

Disability and Homelessness in Central and Northern Scotland

Theme: Inclusive understandings of disability

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Background

The Scottish Executive has formulated national health policy targets to reduce inequities in health status and health care access. In the recent report 'Delivering for Health'³ published by the Scottish Executive in 2005 key action points were formulated to reduce inequalities in health and service access through among other elements the development of 'anticipatory care', care delivery to disadvantaged communities, and supported self care opportunities. Similar public policy priorities have been assigned to providing better support for individuals and families who are threatened by homelessness or without a fixed abode. A Homelessness Task Force (HTF) created in 1999 was instrumental in influencing the 2002 Housing Act that requires local authorities to provide permanent accommodation for all priority need households who are unintentionally homeless. A key target is to ensure that by 2012 every unintentionally homeless person will be entitled to permanent accommodation. There are severe problems of homelessness in many areas of Scotland, with single homelessness rising despite legislative changes (Palmer et al 2004.88).

Harris (2003) demonstrated that disabled people living in temporary accommodation in the UK (such as disabled asylum seekers) experience severe barriers in accessing social, health care and welfare benefits. Ho, Kroll, Bell, Anderson & Mahler. (2002) in the United States showed that homeless disabled people face various challenges in maintaining health and in accessing health and social care services. These authors also found shelter residents highlighted concerns in the areas of safety, hygiene, privacy, and health service accessibility (ibid).

While much research has been focused on disabled people or homeless people, the experiences at the intersection of disability and homelessness are assumed to be largely unexplored by research. For example, it is not known what barriers and challenges homeless disabled people face in interfacing with health and social care services, or what barriers to services exist within the systems and how these might be surmounted. With increasing emphasis on self care and self management of long-term conditions, little is known about how well "evidence-based" programs have been evaluated with homeless, disabled people and to what extent they may have been adapted to serve this population.

Below we present preliminary findings from a comprehensive research programme that is directed towards the health and social care experiences at the intersection of disability and homelessness. We report on findings from two studies, involving a literature scoping review and a local interview study with service providers in

Dundee. Firstly, we describe our orientation using data from the Scottish Household Survey.

Orientation

We used data from the Scottish Household Survey 2003 (n=14880), using two questions that were asked of 'random' adults in households to examine potential associations between disability and homelessness. In order to determine 'disability', we used the question "whether the respondent has any longstanding illness or disability" (RG5). We recoded this variable into a binary variable with "disability yes/no" answer categories. "Homelessness" was estimated based on question RA9 "Have you ever been homeless, that is, lost your home with no alternative accommodation to go to?" A quarter of the sample (n=3588 or 25.7%) reported having a longstanding illness or disability. Around 5% (n=709) of the sample indicated that they had been homeless or with no alternative accommodation to go to. Within the group of people reporting "disability", nearly eight percent (7.6% n=274) said they had experienced homelessness compared with under five percent (4.5%, n=434) in the non-disabled group¹.

This information is likely to underestimate the proportion of homeless disabled people in Scotland due to multiple sampling and implementation issues (outlined in the Scottish Household Survey User Guide). For example, institutionalised individuals (e.g. prison inmates) have been excluded as have travellers and people living in mobile homes.

However, assuming that the observation that homelessness experiences are more frequent in disabled people compared to those without disabilities can be substantiated, it warrants closer examination of the nature of these experiences and how social and health care services are prepared to address them.

The two studies serve two distinctive functions:

Study 1 (Scoping review) examined the gaps in research and practice in terms of supporting self care and self management in disabled homeless populations.

Study 2 (Interview study) examined issues and challenges facing disabled homeless people, particularly in accessing health and social care services at a local level from the service provider perspective.

Study I: Scoping review of the literature

The aim of the scoping exercise was to

Determine the nature of self-care enhancing interventions that have been suggested, implemented and/or evaluated and described in the research literature that focus on disabled homeless people

A defined search strategy was used to identify systematic reviews in the literature that met the following inclusion criteria:

- self care
- homelessness
- disability
- intervention

Data sources

Search strings were developed to run on the electronic literature databases; these were either newly created strings, or adaptations of previously used strings derived from established search strings published by Cochrane and the Centre for Reviews and Dissemination (CRD). Separate search syntax was created for the Ovid databases (MEDLINE, CINAHL, PsycINFO) and Cochrane Library databases (Cochrane, DARE, CENTRAL, HTA). The limits 'human', 'English/English language' and '1995-2006' were applied to searches in Ovid databases. In addition, a search of the PubMed database was carried out, looking for the terms "Homelessness" and "Self care". From 35 hits, this produced 13 relevant articles for inclusion in the review. The Medical Advocates website was also used as a resource for articles, yielding an additional 28 papers from a total of 375 titles. For both of these sources, titles were scanned, before reviewing abstracts which appeared relevant and pulling those which met the inclusion criteria. Data that met the inclusion criteria were extracted by two analysts.

Full abstracts were downloaded to RefWorks for processing. For each of the combination searches, full abstracts were printed for all hits. A team of three reviewers then reviewed these independently, with each abstract checked by two reviewers. Abstracts which seemed to cover at least 3 of the 4 important aspects of the review (homelessness, disability, self care and intervention) were marked, and full articles pulled.

Results

Only 13 of the items pulled were found to meet all four inclusion criteria ('self care', 'homelessness', 'disability', and 'intervention') and were included in the final review. None of the 13 papers was focused on Scottish or UK-specific settings. Most (11 publications) reflected activities in the United States. One paper was from Australia, and one review paper covered research from multiple countries.

Ten publications were classified as research papers and three as reviews. Of the 10 research publications, four were experimental studies (Ball, 2005; Bradford, 2005; Weissman, 2005; Wilk, 2002), five were non-experimental research studies (Galanter, 1996; Gonzalez, 2002; Hanrahan, 2005; S. P. Segal, Gomory, T., Silverman, C.J., 1998; S. P. Segal, Silverman, C.J., Temkin, T., 1995) one was an ethnographic qualitative study (Quine, 2004).

In total, nine papers focused on *mental health and/or substance abuse* as the disabling condition (Ball, 2005). Four papers included individuals with *physically disabling conditions*, including HIV/AIDS (Bride, 2003), hepatitis C (Nyamathi, 2005), diabetes (Wilk, 2002) and multiple respiratory, mobility and sensory conditions

(Quine, 2004), 3 on *multiple conditions* (Bride, 2003; Hwang, 2005; Nyamathi, 2005) (see figures 1 and 2).

Challenges

In particular one publication (Quine, 2004) highlighted the complex challenges that homeless disabled individuals face. The qualitative study examined the health care experiences of homeless older men in Sydney. The men reported that they frequently had to walk considerable distances to reach health and social care facilities, which was aggravated by the lack of suitable footwear or untreated foot problems. Some had arthritis and thus experienced additional, painful mobility limitations. Any change in their ability to walk curtailed their opportunity to reach needed services. Moreover, food insecurity and dietary inadequacies made it more difficult to stay healthy. The inability to reach meal centres due to walking difficulties led to an increase in social isolation. Some reported that they had received unhelpful advice for how they could best manage their condition. For example, one respondent had pointed out that the doctor informed him that it was best to sleep in a bed to keep warm. Respondents also remarked on the observation that they felt health care providers did not always take them seriously. These study findings are similar to those found by researchers in the United States (Ho, et al 2002) that highlight additional challenges for people with disabilities living in temporary shelter accommodation.

Intervention types

The various intervention types identified in the 13 publications are reflected in figure 1. Among the most frequently used interventions are case or individual care management and psychotherapy, psychiatric therapy or mental health counselling. These are followed by interventions that focus on problem-solving or individual goal setting approaches, peer support and peer-directed interventions, and health education. Surprisingly few interventions focus directly on housing or employment support.

Summary of Scoping Study Findings

Mostly, the scoping study revealed a lack of evidence for self-care supporting intervention in homeless disabled individuals. There are substantial methodological challenges to address in conjunction with building an evidence base for self care interventions for disabled homeless adults.

As a recent review has demonstrated there is a great degree of variability in the way self care is being defined and operationalised in the literature (Jones et al., 2006). Similar conceptual challenges exist with regard to the other two concepts that were considered in the present review, 'disability' and 'homelessness'. It may not be surprising that the literature base is scarce as long as these issues are not resolved. Randomized trials of self care interventions are either of insufficient quality or absent from the literature on disabled homeless people. Also, it may be questioned whether this form of design is appropriate to determine the effectiveness of community-based interventions. Most studies are based on small sample sizes and the execution of research is often of substandard quality.

Currently there is a significant lack of self care research with disabled homeless people. Research that examines the situation in Scotland and that explores the issues and challenges at the intersection of health, social care, disability and homelessness is needed to inform service provision.

This leads us to the second study.

Study II: Service provider interviews

The aim of the second study was to:

Explore the issues and challenges for homeless disabled adults from the perspective of service providers in terms of self care and medical and social care service access in one particular geographical location in Scotland

Telephone and face to face interviews were conducted with six service providers who cater for homeless people. These services comprised 6 voluntary organisations and three representatives from statutory services in the Tayside area as follows:

Voluntary Organisations	Statutory Services
Dundee Cyrenians	Housing Office
Salvation Army	NHS Tayside outreach
Women's Aid	Tayside Carers/ NHS Scotland
Jericho House	Dundee Council, Homeless Strategy Unit
National Children's Home	
Dundee Survival Group	

The interviews followed a semi-structured format with a series of fixed questions concerning provision for homeless people who are regularly in contact with the service and aimed to investigate what proportion of these people have physical, mental, developmental or sensory impairment, chronic illness or a long term condition. Further questions related to how much assistance the services could offer to disabled homeless people, how the interviewee rated the quality of the service that could be provided and what would improve the situation for disabled homeless people. Questioning also covered topics concerning self-neglect and self-care issues. Interviews were content analysed and coded for themes.

Summary of Service provider interview findings

1. 'Bed blocking'

The main finding concerned inappropriate use of provision. The service providers all talked of 'bed blocking' – provision for homeless people designed to be used in situations of crisis as a stop gap is being used instead for long periods (sometimes years) of time. This creates numerous issues for those people in the service. Briefly, these services were not set up to deal with long term accommodation problems. The bed blocking itself is due to a number of structural problems such as 'buck passing'

between services. Homeless people are not generally welcomed by statutory services owing to the intractable nature of their condition, chaotic lifestyles, associations with drug and alcohol use, potential for violence and (generally enforced) lack of hygiene. Examples collected of this buck-passing include inappropriate discharge from hospital. One case involved a homeless man with terminal cancer who was discharged from hospital to no fixed abode and ended up in a voluntary organisation service. As far as could be determined, there was no provision for terminal community care of this man, as would be the case with permanently housed individuals.

This type of inappropriate use of short term provision and 'bed blocking' has a number of consequences for specific groups of disabled people within the homeless populations. One of these relates to Korsakov's syndrome (alcohol-related brain damage, ARBD) which is on the increase in Scotland generally (McCrae 2006). Despite this increase, there are very few signs that specialist services are being set up to cope with this issue. In our study, the voluntary service providers surveyed were struggling to cope with homeless people who have ARBD as social services claim they require specialist provision, owing to their chaotic lifestyles and unpredictability (but none is available). This results in bed-blocking within voluntary services again. Arguably, service provided by voluntary agencies to people in crisis situations is better than no service at all, however, this kind of 'crisis mentality' means that issues of appropriateness and adequacy of the services are left undiscussed.

2. Alcohol and drug-related conditions

Our study also showed there may be more provision for drug-takers who wish to rehabilitate than for alcohol-users. One of the service providers made the point that in their experience alcoholics were unwilling to give up their addiction compared to drug addicts who were at least willing to try and get help. All the voluntary service providers surveyed said that there seems to be a lack of understanding at local statutory and indeed at national government levels about just how serious the issue of alcohol abuse within the homeless population has become. Service providers also claimed that it is not only that there is a sharp rise in the number of people they deal with who have alcohol related chronic illnesses but also these people are getting younger. This correlates with the findings of McCrae (2006) which showed that within Scotland the most pronounced increases in problematic alcohol consumption are occurring in the age group 16-24 (McCrae 2006). Voluntary service providers such as the Salvation Army and the Dundee Cyrenians claim that they have seen men as young as 20 with alcohol-related chronic illnesses.

3. Disabling Life Conditions

It must be stated at this stage that many of the service providers found it difficult to respond to our questions on the specifics of disability within the homeless population owing to the fact that none of them keep records of clients' impairment. However, all respondents were unanimous in claiming that a significant proportion of the client base has an impairment. Two services claimed up to 50% of their service users were disabled. These include Dundee Survival Group and NCH. Interestingly, both organisations have a higher proportion of young people aged 16-21 in their service than the other organisations. The rest of the organisations surveyed claimed that most of their service users had mental health problems and additional health care

issues. The majority of clients appeared to have impairments related to extreme socio-economic deprivation, chronic ill-health or alcohol and drug usage. The catalogue of conditions listed by service providers includes in order of prevalence:

- Mental health issues
- Alcohol-related health problems
- Physical impairment
- Chronic illness

As stated above, the majority of clients in touch with the organisations surveyed were currently facing significant life-challenging issues. Thus, the challenge of overcoming homelessness was being addressed concurrently with trying to self-care for one or more disabling life condition. The Salvation Army reported:

‘People with chronic conditions should not be here but they are dumped on us’.

The Dundee Cyrenians reported:

‘All the people here are mainly chronic alcoholics which leads to chronic physical and mental health problems... [we also have] people with physical disabilities due to amputations from addiction’.

Some service providers explicitly stated there is an issue of people with chronic conditions and disabilities inappropriately being placed in short term homeless accommodation. For example the researcher was told of one man who was discharged into the Salvation Army hostel from hospital. This man had terminal cancer and was literally dying in a temporary bed. The hostel was obviously not set up for nursing very ill people and the man was in shared accommodation receiving little in the way of community nursing, since he had no permanent address (see below). Whilst it may be argued that this is an extreme case, this was not the only one of this type that was reported.

4. No address, no service?

Many of the cases known to the service providers had the same problem in accessing health and social care services. Service users found it impossible to gain access to these services. The service providers told the researcher that this was because they had no address and therefore no way of registering with a GP, dentist or social services. Interestingly, it is possible for homeless people to register with all these services², but the service providers in our study did not appear to know this.

Dentists prove the most difficult for them to access since they began limiting intake of NHS patients and increased intake of private patients as a result of privatisation of welfare services. When there is an intake of NHS patients some dentists are selective in who they take on.

The Salvation Army stated the most difficult challenge homeless disabled people face is:

'Accessing services, doctors, nurses, dentists...mental health is the worst since people are in the dark about accessing these services...since if they have no address it is difficult to register with any of these services'

In terms of self-care, this raises an important issue – effectively the system/s render it very difficult for disabled homeless people to self-care in the ways the rest of the population might be expected to achieve this. Interestingly the Principal Housing Officer was aware of this issue and also raised it, but declined to offer a suggestion as to how it might be overcome.

To overcome this issue innovative services are required that bring services (GP, social services, housing officers, Nurses) into the homeless voluntary sector. Where such outreach schemes have been set up, the service providers told us these were successful and circumvented some of the barriers generally experienced. However, further barriers might yet be encountered. For example, some respondents spoke of the homeless person 'not speaking the language' of the service professionals – there is little or no understanding of what the services might be able to offer and therefore it is difficult for the service user to know what can be requested (this again has very strong parallels with the situation of disabled refugees, cf. Harris 2003). However, other service providers noted that setting up specialised services meant that these become instantly stigmatised and the users pigeon-holed:

'Not enough day places and then there is the place it has a big sign over the door for people with mental health ... so in some ways these places also create stigma and social exclusion – 'mental health is stamped on their forehead'.

Many of the shelters suggested that this shows a need for more advocacy for homeless people NHS Tayside in particular have been running a very successful outreach programme that involves advocacy in areas of health/housing. However, this programme was strictly time-limited and is closing due to lack of funding.

5. Barriers to social services

One service provider claimed:

'Social services cannot cope with people who have more than one health problem'

Some of this phenomena could be due to 'silo mentality' on the part of Social Services, as responsibility for action depends upon clients being categorised as having either a mental health issue, physical disability, substance misuse or homelessness. It has to be said that many of the clients in contact with the service providers we interviewed apparently have either all or three of these issues concurrently. It should also be acknowledged that such clients are generally the most difficult to assist, requiring intensive work often in crisis situations and this does not make them attractive to Social Services or ensure they will rise to the top of action lists. The service providers from the voluntary sector spoke of the conflict that exists between Health and Social Services and a certain amount of buck passing that has historically affected all services in the area.

In the homelessness arena, there is multiple agency involvement and a history of the creation of short-term innovative projects. The researchers were told of one called

'Positive Steps' that sought to give service users back lost skills before rehousing them. This project was highly valued locally. This programme has evolved and attendance will soon form a pre-condition to rehousing for homeless people. Homelessness, like many critical issues that are the run by religious charities and government initiatives, suffers from the short-term project funding issue.

Some schemes support the service user initially but withdraw as soon as they are housed. This is often when the most support is required in order to pre-empt tenancy breakdown. There is therefore a 'timeliness' to care provision that few services are responsive enough to address. There is also the fact that service users often have a constellation of related issues to deal with (for example, homelessness and a chronic illness) and sometimes the issue prioritised by the service is not the same as that of the service user. A holistic and user-centred approach is called for, but generally appears absent.

6. Short term provision used long term

Some short term provision is liked by service users. It is certainly preferable to living on the streets and does not encourage users to move on to more permanent accommodation, or consider it. Some service providers claimed their short term provision houses people who have been there 8 – 10 years. However, since the accommodation is designed for temporary stays only, it is far from ideal, especially for disabled people.

Short term accommodation of the type in this study was not set up with disabled people in mind. Most of the service providers said they had little or no attention to access issues and their provision was not suitable for wheelchair users.

Discussion

According to the views of service providers many of the homeless service users had chronic conditions for example, cancer, heart conditions or hepatitis. Service providers believed these conditions resulted from alcohol and substance addictions and "chaotic" lifestyles. The Homeless Strategy Unit at Dundee Council claimed that a significant proportion of their service users have mental, physical and developmental disabilities. Given this situation, it seems reasonable to ask why more use is not made of the existing Community Care legislation³ and whether 'moral judgements' take precedence in such cases. Given the extent of the impairments and conditions evident in the homeless community surveyed, why are governments and local authorities not doing more to assist homeless disabled people? *The prevalence of alcohol and drug-taking within the homeless population appears to colour the government's imperative to alleviate their homelessness.* Could it be that 'moral judgements' based on the criteria of 'less eligibility' reminiscent of the Poor Laws are still operating here?

We know from previous studies, (cf. Harris 2004) that in extreme circumstances, such as those that disabled asylum seekers face, service providers concentrate upon their asylum-seeking status and fail to 'see' impairment. Interestingly, one

possible cause of the service provider's failure to use existing Community Care legislation to gain social services assessments for disabled homeless people could be that they too do not see the impairment - only the cause (alcohol use). The findings point to an evidential lack of attention being paid to the impairment status of the individual, and their consequential rights enshrined in the Community Care legislation. There are distinct parallels here with the situation of disabled refugees and asylum seekers (Harris 2004) who were found to experience down-playing of their impairment by service providers, who seemed only to take account of the asylum-seeker status when arranging service provision. In the present study, the issue of impairment is fuelled by the distinct possibility that it has been caused by alcohol/drugs and possible involvement in criminality. The service response is crucially overlaid with moral overtones of disapproval and pervasiveness of the view that such people are lucky to receive any help at all. In this situation, services such as those described in this study are a 'last resort'.

Conclusion

A comprehensive scoping exercise of the literature that focused on self care interventions for homeless disabled people revealed a substantial gap in evidence-based programs for this population. None of the identified papers were published by UK researchers or focused on UK residents.

The findings of the second study show that services for homeless people in the Tayside area are being used by disabled people with a variety of impairments, who appear to struggle with self-care under very difficult circumstances.

The majority of service providers who are engaging with disabled homeless people are charities. Many of these services originally set out to provide short term service to people in crisis, and appear from the nature of their accommodation to be based on an assumption that the users would be non-disabled. In recent times, the service providers have noticed that the homeless population is changing and is now including large numbers of people with mental health problems, alcohol and drug related illnesses, physical impairment and chronic conditions, often caused by alcohol or drugs. Short term provision is now being used long term. This is a situation that has the hall marks of crisis planning only.

We found that homeless people face registration difficulties with statutory service providers and that there is a widespread belief by service providers that without an address homeless people cannot access services. Many community peripatetic services do not attend clients of temporary accommodation such as those in this survey.

The service providers claimed that there are generalised problems in accessing services, especially GP, Community Nursing, Dentistry and allied professionals. Services need to come to the users and there is a small amount of evidence that when they do, many of the above problems are overcome, however most of these services suffer from scarce or unreliable resources and short term project funding. Homeless disabled people also require assistance in negotiating a way through

services owing to low self esteem and stigma, lack of patience/ tolerance from service personnel and lack of awareness of services available to them.

It is interesting that the title of this theme at the conference is 'inclusive understandings of disability' since homeless disabled people are clearly socially excluded and not generally considered in mainstream discussions of disability.

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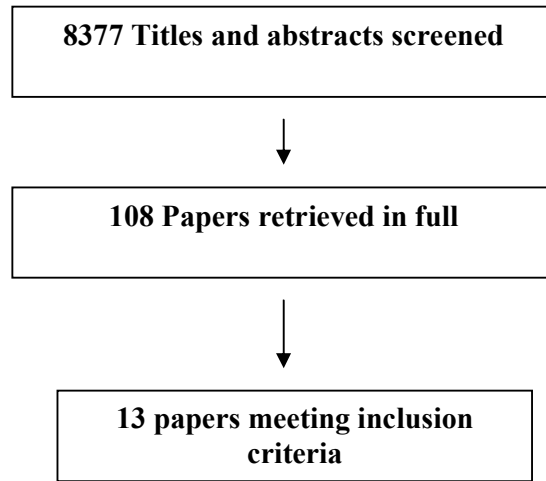


Figure 1. Extraction tree for scoping review.

