

Alzheimer Scotland

Consultation on the Review of the National Care Standards

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 participate in this consultation and to contribute to the review of the National Care Standards.

Alzheimer Scotland supports the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) and our response to this consultation has been informed by those groups, in addition to the experience and knowledge of people who use and deliver our services across Scotland.

Alzheimer Scotland welcomes the publication of an Easy Read version of the consultation and also the events held by the Scottish Government in partnership with the ALLIANCE and Age Scotland, which provide a more accessible format for people to engage in the consultation process. However, we are concerned that the Easy Read version of the consultation was published more than four weeks after the initial consultation document, with no amendment made to the deadline to compensate for this delay. Given the complex nature of this review process and the additional support people may need to allow them to respond, this reduced timeframe is a barrier to participation for people using the Easy Read version as a means to participate.

From our experience, many people who use services and their carers are not fully aware of their rights and entitlements under existing legislation and strategies, including the National Care Standards. It is therefore essential that as part of the process of revision, service providers and professionals ensure that people who use services and their carers:

- Are made aware of the existence of the National Care Standards
- Have access to the National Care Standards in a number of accessible formats
- Fully understand their rights and entitlements in relation to the National Care Standards
- Know what they can do if they feel their rights are not being upheld

Human rights

All legislation, regulation, policies and strategies related to the care and support of people who use services in Scotland should be underpinned by the human rights legislative framework, to which providers should be accountable. People who use services should be

involved in the decisions that affect their lives and that they should be empowered to exercise choice and control over the care and support they receive. By creating a person-centred approach across health and social care services, outcomes for people who use services and their carers will be improved.

The revision of the National Care Standards represents an opportunity, within the context of health and social care integration, to create a common approach to care across disciplines where different values sets may exist. The revision of the National Care Standards and the adoption of a human rights based approach could allow services to work together more effectively to provide improved outcomes for people who use services and their carers.

We therefore strongly welcome the consultation document's proposals to base the revised National Care Standards in human rights. Furthermore, we welcome the recognition of the PANEL principles as the key values which must underpin a human rights-based approach, which is consistent with the Standards of Care for Dementia in Scotland and the Promoting Excellence Framework.

However, embedding human rights within the National Care Standards will not, in isolation, effect change within service providers. The creation of an environment where human rights are promoted and respected must be driven by changes in practice and culture. This will require rigorous enforcement of clear, relevant standards by national regulatory bodies, including the Care Inspectorate and Healthcare Improvement Scotland (HIS). Furthermore, workforce development and training within both health and social care settings must be encouraged to ensure that people delivering services fully understand what constitutes a human right and how their practice can support the rights of people who use services and their carers.

Alzheimer Scotland believes that there must be a balance struck with rights, particularly in instances where a person using services may have conflicting or differing rights to that of their carer. It is imperative that the standards themselves, or any accompanying guidance, should set out how any issues arising from a conflict of rights may be resolved.

The National Care Standards must ensure that empowerment of people living with dementia, as well as with other cognitive difficulties, is taken into account. Alzheimer Scotland is aware that often in the early stages of cognitive impairment, decision making is taken away from individuals, with their views not adequately considered and their rights not respected. It is therefore crucial that the rights of people living with dementia are fully supported, with consideration given to using abilities the individual maintains, even where cognitive deficits may be severe.

Such is the complexity of human rights legislation and its application within the health and social care sector, the National Care Standards themselves, and accompanying guidance, must produce clear guidance on human rights within the context of care and support. They should be set out where these rights sit, with reference to both international law and domestic legislation, as well as the mechanisms by which they can be enforced.

Furthermore, case studies or examples which show how they relate to the National Care Standards and how they may be applied in practice would be useful.

Structure of the National Care Standards

Alzheimer Scotland supports the proposed structure of the National Care Standards and believes that the tiered approach of standards is a useful way of distinguishing between the different intended outcomes of each, as well as making it clear which standards apply to each service. Furthermore, we strongly agree with the proposals for overarching quality standards, based in human rights, should be developed for all health and social care services in Scotland and that these standards should set out essential requirements that services providers must meet.

In addition, we support the Scottish Government's proposals to continue using the existing principles of the National Care Standards as we feel they remain fundamental to the support and care of people who use services and their carers. We further believe that it would be useful if the principles of the National Care Standards were linked to the overarching standards to create a clear understanding for both providers and people who use services how the principles are applied in practice.

Alzheimer Scotland supports the proposals to include aspirational elements within the general standards alongside the essential requirements. We believe that doing so will provide services with the opportunity to work towards improving the quality of the services they deliver, whilst encouraging and supporting innovation and creativity in care services. Furthermore, we believe that the inspection methodologies should recognise and grade accordingly those services which are doing more to achieve the aspirational elements of the standards.

However, Alzheimer Scotland has some reservations about the inclusion of aspirational elements alongside essential requirements within the general standards. Whilst we agree with the principle of continuous improvement of all services, the National Care Standards act as one of the benchmarks against which the progress and quality of services can be objectively measured, as well as the outcomes for people who use services and their carers. We are concerned that the inclusion of an aspirational element within the general standards risks creating ambiguity and inconsistency both within the standards and the inspections by regulatory bodies. In addition, we are concerned that there may be confusion around expectations for people who use services if there is insufficient clarity between essential and aspirational elements of the standards. The standards must therefore make a clear differentiation between aspirational and essential standards. We therefore also require further clarification on how the aspirational elements will be presented and how they will be used within inspections, as we believe the overly prescriptive elements could stifle innovation and creativity in the delivery of services.

Alzheimer Scotland is clear that there is a need for a suite of specific standards as some care settings and individual circumstances and needs will not sufficiently be addressed within the overarching principles or general standards. However, we are conscious that the purpose of

the review of the National Care Standards is to streamline and reduce the number of standards currently in existence. We therefore believe that it is important that the standards are not difficult to navigate and apply.

Alzheimer Scotland supports the proposals for the Care Inspectorate and Healthcare Improvement Scotland (HIS) to develop the suite of specific standards. It is crucial that the standards not only reflect the knowledge and experience of people who deliver services at an operational level, but also people who use services and their carers. Therefore, we strongly encourage the Scottish Government, the Care Inspectorate and Healthcare Improvement Scotland (HIS) to ensure that groups of people who use services and carers' groups are consulted with and involved in the process of developing the National Care Standards, to ensure that the standards created have the confidence of the people who rely on them most.

Alzheimer Scotland has particular interest in the specific standards in relation to care provided for people with dementia. Whilst the Standards of Care for Dementia in Scotland provide an excellent resource in relation to the principles of care a person living with dementia should expect to receive in a care setting, we believe that specific Care Standards must be developed that include the practice and delivery of care for people living with dementia. We suggest that each set of Standards is structured in a common way, to make it easy to understand and navigate. The structure we suggest is:

- What is the right that this standard relates to?
- What would a person expect to see happen at each point along their care pathway, from commissioning to discharge as applicable, that demonstrates that this standard is being upheld?
- What communication can they expect about this standard?
- What timescales should the processes attached to this standard adhere to?

This structure will identify the accountabilities in each part of the system that affect care provision. Furthermore, it will ensure that providers are inspected only on what is relevant, but will also make sure that quality is expected in every area that has an impact on care provision.

Alzheimer Scotland would welcome the opportunity to contribute to the development of these standards, as well as the other standards which may affect people living with dementia and their carers. Furthermore, it would be useful if the Scottish Government, the Care Inspectorate and Healthcare Improvement Scotland (HIS) indicated the time-frame for the development of these specific standards, what areas will be covered by these specific standards and details on the engagement process for organisations to contribute to their development.

Writing the National Care Standards

Alzheimer Scotland believes that people who use services and their carers should have access to all information relating to the provision and performance of services that are relevant to their interests. If the National Care Standards are to set out and explain to people who use services, their families and carers what level support and quality of care that they should expect from services providers, they must be written in such a way as to take into consideration their needs and circumstances, whilst maximising accessibility.

To achieve this, the revised National Care Standards must:

- Be written in 'plain English'
- Avoid potentially ambiguous language and phrasing
- Be written in a way that is accessible for the widest possible audience
- Be concise

The Scottish Government, the Care Inspectorate and Healthcare Improvement Scotland (HIS) should also give consideration to alternative formats for the National Care Standards to maximise their accessibility, including the use of Easy Read versions of the documents. To ensure that the National Care Standards are easy to understand, accessible and meaningful to people who use services, their families and carers, the Scottish Government must ensure that both groups of people who use services and carers' groups continue to be consulted and fully involved in the process of revising and developing the standards.

Alzheimer Scotland welcomes the reference to the Standards of Care for Dementia in Scotland and the Care About Rights documents as potential models on which the revised National Care Standards may be based. We believe that these are excellent examples of documents which are easy to understand, accessible and clear in setting out the minimum level of care and support which a person using services can expect. However, the National Care Standards must include the practical information about how principles are to be put into practice, as set out above, in order to ensure clear accountability at each stage of the process of accessing care. We therefore strongly support the revised National Care Standards mirroring these documents, with the developments proposed above.

Alzheimer Scotland does, however, have some concerns in relation to the provision of separate explanations for what is expected of providers and what a person using a service should expect when receiving care and support. We are concerned that this may lead to differing interpretations of how needs should be met and may potentially create conflicting expectations between people who use services and providers. We believe that if the standards are written in a suitably clear manner, there should not be for two separate explanations as displayed in the example.

Regulation and Accountability

Alzheimer Scotland broadly agrees with the Care Inspectorate and Healthcare Improvement Scotland (HIS) holding the services they regulate to account for meeting the proposed overarching standards, the general standards and the suite of specific standards. Both

organisations must continue to consider and review their inspection methodologies to ensure that all 'tiers' of the National Care Standards are being reflected in practice. Until the review of both the National Care Standards and the inspection methodologies is completed, there remains ambiguity and uncertainty over how a human rights-based approach can be prioritised and implemented in practice within individual services. Similarly, the Standards must be clear about how inspections will measure adherence across each tier of the standards. It is therefore vital that the Scottish Government, the Care Inspectorate and Healthcare Improvement Scotland (HIS), as well as any other regulatory body who may be involved in scrutiny of services, ensure that the expectations and practicalities for service delivery are clearly defined, including support for providers in relation to how practice may be evidenced. Furthermore, it would be beneficial if the inspection regime were to adapt accordingly to the revised National Care Standards, with greater support for services seeking to improve and a move away from inspections focus on paperwork.

Alzheimer Scotland believes that the National Care Standards in their current form have a disproportionate focus on inputs which should be balanced by more clearly relating them to the outcomes achieved for people who use services and their carers. The revised standards will ideally be seen as a toolkit to encourage, develop and support the aspirations of people who use services and their carers.

There will be a role for workforce regulatory bodies, such as the Scottish Social Services Council (SSSC) to support the move to a human rights based approach to providing care that we wish to see driven by the new Care Standards. It is crucial that a common understanding and approach to promotion and respect for human rights is shared by professionals of all disciplines. In this context, we welcome the professional bodies' support for the Promoting Excellence Framework, which supports the workforce to develop their skills to provide high quality care and support for people with dementia, embedding a culture of rights within their practice. Similarly, professional bodies must ensure that all practice for professionals working within regulated services respects the rights of people who use services, in line with the National Care Standards focus on human rights.

Alzheimer Scotland is clear that providers must be held to account by regulators in instances where they fail to meet the National Care Standards in order to provide assurances to people who use services, their families and carers that poor provision of care is unacceptable. The standards should set out how people who use services, their families or carers may go about addressing or raising concerns if they feel that any aspects of the National Care Standards are not being met.

Where the Care Inspectorate or Healthcare Improvement Scotland (HIS) do not have a remit to inspect services and ensure their compliance with the National Care Standards, we believe that the commissioning organisation of the service must have responsibility for ensuring compliance with the Care Standards, which should form a part of the conditions of the commission. This role may be carried out by a local authority, health board or integrated authority. We recognise that there are examples of good practice and innovative working in non-regulated care which further underlines the need for the new Standards to be written in a way which supports innovation and creativity.

The National Care Standards should be reviewed regularly, with the frequency specified, to ensure that the standards are up to date and reflect the continuously evolving nature of health and social care. This will be of particular importance in the suite of specific standards as developments and changes in practice take effect.

Equalities Impact Assessment

Many people who use services, their families and carers will have at least one of the protected characteristics set out in statute. From our experience, people with dementia, their families and carers can experience difficulty in being involved in decision-making around their care, particularly in cases where capacity is an issue. We therefore note that the revision of the National Care Standards, and the proposals for them to be based in human rights, represents an opportunity to support and uphold the rights of people who use services, their families and carers, consequently improving their outcomes.

Business and Regulatory Impact Assessment

Many service providers currently deliver services using a human rights-based approach and that so will not require significant change to meet the new National Care Standards.

If, as the consultation document sets out, it will be the responsibility of the Care Inspectorate and Healthcare Improvement Scotland to uphold each 'tier' of the National Care Standards, we believe that adherence to the new standards may require additional evidence of activities and potentially a change in practice, which will likely require training of staff on an on-going basis. Specifically, the impact will be determined by the focus of the inspection methodologies. If there is a focus on outcomes for people who use services, the impact and regulatory burden upon services will be minimal. However, if inspection methodologies continue to focus on inputs, staff training and changes to paperwork will be required. As a result, Alzheimer Scotland notes that such a transition has the potential to be resource intensive for providers and believes that providers should be supported by the Care Inspectorate to undertake any process changes required to be able to evidence adherence to the new standards.

Consideration should be given to the frequency of inspection, and whether there are other ways of monitoring quality, as compliance and standardisation become more widespread through the revised National Care Standards.

Owen Miller
Policy Officer
23 September 2014