



EBU Elderly Steering Group

Concept paper on engaging with Elderly Blind People

1. Extent of the challenge

The benchmarking exercise carried out by the Diversity Group of EBU, and in which 39 out of 45 member organisations had responded, provided clear evidence of the extent of the under-representation by elderly blind people in national member organisations. The average managing board had 14.1 members and an average of only 2 members over 65 years of age. 12 out of the 39 responding organisations had no member over 65.

Given that the blind and partially sighted population in Europe is predominantly over 85 years of age and have newly acquired sight loss, managing boards were not representative of users. This presented problems in that their views were not represented at a national organisation level.

2. Barriers to engagement

There are obvious reasons as to why older people might be less likely to engage in representative organisations. They will be less fit, have more health related issues, and are likely to have additional disabilities such as a hearing loss. Younger people on the other hand have life ahead of them, and may be more interested in being included and making their mark on society.

There are many practical barriers to engagement by elderly blind people:

- Travel and mobility to attend meetings
- Access to information in accessible formats
- Having been related to a sighted world and finding it difficult to engage with blind world
- More likely to be experiencing continuous deterioration in sight loss
- Accessibility issues, especially in that technical solutions may not be appropriate for older people; they have less knowledge of IT and web solutions
- Negative expectations of engagement with older people by some professionals and younger members

-
- Will be more accepting of their situation and having lower expectations
 - Psychological distress at the issue of the sight loss may mean that they are not at a stage to engage with user forums
 - “Nothing more that can be done” messages from health and social care settings may make engagement seem pointless

3. What we know about engagement with older people

If older blind people are to engage with national organisations they need to be motivated to do so. To achieve this it is necessary to increase the benefit to individuals, decrease cost to them in physical, social and financial terms, and enhance their confidence in that they can do it. Motivation to be involved is based on this formula:

$$\text{Motivation} = \frac{\text{Am I able to do it} \times \text{Value, what will it bring me}}{\text{Costs – financial, social, physical}}$$

A review of existing engagement of elderly blind shows paucity of information and of good practice. Research that had been carried out by a group of service users with a sensory impairment in Scotland looked at their views on user engagement. Conclusions included the use of facilitators to allow users to concentrate on expressing their views, providing a more 'social' environment for engagement and ensuring that issues were relevant.

The user's comments on barriers to engagement were:

- Need to make engagement relevant to them.
- More likely to engage if there was a social element.
- Facilitation was important, the business could take over the meetings – so important to have an independent facilitator so people.

Some work has been carried out in the UK with a partnership of Alzheimer's Society, RNIB and Thomas Pocklington looking at engagement by people who have a sight loss and dementia. In particular service users have been encouraged to speak about their condition and to participate in groups to ensure that their needs and experiences were central to the determination of services. The experience of this work is that users can be given a very powerful voice, changing a patronising and negative attitude to people with dementia and sight loss in that they could not speak for themselves.

Further evidence has been looked at in terms of user panels for frail older people, 'Encounter Groups,' to the macular and glaucoma groups which have been motivated to seek information on treatments. Techniques that have proved successful include use of a tele-conferencing facility – Talk and

**With the contribution of the Community Programme
For Employment And Social Solidarity - PROGRESS**



Support – that has been used by RNIB in the UK to bring groups of older people together.

4. A strategy for engagement

A strategy for improving engagement by elderly blind people needs to build on the learning and practice to date. Developments are likely to come from a programme of activity working with people who lose their sight in later life. The programme will focus on:

- Confidence building
- Peer support and leadership
- Understanding how organisations operate and are governed

In parallel national organisations need to focus on steps that will help to encourage and retain participation by elderly people:

- Find ways to increase the benefit of engagement by demonstrating the importance to status and improvement to self esteem
- Making organisational information part of the eye care pathway as this group is hard to reach
- Providing transport, buddy or facilitator
- Adopt less formal ways of approaching business meetings
- Consider the opportunities for inter-generational activity
- Change the way the business of meetings is carried out, such as:
 - Meetings held at an appropriate time of day
 - Enough time to cover the items to be discussed
 - Transport provision and support
 - Accessible meeting venues
 - Interpreters for Deafblind people
 - Translators for BME members where appropriate
 - Hearing loop provision
 - Decent lighting
 - Jargon free, informal meetings
 - Feedback to participants

5. Future Steps

The ambition of EBU is for an improvement to direct engagement by individuals in national organisations, having got comfortable in expressing their views and having

**With the contribution of the Community Programme
For Employment And Social Solidarity - PROGRESS**



been empowered as advocates. It is proposed that this would be achieved by recruiting and working with small regional or national groups of older people with a newly acquired sight loss. Over time individuals from these groups can be facilitated or mentored to participate in the governance of national organisations.

By supporting improved engagement of older people, EBU see this as a user involvement journey or continuum, where organisations would engage with older people in general through a range of activity, to supporting some older people to participate on management boards.

May 2010