Alzheimer Scotland

Introduction

Alzheimer Scotland is Scotland’s leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally and through facilitating the involvement of people living with dementia in getting their views and experiences heard. We provide specialist and personalised services to people living with dementia, their families and carers in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website (www.alzscot.org) and our wide range of publications.

General Comments

Due to the extremely short timescales set by the Health and Sport in place for this call for evidence, Alzheimer Scotland’s response is limited to providing an overview of the experiences of people with dementia and their carers, as well as with Alzheimer Scotland as a third sector organisation.

In addition, the committee must recognise that the large number of Integrated Joint Boards (IJBs) mean that practice is highly variable across Scotland. Whilst some areas engage well and have strong processes in place for engagement of people who use services and the third sector, the majority of areas do not.

Third Sector Engagement

As a third sector organisation supporting people with dementia, their families and carers in Scotland, Alzheimer Scotland aims to engage with every IJB in Scotland, seeking to ensure that the experiences and views of people with dementia help inform the planning and delivery of health and social care services.

Colleagues engaging with IJBs have reported that the ability to engage and influence strategy and service delivery is limited. IJBs frequently only engage in relation to high level information and strategy, with invitations to contribute being purely consultative in nature, around themes which have already been broadly agreed; there is little scope for change rather than anything close to a co-productive process. This level of engagement cannot be said to be meaningful, and does not demonstrate commitment to co-production or partnership working.

Whilst understanding that services and support for people with dementia must be delivered within the wider context of provision of health and social care services for other conditions, the recognition of the distinct nature of dementia as a progressive condition which requires evolving and increasingly complex and intensive care and support is not recognised; it is too often subsumed under generic ‘mental health’, ‘older people’ or ‘long term condition’ headings.

From our experience, there is limited further engagement and opportunity to be involved in the work of the IJB once the Strategic Plan has been developed and published. In areas where this does take place, it is largely limited to invitations to events.

In some IJB areas, we have had some positive engagement in relation to IJBs working at the locality levels to establish the type of engagement we would like to have. However, this is not widespread across Scotland and we believe there is greater potential for these to be used to ascertain the issues
which matter most to people who use services, carers and third sector organisations, and how these groups may be involved in a way which is accessible, meaningful and purposeful. In doing so, Third Sector Interfaces could perform their role as intermediaries between the local sector and IJBs in a more effective and representative manner. This would allow IJBs to ensure that both the strategic planning and delivery of services more closely reflects the needs and wishes of people in the sector.

As many IJBs are still undergoing structural and personnel changes, many of the barriers to effective engagement and involvement are the result of these ongoing structural developments. However, where local engagement is in place, the representation and ability to engage in local groups is variable. Alzheimer Scotland has its own local networks of people with dementia and carers who are keen to be involved and influence change to improve the lives of people with dementia and their carers, however, the ability influence these is sporadic. From our experience, some areas use existing networks of people who use services and carers to engage and ensure these groups are informed about how they can be involved, however, this is not universally done by all IJBs.

We are aware that in one IJB area, the TSI actively recruited a Third Sector rep for the Board, differing from the majority of TSIs who have undertaken the role themselves. This area has a reference group of voluntary sector providers that meet the day before the IJB meeting, allowing them to review the agenda items, gathering views and opinions on these. In this area, the Third Sector rep also sits on the Strategic Planning Group.

However, we are aware that in the majority of IJB areas, the TSI takes on the role of the Third Sector representative and our experience has been that communication and engagement from these representatives has been poor, with no ability to feed into how the third sector can contribute to health and social care integration or what issues the third sector as a whole would like raised at these meetings. Additionally, in these areas, it is not always clear who represents the third sector on the Strategic Planning Groups. If the TSIs are to continue to represent the third sector on IJBs, we believe there is an imperative for them to more thoroughly engage and consult with the third sector within their IJB area and localities.

The provision of accessible information by IJBs to the public is highly variable across Scotland. The ability to find and access information about those who sit on the IJBs, how the boards operate, find meeting papers and minutes, and contact details for members or how to become involved in the decision making process, is inconsistent at best. We believe that IJBs, as a minimum, should have this information available online and easily accessible to the public.

**Engagement of people with dementia and carers**

Through our work with people with dementia at a national and local level, Alzheimer Scotland understands the importance of providing support to these groups to ensure that they are involved in decision making around the development and delivery of services, policy and strategy where it is likely to impact on them. As part of this, meetings and conversations must accommodate their specific needs.

We have heard from carers that those involved in this area, including IJB meetings and sub-groups often receive little or no support going through papers. This means that lengthy papers, which may be complex or include jargon, may be inaccessible and difficult to understand. Often these papers are provided at short notice, with no alternative formats (e.g. easy read, plain English etc.), and no opportunity for a pre-briefing or to ask questions in advance to allow the person to meaningfully take part in a meeting or event. In addition, carers often need to make complex arrangements to
ensure the cared-for person is supported whilst carers attend the meeting; this can be particularly challenging in rural settings. Alzheimer Scotland is aware of instances where locations have been changed at short notice which has resulted in the carer being unable to attend the meeting. It is therefore essential that the additional needs of both people with dementia and carers are taken into consideration, with IJBs providing additional support and accommodations to ensure that these barriers to involvement are removed.

Alzheimer Scotland is aware that some work is beginning to be undertaken by national organisations to support both people who use services and carers to participate meaningfully and effectively on IJBs. It would be helpful for this work to be coordinated and undertaken in such a way as to complement each other, but also to link into IJB and locality level to ensure that the work supports people and responds to their specific needs.

Alzheimer Scotland understands that carers are often involved on the IJBs in an ad-hoc manner, which means they rarely have an established network of carers behind them to consult on issues being discussed at meetings. In addition, they are given little or no support to network with carers to gather feedback; where it does happen, the burden of responsibility is primarily left to the carer. From our experience supporting carers to be involved in both internal and external meetings, if involvement is to happen in a meaningful way there must be resources put in to help this process. By not having these structures in place IJBs are often hearing the voice of a lone, activist carer as opposed to a more collective voice.

Alzheimer Scotland is happy for this evidence submission to be published on the committee’s website. A copy will also be placed on Alzheimer Scotland’s website.