

UKCoD Conference Report

Ageing and Deafness – Implications for Health and Social Care – 16th October 2013

1. Introduction – Bencie Woll

Bencie opened the conference by setting the context: that there is a direct relationship between ageing, cognitive decline and deafness. In doing so she established the main objective; to get deafness on the agenda when considering the needs of older people in the community.

2. Deafness and Dementia Project – Joanna Atkinson, University College London & Emma Ferguson-Coleman, University of Manchester

Assessment - Jo

Existing testing for dementia is not culturally appropriate for Deaf people and subsequent care is inaccessible. Communication issues are often misinterpreted as signs of dementia; i.e. confusion, forgetfulness etc.

Interpreters are not a viable solution for assessment and testing as they may inadvertently 'edit' responses.

The Deaf with Dementia project has established a 'norm' for Deaf people's cognition and language – a healthy bench mark against which they can be tested. A national memory clinic for Deaf people has been set up at the National Hospital for Neurology.

Planning for future care – Emma

Interviews have been carried out amongst Deaf people, including professionals and the 'grass roots' community. Access to information is extremely limited and not provided face-to-face, so Deaf people are unable to make informed choices about future care.

Two main issues were identified by the research as being most important to Deaf people when dealing with dementia and subsequent care:

1. Trust: it's important to take time, guide the person through the relevant information in their first language – and enable them to make an informed choice
2. Maintaining engagement with the Deaf community.

Deaf carers empowered the person with dementia and acted as a guide and supporter. Their personal knowledge of Deaf culture, language and experience and ability to empathise was felt to be key.

3. Preferences for Residential Care Provision – Rosemary Oram

This project was commissioned by the Welsh Assembly, to ascertain Deaf people's preferences for care as they get older. The main issue raised here was the need for specialist provision, as current care provision is not appropriate. A model of good practice is needed in order to meet the needs of Deaf people and enable them to keep their dignity when receiving, at times, quite personal care.

Assessments of need currently focus on physical rather than social needs. The main issue for Deaf people is communication – specifically, a fear that they will be placed in residential care, removed from the Deaf community and unable to understand or be understood by staff and other residents: in other words 'cut off' from society and all social contact. Such inappropriate care provision has a direct effect on mental health, leading to more complex needs developing and therefore more costly services required.

Deaf people have limited knowledge of the options available to them because of lack of accessible information. Many said they would be prepared to move away from friends and family if it meant that they would receive appropriate, accessible care.

An interesting side issue was raised here about how researchers and decision makers can access the Deaf community in order to inform their policies and care provision. This piece of research was carried out in Deaf clubs; however, as many Deaf clubs have now closed, this may have implications for the future and the ability of Deaf people to express their views.

4. Residential Services for the Deaf Community in De Gelderhorst, the Netherlands – Jan Tempelaar

Jan described the provision of residential care for older Deaf people living in De Gelderhorst. Both residents and staff are Deaf – or can use sign language fluently. This type of provision is rare and they receive many visits from all over the world.

A short film showed Deaf people expressing their views about De Gelderhorst: they felt empowered by living together with other Deaf people – and by being cared for by fluent sign language users (both Deaf and hearing).

Deaf people described how isolated they felt in mainstream society and being cared for in mainstream settings. Social contact is a major issue.

Jan remarked that Deaf people have the same needs wherever they live in Europe and that they are faced with the same choice – stay within their community or move away to receive specialist care.

5. The provision of social care for people with hearing loss – Louise Pritchard, Action on Hearing Loss

Louise described services provided by Action on Hearing Loss' Care and Support Directorate. They provide specialist residential care, day services within the community and supported independent living for Deaf people who have additional needs.

The main issues that care providers need to get right were:

- Communication, enabling informed choice – this is a priority
- Quality services, person centred, above and beyond regulatory compliance
- Choice and control for clients, ensuring dignity and respect
- Effective outcomes measurement

Action on Hearing Loss have developed an outcomes measurement tool. This is an online tool used by staff that enables them to track the effectiveness of the care that is being provided against the personal goals of clients.

6. A Case Study of Residential Provision for the BSL Community – Paul Elvins, Sonus

Sonus provide a specialist residential care setting for older Deaf people on the Isle of Wight.

Paul described the case of an elderly Deaf lady, who went through a series of unsuitable placements before eventually moving to the right home which provided dignity and respect. Again the issue is a lack of specialist care and the difficult choice of whether to remain close to family and friends or move away to receive care in an appropriate setting.

Paul raised the issue of support and guidance – the example was a personal one and he was able to explain first hand the lack of support and guidance available not only for the Deaf person themselves but also for families.

The issue of mental health was also addressed; inappropriate care has a direct affect on mental well being – lack of stimulation, discussion and access leads to lack of confidence and lack of ability to express oneself.

Paul announced that a report based on research carried out by Sonus and RAD will be released soon, entitled ‘Older Deaf People and Social Care – A Review’.

7. Meeting the needs of those with hearing loss in residential provision – Paul Mancey, Orchard Care Homes.

Paul is the Director of Orchard Care Homes, a private provider of residential care for older people.

Paul identified the need for mainstream residential care to address the needs of people with sensory loss – sight as well as hearing – as this is directly related to the ageing process and therefore affects the majority of older people.

Orchard have worked closely with Action on Hearing Loss in order to improve the care given to clients with a hearing loss. The ethos of Orchard is that quality comes from attitude – particularly of staff – and not cost. He gave the example of using yellow plates for meal times which enables residents with sight loss to see what they are eating and therefore make choices and feed themselves – thus maintaining choice, control and dignity.

As a result of their work with Action on Hearing Loss, Orchard use Hearing Loss Champions at each home, who are responsible for ensuring that the needs of those with a hearing loss are addressed. Hearing aid support is built into care plans – ensuring residents are able to communicate and participate.

An interesting side issue – Paul closed his presentation by commenting that all the other presenters had identified the need for specialist provision but he felt that we should be looking to integrate clients with a sensory loss into mainstream services rather than segregate – this raised the issue of differences in care needs depending on communication needs.

8. Hospital Based Standards - Dr Andrew Alexander, Sign Health

Dr Alexander's presentation dealt with the issue of hospital health care standards in relation to older Deaf people and those with hearing loss.

He reminded the conference that the Government are currently targeting the needs of older people – as hospital stays are very expensive, better standards of care would make it possible for people to return home sooner. So it is a good time to ensure that the needs of Deaf and hearing impaired older people are addressed.

He identified some of the main issues in accessing hospital health care:

- Telephoning to book an appointment
- The practice of calling out names in the waiting room
- Communicating with the doctors and other health care staff
- Access to interpreters
- Being admitted without glasses and hearing aids
- Hearing aid batteries not being available

Dr Alexander has taken steps to address the above issues, creating a code of practice at his own hospital including:

- Improved interpreter provision – information on obtaining interpreters is available on-line to all staff, and video interpreters can be accessed as necessary
- Guidelines on how to use an interpreter are also easily available to all staff and have been written into hospital policy.
- Checks are made at admission stage for glasses, hearing aids etc – this is now part of the admissions process
- A communication plan is written for each patient
- Each ward has a stock of hearing aid batteries

He summed up his presentation by stating that if patients have access to communication and information they are better able to manage their health care needs and remain healthy – reducing the need for expensive, complex care.

9. Sense – Nicola Venus-Ballobin

Sense provide specialist services for Deafblind people and people with a dual sensory loss. Nicola explained that for the purposes of their work in this area (i.e. the ageing process) the term “dual sensory loss” is used

Sensory loss is directly related to the ageing process and therefore most elderly people will experience it. This is a huge number of people, therefore Sense are urging the Government to address this issue. In addition to the needs of those experiencing sensory loss as a result of ageing, advances in technology, medicine etc are resulting in those who are congenitally Deafblind living longer – their needs as elderly people have yet to be addressed.

Sense have developed an early intervention screening tool that will help to effectively identify those experiencing sensory loss. This is known as the SIM tool – sensory impairment monitoring tool.

The lack of appropriate communication for people experiencing sensory loss, leads to frustration and sometimes challenging behaviour. This can often be misdiagnosed as a mental health issue if clients are placed in inappropriate care settings.

10. Open Forum Discussion

Questions were collected for discussion by the presenters; as there would be a House of Lords Debate on Social and Health Care in the week following the conference, questions were also collected to be forwarded to the peers taking part in the debate. Most questions were concerned with

- The apparent inequality between the provision of funding etc for those with sight loss compared to that for people with hearing loss
- The need for better statistics on the prevalence of sensory loss and support needs.
- What plans the Government has to address the needs of older deaf and hearing-impaired people in terms of mental health.

The panel consisted of all the presenters (apart from Paul Mancey). Questions were taken from the floor covering various issues;

- Who do we need to lobby to raise the profile of the needs of Deaf people?
- How can UKCoD help?
- How are care standards established for people who are Deaf or who have a hearing loss? Are appropriately qualified people involved? How can we ensure that research is accessible?

Responses from the panel included the following comments;

- We need to lobby the Government, raise the profile of the needs of Deaf people within the political arena – particularly amongst commissioners.
- Deaf organisations etc. must take on the responsibility for lobbying – maybe UKCoD can help to mobilise this

- We should tap into existing areas of funding such as Health Watch.
- We could make better use of existing legislation such as the DDA. Equalities Act etc.
- The audiogram needs to become a legal document – as the Certificate of Visual Impairment (CVI) is for those with a sight loss. If the needs of Deaf people are ‘certified’ then it would be easier to enforce regulation on standards of care – similar to Section 7 for Deafblind people.
- CQC should be regulating provision but they do not have the expertise to do so – this should also cover the regulation of interpreters and others providing communication support services.

12. Summary and Close – Michael Quinlan

Michael closed the conference highlighting the variety and high quality of the presentations. He identified the key messages of the day as follows;

- More research is needed into the needs of people who are Deaf or who have hearing loss
- We need to raise the profile of the needs of these groups with Government – get the politicians talking about hearing loss;
Better care = better health = less money spent on complex services
- Learning from the models of good practice that were presented today needs to be consolidated and repeated – not lost.
- Social care and health services need to improve in terms of:
 - (i) communication – this is a priority
 - (ii) accessibility and culturally appropriate care
 - (iii) guidance and information for both clients and families

Michael informed the conference that a special interest group (SIG) within UKCoD, would tackle the issue of health and social care for people with a hearing loss, and would continue to work on these issues and keep all interested parties informed of any progress made.

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