

## Health and Community Care Research

# Community Care and Mental Health Services for Adults with Sensory Impairment in Scotland

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This paper outlines the key findings from a study which examined the community care and mental health needs of, and current service provision for, sensory impaired adults in Scotland. The study involved a literature review, a mapping exercise of existing services, and consultation with service planners and providers and with service users and their carers. The research focussed on Deaf, deafened, blind, partially sighted and dual sensory impaired adults.

## Main Findings

- Across sensory impairment categories, the main community care needs identified were rehabilitation, mobility, communication, benefits and services, accessibility and social inclusion.
- The research literature suggests that sensory impaired adults are at higher risk of social exclusion and isolation than other members of the community, which can impact on mental health. Other factors combine making mental health needs complex among sensory impaired adults.
- A mapping exercise revealed sporadic service provision for sensory impaired people in Scotland. There was considerable variation in approach to community care provision across local authorities, and eliciting information about specialist local authority services also proved difficult. There was only one dedicated statutory mental health service for hearing impaired people, and this was limited in resources. Rural areas had few services. Cross-sector joint working appeared to be working better in some areas than others.
- Across sensory impairment categories, specific areas of unmet need included a lack of social work contact, particularly an on-going relationship with an individual social worker; a lack of pro-active dissemination of information regarding services and entitlements, and a lack of joint working between health professionals and social work services.
- Lack of qualified staff was a key concern for all groups (BSL interpreters, rehabilitation workers for the blind and guide communicators for deafblind people). In all cases, the number of qualified staff was felt to fall considerably short of demand.
- Access to counselling and mental health services was found to be especially difficult for hearing impaired and dual sensory impaired adults. Counselling for blind and partially sighted adults appears to often be vitally needed at the time of onset of sensory loss. However, this does not appear to be routinely or systematically offered. Concerns were raised at the imminent withdrawal of the Healthy Living Centre for deafblind people, which was felt to offer a valuable 'lifeline' of support to vulnerable and isolated deafblind people.
- At the fundamental level, the research suggests that there is a need for more systematic, routine identification and monitoring of sensory impaired adults to more accurately assess need and demand for services in Scotland.

## Introduction

This study was conducted to satisfy an element of the Scottish Executive's Action Plan *Community Care Services for People with a Sensory Impairment* (2004). The aim was to examine the needs of, and community care services available for, adults with a sensory impairment in Scotland. This included identifying good practice and gaps in service and investigating the experiences of people with sensory impairment who use community care services. Recognising the centrality of mental health and wellbeing to community participation, the research also offered an opportunity to consider the mental health needs of sensory impaired adults alongside their community care needs.

## Research Method

The research consisted of three elements:

1. A literature review of national and international literature, primarily from the last five years. The focus was on care needs and services for sensory impaired adults, including those relating to mental health. In some cases, due to a lack of contemporary literature in the field, documents were sourced from earlier years. This was especially true for literature on deafblindness.
2. A mapping exercise and consultation with service providers. A database of services was developed, and all services identified were invited to respond to a questionnaire survey to obtain information about services. These were followed up with telephone and face-to-face interviews with service planners and providers. It proved difficult to make contact with dedicated support workers in the statutory sector and this meant that there were inevitable gaps in the data that were gathered.
3. Consultation with service users and carers. Over 100 sensory impaired adults and carers were consulted by means of face-to-face interviews, focus groups, and (in a few cases) written submissions.

## Prevalence of Sensory Impairment in Scotland

**Hearing Impairment:** Estimates of the hearing impaired population are recognised to be unreliable due to under-reporting and lack of a formal registration process. However, an estimated 758,000 people in Scotland have a hearing impairment, of which 57,000 are severe or profoundly deaf (Scottish Executive, 2004). Given that 80% of hearing impaired people are aged over 60, demographic projections infer a 20% increase in the hearing impaired population in Scotland over the next 20 years.

**Visual Impairment:** Just over 38,000 people are registered as visually impaired (60% of whom are blind and 40% are partially sighted). Registration is voluntary, and although estimates vary, it is likely that as few as a third of eligible people register (RNIB, 2001).

**Deafblindness:** There are no official figures for people with dual sensory loss in Scotland. 'Think Dual Sensory', published in 1997 by the Department of Health suggested that some 2,000 people in Scotland could have some degree of deafblindness. In 2005, Deafblind Scotland estimated the number to be around 5,000.

## Community Care Needs

Across sensory impairment categories, community care needs can be summarised as:

**Rehabilitation** – skills for independent living including domestic skills, personal care and life skills. This includes the need for specialist equipment/adaptations.

**Mobility** – training in safe access and movement outside the home and safe navigation within the home.

**Communication** – help with reading and writing, and access to human aids to communication. This may include training in communication media (Braille, moon, etc) and access to information in appropriate formats.

**Benefits and Services** - help with accessing mainstream health and specialist services and learning about the availability of benefits, statutory concessions, etc.

**Accessibility and Social Inclusion** - help with accessing education, employment and other social arenas including leisure pursuits to ensure equality of opportunity.

## Mental Health Needs

Research generally suggests that deaf people are more likely to suffer from mental health problems than their hearing counterparts. Many deaf people feel socially excluded and isolated, which can impact on mental health and also the accessibility of mental health services. High levels of unemployment among deaf people are also a factor given the established link between employment and psychological wellbeing. Communication is clearly an important factor. Poor communication has been shown to lead to misdiagnosis of mental health problems, and can be a barrier to accessing other services.

For people with acquired visual impairment, a pattern of emotions following the onset of impairment has been recognised consisting of shock, denial, distress, depression and adaptation.

Congenitally blind people have a different set of challenges. They are more likely to have difficulty learning rules of communication, and have depersonalised relationships. Such factors can lead to misdiagnosis of mental health problems.

As with hearing impaired people, visually impaired people can suffer from social exclusion as a result of mobility difficulties, discrimination, and difficulties obtaining employment, all of which can impact on mental health.

Those with dual sensory impairment are particularly vulnerable to isolation and social exclusion. Those born deafblind can sometimes exhibit self-harming behaviour in an attempt to communicate. As with acquired visual impairment, acquired dual sensory impairment is likely to be associated with emotions akin to bereavement, and there is a risk of social withdrawal and depression.

## Current Service Provision

The mapping exercise and survey of services showed sporadic service provision for all sensory impaired groups throughout Scotland. A total of 409 services were identified, largely concentrated in the central belt. Rural areas, particularly Highland and island areas have very few services.

Data suggest that much work is undertaken by a small number of organisations, largely working in the voluntary sector. Many of these voluntary sector services receive statutory funding. Joint working seems to be apparent between voluntary sector sensory impairment workers and mental health workers but there is perhaps less sharing of expertise cross-sector.

There is much variability in practice between local authorities. Some provide no statutory community care to sensory impaired people (but contract it to voluntary agencies), others provide generic community care, assisted by contracted interpreters etc as required; others have dedicated sensory impairment teams.

There is a particular dearth of specialist mental health services. There is only one statutory NHS service offering access to psychiatrists with BSL skills (The John Denmark Unit). This operates from Manchester, but currently runs satellite clinics in Glasgow and Edinburgh.

## Gaps in Service Provision

Key shortcomings of current service provision identified by service users from all sensory impaired groups were:

**Social Work Contact** – many consultees lamented the demise of dedicated support from social work services in recent years, and, in particular, a lack of continuity of care from a single social worker.

**Information Sources** - there appears to be widespread difficulty in finding out about services available, benefit entitlement, etc. 'Word of mouth' was usually relied upon, and formal channels of information appeared to be scarce.

**Pathway to Services** – in addition to the scope for more cross-sector sharing of information in some local authority areas, there appears to be a need for more joint working between hospitals/GPs and social work services. There is a clear need for an early systematic intervention and referral system at the point of diagnosis or registration.

## Hearing Impaired: Unmet Needs

The availability of BSL interpreters was felt to be wholly inadequate by service users. There are currently only 49 registered interpreters and 10 trainees in Scotland. Lack of interpreters serves to compound common feelings of social exclusion among hearing impaired people due to lack of social interaction and access to mainstream services. Hearing impaired people also felt that they waited too long for equipment (particularly hearing aids), and also that they had to proactively 'push' to get equipment they need.

## Visually Impaired: Unmet Needs

There are currently 44 full time equivalent qualified Rehabilitation Workers in Scotland. This was felt to be too few by both professionals and visually impaired service users. Other key areas of unmet need for visually impaired people were transport (particularly rail travel was felt to be poorly accommodating), lack of access to affordable adaptive equipment, and a need for confidential personal readers.

## Deafblind: Unmet Needs

The guide/communicator service provided by Deafblind Scotland was described as a necessary 'lifeline' by those experiencing and caring for people with dual sensory impairment. Currently there are 40 guide communicators who, in 2004-2005 provided 41,000 hours of guide communication contact. However, all expressed a need for more contact with guide communicators. Few consultees had more than four hours contact per week, which considerably limited their social interaction.

## Gaps in Mental Health and Counselling Services

**Hearing Impaired:** For hearing impaired adults, access to counselling was considered to be very difficult unless the counsellor was deaf aware. Even then, there can be an assumption that deaf awareness equates simply to use of BSL or access to interpreters. Some consultees were keen to point out that a large proportion of hearing impaired people do not use BSL, and are therefore still disadvantaged even when working with 'deaf aware' counsellors. The John Denmark Unit was cited as an example of good practice. However, some consultees suggested that it is under-resourced and has a limited presence in Scotland.

**Visually Impaired:** Counselling for blind and partially sighted adults appears to often be vitally needed at the time of onset of sensory loss. However, this does not appear to be routinely or systematically offered.

**Deafblind:** In addition to the difficulties described above for single impairments, having adjusted to one sensory loss, the loss of a second sense can be particularly devastating. The development of a Healthy Living Centre for deafblind people was cited as good practice and was praised for promoting positive mental health. Concerns were raised that the imminent cessation of this project might result in the withdrawal of valuable lifelines for people who might otherwise have limited social contact.

## Good Practice

Features of good practice include:

- Equality of access to up to date information about services, delivered in client-friendly formats;
- Affording clients independence to make decisions about things that affect them directly;
- Routine access to support equipment and training using that equipment;
- Access to aids to communication to enable clients to communicate one-to-one with service providers rather than a third party interpreter;

- Clear explanations of treatment, assessments and diagnosis direct to the client and an allowance of time for detailed communication; and
- Early interventions for clients with sudden onset of sensory loss to avoid development of depression and social isolation.

Service development which takes cognisance of client feedback is also key.

## Recommendations

The main priorities appear to be:

For hearing impaired adults:

- A need to increase the numbers of qualified BSL interpreters;
- BSL and deaf awareness training for GPs, nurses and counsellors;
- Statutory services to provide interpreters for GP, hospital and counselling appointments; and
- Awareness raising among hearing impaired people about the mental health system and services available.

For visually impaired adults:

- A need for more rehabilitation workers and better training of social work staff ;
- Consistency in training standards for all rehabilitation workers and rigorous ongoing training and assessment of workers regardless of sector; and

- More regular contact with statutory service providers to ensure appropriate use and maintenance of equipment and to provide valuable social interaction.

For deafblind adults:

- A need for reliable prevalence data on dual sensory loss, and an agreed definition of deafblindness;
- A need for greater awareness raising in the professional and public domain regarding deafblindness;
- Increased numbers, training and funding for guide communicators; and
- Exploration of potential for developing a centrally funded guide communicator service.

Across sensory impairment groups:

- Improved statistics on the prevalence of sensory impairment;
- Improved communication between services and service users;
- Geographical consistency in community care;
- Specialist services for people with mental ill health; and
- A clear, systematically applied procedure for early intervention for people at the time of onset/diagnosis of sensory impairment allowing follow up of communication, mobility, equipment training or counselling as required.

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The research report, "Community Care and Mental Health Services for Adults with Sensory Impairment in Scotland", which is summarised in this research findings, is available on the Scottish Executive Social Research website:

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