. Ms Smith says that it is a misconception that people need 24-hour nursing care when they're dying. 'Hostels don't have to offer services themselves, they can benefit from support from community health services. No hostel can do this in isolation,' she says.

Appendix 3. Continued

5. *Care in last days of life*

When an individual enters the dying phase, it may appear to happen suddenly or as the culmination of a gradual process. It is vital that staff can recognise when someone is dying and take the appropriate action. 'There are people who appear to be very unwell and then get through it,' says Ms Smith. 'For some people, it is a rollercoaster approach to the end of life. Preparedness can never come too early, but don't run in saying, "This is the end".'

Every client's needs at the end will be different. 'The key is knowing who is local - who is the local rabbi, who is the Greek Orthodox priest? At the eleventh hour, if people do want someone, you don't want to be scrambling around,' says Ms Smith.

She also warns not to make assumptions. 'Sometimes people think there has to be a "Cilla" moment - if someone is unwell they must be reunited with someone. It comes back to asking that individual what they need and who they want to see. There is an urge to want everything tied up in a neat bow, but life isn't like that.'

Hostel managers should also consider the distress that watching a client die could cause staff and residents. 'Obviously if you work with somebody over several years, it's very hard to watch them die,' says Mr Cockersell.

Hostel workers also have an important role to play in managing the grieving process for other hostel residents.

'There's quite a lot of death around people in the homeless community - many will suffer from serial bereavement. If you aren't addressing death, you can't mourn properly,' he says.

6. *Care after death*

Death itself is not the end. Staff need to continue following good practice for the care and a viewing of the body, respect family wishes, and help friends and relatives of the deceased to cope with their loss. 'End of life care is about people dying - that continues after death,' says Ms Smith.

'When someone has died, they are still a person and they must be treated with dignity and respect. Who needs to come and see that person? Has the individual stipulated that they want no one to see them? Are there customs that need to be carried out?'

Above all, the guide stresses that residents' own choices are respected throughout, however hard that may be for hostel staff. As Mr Cockersell says: 'These people won't recover but, with good end of life care, they will recover some dignity and control over their lives.'

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