

Alzheimer Scotland

Healthcare Improvement Scotland – Role of the Scottish Health Council

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.

Alzheimer Scotland welcomes the opportunity to contribute to the Scottish Health Council's (SHC) consultation on its work to ensure that people who use health and social care services are heard.

General Comments

Alzheimer Scotland's response represents an overview of the experiences of people with dementia and their carers, as well as our experience as a third sector organisation.

It is helpful to note that across Scotland, the approach to involvement varies considerably across health boards, local authorities and integrated joint boards. Whilst some areas engage well and have strong processes in place for the involvement of people who use services and the third sector, many do not.

Involving People with Dementia and Carers

Alzheimer Scotland agrees with the proposed approach set out by the SHC to engage with different stakeholders. As part of this, the consultation document references the importance of supporting people to engage, particularly where a condition may necessitate specific accommodations to allow for meaningful involvement to take place. It is welcome that the SHC is looking to work in partnership with organisations across the third sector to make this happen. We would welcome clarity about how the SHC will ensure that relevant stakeholders are aware of the work of the SHC and are informed about their opportunities to contribute their expertise and knowledge to its work.

Alzheimer Scotland has considerable experience in supporting people with dementia, their families and carers to ensure that both nationally and locally, their voices are heard in the development and delivery of services, policy and strategy which will affect them. However, this requires commitment on behalf of those seeking to engage to ensure that the planning and running of sessions are done in a way that is meaningful, accessible and responsive to the specific needs of people with dementia and their carers. This may include considerations about the location of engagement, the format of sessions and how information is provided.

As many IJBs are still undergoing structural and personnel changes, many of the barriers to effective engagement and involvement are exacerbated by this ongoing reorganisation. 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 inform them about how they can be involved, however, this is not universally done.

Carers we work with who have been involved in their local IJBs, both on the IJB itself and sub-groups, have told us that whilst they are pleased to be involved, it has not always been in such a way as to allow them to meaningfully participate. The carers have received little or no support to go through papers before the meeting to ask questions or get advice. As papers can be lengthy, complex and/or include jargon, it can make the meeting and discussions inaccessible and difficult to understand.

Additionally, papers are often provided at short notice, with no alternative formats (e.g. easy read, plain English etc.). Furthermore, carers often need to make complex arrangements to ensure the cared-for person is supported whilst they attend the meeting; this can be particularly challenging in rural settings. We are also aware of instances where locations have been changed at short notice resulting in the carer being unable to attend.

Alzheimer Scotland understands that carers are sometimes involved on the IJBs in an ad-hoc manner, meaning they rarely have an established network of carers behind them to consult on issues which will be discussed. 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.

These barriers to participation are unlikely to solely affect people with dementia and carers, and from our experience, are not solely local issues which affect IJBs, local authorities or health boards; these barriers also exist in engagement by national organisations. We believe that the SHC, with its experience of working with health organisations and professionals, as well as its existing resources and knowledge of developing capacity for more meaningful involvement is well placed to work in partnership with people who use services, their carers, public, independent and third sector organisations to improve involvement in at different stages of policy, strategy and service delivery decision making processes.

One key challenge which the SHC must address is the ability to involve a representative and diverse range of people who use services and their carers. Barrier to participation can take many forms, including socio-economic status, race, sexual orientation etc, with each group having specific challenges to their involvement. Alzheimer Scotland has found this to be a challenge in its own work and some of these issues of representation were highlighted in work carried out in partnership with NHS Health Scotland as part of the equalities remit of commitment 16 of the Scottish Government's Second National Dementia Strategy 2013-16. This requires ongoing work to ensure a diversity of opinion is gathered and we would welcome further information from the SHC with regards to how they will engage with these different communities.

Alzheimer Scotland works in partnership with organisations both nationally and locally to ensure meaningful involvement of people with dementia and carers with who have lived experience of health and social care services. We would welcome the chance to work with the SHC to improve the opportunities people with dementia and their carers have to influence decisions which affect them.

Function, Remit and Name

In the current context of health and social care integration, we believe that it makes sense for the Scottish Health Council to consider the way in which both health and social care organisations involve people who use services. Whilst statutory services have distinct structures and ways of working, individuals with experience of using services delivered or arranged by a statutory body are unlikely to view their experience with consideration to each sector in isolation.

Related to this, we note the Scottish Parliament's Health and Sport Committee recently published report into following an inquiry into whether Integrated Joint Board's (IJBs) were doing enough to involve people who use services, carers, the third sector and other stakeholders over the design and future of health and social care in their local area. This report highlighted the ongoing of review of the role of the SHC and the possible ways in which the SHC could support engagement of people with experience of health and social care services.

As part of this inquiry, there was discussion around who should provide information, guidance and good practice examples around exemplars of involvement. Whilst we believe that organisations across sectors have a wealth of experience to offer in this area, we believe that the primary responsibility for the collation and dissemination of such information should ideally sit with a national body with statutory underpinning, such as the SHC.

Alzheimer Scotland would welcome further detail on how SHC envisage such a shift in focus to their work will operate across health and social care as part of the wider policy context in Scotland, including the inspection of regulated services, the Carers (Scotland) Act 2016 and the new Community Empowerment (Scotland) Act 2015. For example, the role of the Care Inspectorate as the regulator of social care and social work services and the joint strategic inspections taking place by Healthcare Improvement Scotland (HIS) and the Care Inspectorate both include examining how well people who are affected decisions taken are involved in the process, whether in relation to an individual care package or as part of wider strategic planning and commissioning of services. From April 2018, these inspections will use the new national Health and Social Care Standards, which focus on outcomes for individuals and how well people are involved in the decisions which affect them. The existing role of the SHC places means it is well placed to offer improvement support to health boards as part of HIS; however, it is not clear how this would be done for social care and how the different organisations, both statutory and non-statutory (e.g. CoSLA, the Improvement Service, etc.) would work together to deliver improve practice for involvement.

If the name of the Scottish Health Council is to be changed to better reflect its role, the name should reflect the integrated nature of health and social care services and include some reference to its purpose as an organisation with a primary focus on the involvement of people who use services. This should be done with as wide a range of consultation stakeholders as possible, both individually with people who use services and with partner organisations who can share information and help raise awareness about role of the body and how people can become involved in its work.

Working with Partner Organisations

Alzheimer Scotland has over 8,500 members and supports people with dementia, their families and carers in Scotland; the experiences and views of this group are at the heart of Alzheimer Scotland's work, helping to set our priorities, informing and helping to drive our campaigns for transformation way in which supports and services are delivered. We are working to engage with every IJB in Scotland to ensure that the experiences and views of people with dementia help inform the planning and delivery of health and social care services.

To avoid duplication, the SHC should look to work with and draw on the expertise of existing networks of people with experience, both locally and nationally. These networks are often well placed to articulate the difficulties and barriers to involvement, particularly at local level.

Alzheimer Scotland believes that it would be useful for the SHC to facilitate more open and partnership working between IJBs and other organisations who support people who use services within local areas. It is our experience that some IJBs are reluctant to working with non-statutory organisations, engaging in a limited way, only on high level and broad policy areas. Additionally,

invitations to contribute are often purely consultative in nature, around themes which have already been broadly agreed; there is little scope for changes to be made. This level of engagement cannot be said to be meaningful and does not demonstrate commitment to co-production or partnership working. 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 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 and what would be most conducive for people living with dementia. However, this is not widespread across Scotland and we believe there is greater potential for this type of engagement to be used to ascertain how best to ensure that involvement is accessible and meaningful. 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 include working with national organisations who are active at a local level. 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.

Alzheimer Scotland believes that the proposed changes to the remit and focus of the SHC would be particularly helpful in driving improvements, to ensure that the planning and delivery of health and social care services could truly be described as co-produced. We would envisage that the role of the SHC in such circumstances would be to facilitate and improve ways of working amongst partners, including TSIs and IJBs.

Another issue which is widespread across Scotland is the provision of accessible information by IJBs to the public; this 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. As part of the SHC's future work, we believe there should be a focus on the provision of information about how people can be involved and how the process of transparent can be made more accessible and more transparent. As a minimum, we believe this information available online and easily accessible to the public.

Conclusion

Alzheimer Scotland welcomes the approach set out by the Scottish Health Council to encompass social care as part of its work is both welcome and timely. We believe there is an opportunity for the expertise and knowledge of the SHC to drive improvement in involvement within social care and more broadly, in the IJBs. A key factor to the success of this work will be working in partnership with organisations across Scotland.

Ensuring that the voices of people with dementia and their carers are heard both at a national and local level is a key priority for Alzheimer Scotland. We are keen to be involved with the SHC as this works progresses and to continue to work in partnership, sharing our knowledge and expertise to ensure that people with dementia and their carers are involved in the decisions which affect them across Scotland.

Alzheimer Scotland is happy for this evidence submission to be made publicly available. A copy will also be placed on Alzheimer Scotland's website.

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Alzheimer Scotland
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