Alzheimer Scotland

Public Bodies (Joint Working) (Scotland) Act 2014 – Regulations – Set One

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. We welcome the opportunity to respond to this consultation and to take part in developing the integration agenda as it progresses.

Alzheimer Scotland believes that an easy-read version of the consultation would have been of value as consultation documents of this length and complexity are, in our experience, often a potential barrier to people who use services and their carers participating in the development of legislation directly related to their interests.

Alzheimer Scotland believes that broadly, the regulations will set clear and achievable expectations of how integration should take place, what services should be included within the scope of integration and the outcomes that people who use services, their families and carers should expect. We do, however, have some specific comments about some aspects of the regulations and have addressed these points in the sections that follow.

One of the main concerns we have is the lack of reference within the regulations to choice, control or rights for people who use services, their families and carers. The Scottish Government's stated aim for the integration agenda is to "improve services for people who use health and social care services". We therefore believe that it is in the interest of all partners involved in the integration agenda that a human rights legislative framework be reflected in all areas of the legislation, including both the regulations and statutory guidance, as these will ultimately shape the way in which services are procured and delivered. This would be consistent with the approach taken in the Social Care (Self-Directed Support) (Scotland) Act 2013 and the Adults With Incapacity (Scotland) Act 2000.

Prescribed information to be included in the Integration Scheme

Alzheimer Scotland would welcome clarification on the different prescribed matters and prescribed information which varies depending on which section of the Act to which it relates. Specifically, where the integration scheme is prepared under section 1 (3) or 2 (3), the regulations do not require the local governance arrangements for an integration board or an integration joint monitoring committee to include information how staff, carers, people who use services and third sector organisations will be included. This is in contrast to integration schemes prepared under 2 (4) of the Act which mandate that this information be included.

We would welcome further explanation of this in the accompanying explanatory notes and would hope this would account for the reasons why no arrangements must be made under 1 (3) or 2 (3) for the involvement of the aforementioned groups.

Prescribed functions that must be delegated by Health Board and Local Authorities

Alzheimer Scotland believes the list of delegated functions to be fairly comprehensive. We further believe that the regulations, as well as any future guidance, should ensure that the delegated functions encapsulate all services that may be required by people living with dementia, including any services which support younger people living with dementia (people under 65), as well as contracted services and complex continuing care.

Prescribed National Health and Wellbeing Outcomes

Alzheimer Scotland welcomes the overall principles contained within the National Health and Wellbeing Outcomes, but would wish to see the language of human rights reflected within the Outcomes. The Charter of Rights for people with dementia, the National Dementia Standards and the Promoting Excellence Framework are underpinned by the PANEL (Participation, Accountability, Non-discrimination, Empowerment and Legality) rights based approach.

The Cabinet Secretary for Health and Wellbeing amended the Act at Stage Three to include a provision that guaranteed that the integration planning principles and integration planning principles must: "*Take account of the particular characteristics and circumstances of different service-users*" and "*Respect the rights of service-users*".

The Cabinet Secretary, whilst speaking in the Stage Three debate, prior to parliament voting against amendments put forward which would have embedded the language of rights, choice and control on the face of the Act, said:

> "*I am fully committed to continuing that dialogue and to examining ways that we can build those considerations into regulations and guidance."* [Official Report, 25 February 2014; c 28082.

We do not believe that at present the Outcomes adequately reflect the need for individuals to exercise choice, control and involvement in the health and social care decisions that will determine their experience and outcomes. We would therefore welcome a more explicit reference to human rights within the health and wellbeing outcomes, as well as greater reference to coproduction, partnership, choice and control.

Whilst Alzheimer Scotland welcomes the policy background to Outcome Three stating that "*It is important that health and social care services take full account of the needs and aspirations of the people who use services*", we believe there would be value in making clear that both people who use services and their carers should be involved in choosing what services they need, the way in which care is delivered and that both should be treated as equal partners in the decision making process.

Alzheimer Scotland believes that the wording of Outcome Nine: "*Resources are used effectively in the provision of health and social care services, without waste"* does not fully reflect health and wellbeing outcomes as being about the experience of people who use services, their families and carers. Whilst we are fully supportive of the policy background behind it and the need for health and social care services to take a preventative approach, we believe that the reference to "*Integration Authorities … fulfilling their legal duty to achieve best value*" is focussed on organisational structures and not the individual. We would therefore suggest that Outcome Nine and its policy background be re-written in such a way as to emphasise the importance of the provision and availability of services which suitably reflect the needs and aspirations of people who use services.

Alzheimer Scotland would also be interested in seeing further detail around the indicators that will accompany the National Health and Wellbeing Outcomes, and would welcome the opportunity to input into their development.

Interpretation of what is meant by the terms health and social care professionals

Alzheimer Scotland believes the section covers a comprehensive range of health and social care professionals.

We would propose that Dementia Link Workers should also be recognised in this list, owing to the nature of their work.

Post Diagnostic Support Dementia Link Workers provide a key service in helping to deliver the Scottish Government's commitment to one year of post-diagnostic support for people with a diagnosis of dementia. Link Workers are fundamental to the delivery of post diagnostic support to people with dementia, their families and carers, through the Five Pillars Model, helping individuals to understand the illness and manage symptoms, maintaining the community connections of the individual, providing the opportunity to meet other people with dementia, their partners and families, helping individuals plan for future decision-making and helping them plan for future support. This role oversees the coordination across both health and social care services to support the person with dementia, their families and carers, and we believe that this crucial role should therefore be on the identified list of health and social care professionals.

Alzheimer Scotland seeks further clarification on the discrepancies in the identification of social care professionals. Under adult day care services, only managers are recognised, whereas all other services identify managers, supervisors, practitioners and support workers.

The regulations define anyone social care professionals as anyone registered with the Scottish Social Services Council (SSSC) and "Other Social Care Professionals who are not regulated by the Scottish Social Services Council but provide care or support to users of social care services". This definition is vague and broad, and could include a personal assistant, with no health or social care training, who is employed by the person using services, either through Self-Directed Support or other means. Alzheimer Scotland fully

supports Self-Directed Support and the choice and control it allows people who use services to exercise and would not seek to restrict this in any way. We do, however, believe that there should be a distinction made and that those employed through Self-Directed Support are not necessarily health or social care professionals by virtue of being employed in this manner. We would therefore encourage the Scottish Government to revise the vague wording in this section.

Prescribed functions conferred on a Local Authority officer

Alzheimer Scotland has concerns about this section of the regulations and how they define who is authorised to carry out investigations or other tasks under the Adult Support and Protection (Scotland) Act 2007.

The regulations state that only 'Council Officers', that is social workers registered with the Scottish Social Services Council (SSSC) or equivalent bodies; occupational therapists or nurses can carry out investigations but they must have had '*at least 12 months experience of identifying, assessing and managing adults at risk'.*

Alzheimer Scotland is concerned that the regulations no longer state that workers should have undergone training in assessing and investigating situations relating to adults at risk. Alzheimer Scotland recommends that the regulations are amended to state that the relevant health and social care professionals must, in addition to the required experience, have completed specific training about carrying out such investigations.

It is important to recognise that while social workers, occupational therapists and nurses will often work with the same service user groups, they are in professions with different professional cultures. Each will have training in working with adults at risk, but Alzheimer Scotland would suggest that the Scottish Government give consideration to the possibility that the regulation should include, "*experience of identifying, assessing and managing adults at risk with appropriate multi-disciplinary training which underpins this experience*".

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Policy Officer
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