National Care Standards Review

Response to Scottish Government Consultation on the new National Health and Social Care Standards

My Home Life Scotland – January 2017
INTRODUCTION

My Home Life Scotland welcomes the opportunity to participate in the Scottish Government’s public consultation on the new National Health and Social Care Standards. My Home Life was established in Scotland in 2013 and is led by the University of the West of Scotland in partnership with Age Scotland and Scottish Care – to date we have provided leadership support to over 300 health and social care professionals across 14 different local authority areas including care home managers, care at home, third sector and NHS staff.

Our vision is a world where all care homes are great places to live, die, visit and work.

Where all care homes are:
• Supported to deliver their potential;
• Valued and trusted by external professionals; and
• Cherished by their local communities.

This response was prepared by Karen Barrie, David Innes, Belinda Dewar, Tamsin MacBride and Edel Roddy.

If there are any questions about this response, please contact Professor Belinda Dewar
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Q1: To what extent do you think the Standards will be relevant and can be applied across all health, care and social work settings?

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Comments
My Home Life is a UK wide social movement that is working to improve quality of life for everyone living, dying, visiting and working in care homes. Over the past decade My Home Life has developed an international reputation for facilitating positive culture change and enabling care homes to both professionalise and articulate their expertise. We are heartened to note that My Home Life is identified within the consultation document as a Scottish Government priority. We welcome the opportunity to respond to this consultation on the new National Health and Social Care Standards for Scotland and to contribute to how our services are planned, commissioned, delivered and improved in future. Before commenting on the applicability of the standards within the care home setting, we would like to make some general remarks.

General Remarks
We welcome the shift away from the emphasis on the technical requirements of care in the previous standards. We commend the authors for the clarity of the document, the accessibility of the language used and in particular, the place and value of ‘care’ within the standards. We fully endorse the combined focus on human rights and personal outcomes. The emphasis on rights for older people is important and overdue. It calls attention to essential human freedoms that are often taken for granted until lost and supports the identification and eradication of discriminatory practices, such as the denial of certain health care services to older people living in care homes. The recognition of fundamental individual entitlements mounts a direct challenge to the sense of burdensomeness that can make older people reluctant to seek help. However, the focus on universal human rights alone is not capable of taking into account the particularities and situated nature of human needs and aspirations, or the relationality of the processes through which needs are met, aspirations fulfilled and personal outcomes understood and worked towards. The complementary focus on personal outcomes is therefore critical. Consistent with the My Home Life ethos of relationship-centred care, a personal outcomes approach recognises that we are relational, interdependent beings and that authentic care is grounded in positive relationships.

While applauding the emphasis on personal outcomes within the ministerial foreword and background text, we note that there is a tendency to revert to the language of ‘needs’ within the standards themselves. This may be a consequence of efforts to make the language of the standards accessible and we note that there is no definition...
of personal outcomes in the glossary. However, there are other more implicit ways in which a more outcomes focused ethos could be achieved, particularly through greater emphasis on reaching shared understandings and recognition that achieving personal outcomes is everybody’s business. While the enabling, strengths-based approach that underpins a focus on personal outcomes is evident, the collaborative, negotiated nature of decision-making is underplayed. Further, while there is some recognition of the importance of relationships between people accessing and providing care, relationships with family members, good working relations between staff and, to a lesser extent, organisational responsibilities for creating the conditions that foster positive relationships, we anticipated and would encourage a greater emphasis on relationships throughout the standards.

Applicability of the Standards
In responding to question 1, our primary concern is the applicability of the standards within the care home setting, particularly care homes for older people. In constructing this response, we have considered the needs and interests of those living and dying in care homes, their families and friends, and those working in care homes, consistent with the ethos of relationship-centred care.

We endorse the aspiration that people should receive the same general standard of care in many respects, irrespective of where that care is provided. We consider the development of a generic set of standards applicable across all care settings, coupled with more context specific additions an appropriate way forward. We find the breakdown of the generic standards under the four headings helpful in calling attention to the responsibilities of provider organisations and commissioners. However, the translation of the standards into ‘I’ statements works less well for those with a more strategic orientation, particularly those that rely on causal connections between what the person accessing a service can expect and what the provider must do e.g. 3.17 My needs and choices are met because I am supported by the right number of people with the right skills and experience.

Many of the standards are consistent with our experience of the good practice that already happens in care homes across Scotland. Often these standards are being achieved under extremely challenging circumstances due to the resource constraints under which much of the sector is currently operating. The inclusion of standards that address the responsibilities of provider organisations and commissioners is therefore welcome. In addition, people are now entering care homes when they are older, frailer, with complex and multiple conditions, and increasingly high levels of cognitive impairment. Implementation of the standards within this context inevitably raises some particular concerns.

We recognise that what appears in the document is the result of complex compromises and that some inconsistencies and contradictions between standards is inevitable. Often these are the result of tensions between standards directed at providers and commissioners and those that concern caring interactions in practice. Examples include tensions between respecting lifestyle preferences and normative assumptions about what people should be eating or the types of activities they should be doing. Others refer to provisions that organisations should be making, but which may not be important or applicable to many older people living in care home, especially those with advanced dementia and at the end of life. Many of these tensions could be addressed by increased use of appropriate qualifiers that are respectful of personal preferences and capacities, such that applied in standard 2.1 ‘as I want to be and can be’.

Our greatest concern is the tension
that arises in practice between the underpinning wellbeing principles:

- I am supported to make informed choices, even if this means I might be taking personal risks.
- I feel safe and I am protected from neglect, abuse, or avoidable harm.

Often the most complex negotiation of ethical and practical dilemmas falls to so-called unskilled frontline staff helping older people to negotiate everyday life in the home. This complexity is compounded when severe cognitive impairment is layered on top of an already physically frail body, whereupon everyday undertakings such as hair washing, nail cutting or shaving may be misunderstood. Thus these seemingly ‘simple tasks’ require skilful negotiation between the need to respect individual choice, avoid potential harm, maintain dignity, and also to respect the wishes and preferences of different family members, amidst the complexity of group living. We believe there is a need for greater honesty about these tensions if care home staff are not to be set up to fail. Much of the challenge lies in the way in which the necessarily high level standards are interpreted, implemented and assessed in the short-term and in the future. We address these issues in our response to Question 10.

Q2: To what extent do these Standards reflect the experience of people experiencing care and support?

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What is missing/should be added:
The My Home Life evidence base is founded on what matters most to older people living in care homes, their families and care staff, and what is known to work. In responding to this question we have compared the standards with the My Home Life evidence based themes that relate directly to people experiencing care and support, namely maintaining identity, shared decision making, creating community, managing transitions, health/healthcare and end of life. The associated best practice themes are known to be necessary if older people are to experience the six senses of security, belonging, continuity, purpose, achievement and significance.

We have found that the elements relating to managing transitions, creating community and end of life are almost entirely absent within the standards. Many older people need considerable support when they first move into a care home and this is not adequately captured by being able to visit the home prior to moving in where possible. The majority of people who move into a care home will die there and only one standard alludes the possibility of death and it thus remains a great taboo. Community is only referred to within the standards as something ‘out there’ and there is no suggestion that community can or should be created within the care home. This concern is revisited in the response to question 7. Running through this, relationships, as highlighted in our response to question 1, are known to crucial to older people living in care homes, and they are underplayed within the standards. We note that some of the standards specifically for children’s services make for an interesting comparison, particularly 7.2 I live in a place that feels like a home and I am supported and cared for by people who make me feel valued, special, loved and safe. Love is something we all need in our lives, but we recognise that perhaps it cannot be mandated.
In terms of the standards that are set out in the document, while recognising the importance of the standards set out under heading 4 that relate to confidence in the organisation, we believe that many may be less salient to many older people living in care homes. They may however be important to family members.

Q3: (Standard 1: I experience high quality care and support that is right for me). To what extent do you think the standard describes what people should expect to experience from health, care and social work services?

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Is there anything that is missing or should be added to this Standard?

We reiterate the point made in response to question 1, namely that many of the standards under this heading would benefit from the addition of appropriate qualifiers that respect what matters to and is possible for a unique and particular person.

We recognise that older people living in care homes should be supported to take part in meaningful activities as often as is possible and in line with their wishes and preferences. However, we have some concerns about the focus of standards 1-36 – 1.39. Our work has found that different stakeholders often express different ideas about the form and purpose activity should assume, with varying emphases placed on ‘doing’ and ‘being’. Many group and communal activities are highly valued by some older people, while others prefer solitary and more sedentary pursuits. The need for both planned and spontaneous activity is also evident. Some older people are keen to sustain former roles and emphasise their retained abilities, while others are aware that activities once enjoyed no longer bring about the same pleasure, or they are physically or mentally unable to engage in them. Often relatives place greater emphasis on ‘doing things’ than older people themselves. The importance of support to come to terms with inability to persist with favoured interests is an important accompaniment to the emphasis on activity. This is an example of a transition highlighted in or response to question 2, which we feel is largely missing from the standards.

Other Comments

We particularly welcome standard 1.7 I experience encouragement and warmth and my strengths and achievements are celebrated. However, much of the language in this section is inconsistent with the emphasis on personal outcomes set out in the background, and the notion of needs being ‘fully met’ can be problematic, as evidence by the recent ESRC funded Meaningful and Measurable project.

Our greatest concern is standard 1.17 I am supported to live in my own home if this is possible.

Research shows that many older people value the sense of security that comes with living in a care home. The persistent policy depiction of care homes as the last resort compounds negative public perceptions. This presents significant challenges for older people and their families, with the move to a care home often associated with failure and loss, rather than finding the care and support needed to continue to lead as fulfilling a life as possible in the changed circumstances of advanced old age. We would therefore like to see this standard
modified to convey that staying at home might not be everyone’s preferred choice and that the move to a care home can be a positive choice.

1.20 I fully participate in developing and regularly reviewing my personal plan.

This standard requires a broad interpretation of full participation. We believe that it would be preferable to emphasise that individuals should be supported to contribute to their care plans as fully as possible. It is also important to convey that this may involve other significant people in my life (e.g. family members) according to my circumstances and preferences.

While generally applauding the accessibility of the language used, we have slight concerns about the interpretation of certain terms e.g. 1.25 - ‘proper planning’ and 1.26 ‘the right place’.

Standard 1.31 I can enjoy unhurried snack and meal times in as relaxed an atmosphere as possible also requires careful interpretation and can be at odds with certain food hygiene or health and safety stipulations regarding the length of time food can be left out and the temperature range that certain foods must be eaten within.

Q4: (Standard 2: I am at the heart of decisions about my care and support). To what extent do you think the standard describes what people should expect to experience from health, care and social work services?

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Is there anything that is missing or should be added to this Standard?

Again we reiterate the point made in response to question 1, namely that many of the standards under this heading would benefit from the addition of appropriate qualifiers that respect what matters to and is possible for a unique and particular person.

2.11 If I have expressed my own views and choices, these will be respected if I lose capacity.

This standard raises particularly significant ethical challenges and requires careful qualification. Views and choices may change over time even amongst individuals who have lost capacity. When verbal communication is no longer possible, individuals are often able to use non-verbal means to signify a new choice or preference.

2.16 I make informed choices and decisions about the risks I take in my daily life and am encouraged to take positive risks which enhance my quality of life – We reiterate the general point made in response to question 1, and while fully supportive of positive risk taking, would
recommend a slight amendment to this standard to recognise that within a communal living arrangement there may be a need to consider possible risks to others.

Other Comments
2.14 If I am living in a care home, I can receive visitors in private and have a friend, family member or partner to sometimes stay over in the home.

We endorse this standard but question why it does not appear under heading 5, as it seems to relate directly to premises.

Q5: (Standard 3: I am confident in the people who support and care for me). To what extent do you think the standard describes what people should expect to experience from health, care and social work services?

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Comments
While welcoming the emphasis on creating the conditions to support and foster positive working relations between staff, many of the standards under this heading rely on the making of causal connections or conflation of seemingly unrelated aspects of care. For example:

3.1 I experience people speaking and listening to me in a way that is courteous and respectful, with my care and support being the main focus of people’s attention. We feel this Standard brings together two areas which are not necessarily related.

3.17 My needs, wishes and choices are met because I am supported by the right number of people with the right skills and experience. We recognise that this standards is directed towards providers /commissioners, but are concerned by the wording ‘right number of people’ as it is not clear who gets to decide this. We would also emphasise that whilst having the right skills and experience is essential having the right attitude is equally important. The causal connection is particularly problematic in this standard.

3.24 People help me to extend my learning and development, and they ask questions and involve me in genuine dialogue? As above, this standard appears to bring together two areas which are not obviously related. It also makes assumptions about cognition and verbal capacity.

Q6: (Standard 4: I am confident in the organisation providing my care and support). To what extent do you think the standard describes what people should expect to experience from health, care and social work services?

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Comments
Is there anything that is missing or should be added to this Standard?
We recognise the importance of the standards set out under heading 4, understand that they are largely directed at provider organisations
and commissioners and as such are not optional. However, their translation into ‘I’ statements is somewhat problematic and suggests the need for the customary qualifiers to indicate that they may not be important to or possible for many older people living in care homes. We recognise that much depends on how these standards will be interpreted and assessed.

We particularly welcome the provisions made to ensure that staff are better supported. Many of the standards may be important to family members of older people living in care homes. We are slightly concerned by the weighting of the content towards what is expected of the organisation when things go wrong.

Other Comments
4.20 I am supported to reach my full potential by people who are encouraged to be innovative in the way they support and care for me – We support this standard and would welcome the opportunity to contribute to accompanying guidance on how care staff can be encouraged to be innovative.

Q7: (Standard 5: And if the organisation also provides the premises I use). To what extent do you think the standard describes what people should expect to experience from health, care and social work services?

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Q8: (Standard 6: And where my liberty is restricted by law). To what extent do you think the standard describes what people should expect to experience from health, care and social work services?

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Is there anything that is missing or should be added to this Standard?
No comments

Q9: (Standard 7: And if I am a child or young person needing social work care and support). To what extent do you think the standard describes what people should expect to experience from health, care and social work services?

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Is there anything that is missing or should be added to this Standard?
No comments

Q10: To what extent do you agree these new Standards will help support improvement in care services?

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Comments:
We recognise the importance of national care standards and believe they have a significant contribution to make to improvement in care services. As stated throughout our response, much depends upon the way in which the necessarily high level standards are interpreted and applied in the context of the lives of unique and particular persons. The development of guidance to facilitate their implementation in a way that enables the desired ingredients of innovation, flexibility, enablement and positive risk taking will be critical. Alongside the standards themselves, and guidance to support for their implementation, a full package of renewed support to the care home sector is needed including the provision of more training and career development opportunities for care staff.

The perceived purpose of care homes, operational rules, norms, staffing levels, relatives’ health and contributions, together with the influx of people from the wider community all play a significant role in shaping the genuine opportunities that older people living in care homes have to be and do the things that matter to them. Within policy documents, the depiction of care homes as an integral part of future public care provision that can constitute a positive choice is a necessary and important corrective.
Q11: Is there anything else that you think needs to be included in the Standards?

| Yes |  |
| No | ✓ |

Comments:
We simply reiterate the additions highlighted in response to the previous questions, particularly the relative neglect within the standards of the management of transitions, creation of community and end of life care for older people living - and dying - in care homes, and the emotional support for them and their families that is anchored by positive and trusting relationships.

Q12: Is there anything you think we need to be aware of in implementation of the Standards that is not already covered?

Comments:
We recognise that the previous standards have been in place for almost 15 years and that the new standards must be fit for the future. We would welcome clarification about the envisaged timescales for implementation of the more aspirational standards. In addition, many of the standards relate to the adequacy of resourcing. The care home sector is a mixed economy and while an estimated 40% of people currently self-fund their care, the majority do not. Alongside the responsibilities of care staff, provider organisations and commissioners, we conclude by calling attention to our collective responsibilities to ensure the best possible care of older people in the final years of their lives, and to talk about the need for such provision in a way that does not increase the feelings of burdensomeness that many older people experience.

Q13: What should the new Standards be called?

| National Care Standards |
| National Health and Social Care Standards ✓ |
| National Healthcare and Social Care Standards |
| National Care and Health Standards |

Q14: Any other comments, suggestions:
We conclude by thanking those involved in the development of the standards for their efforts and would like to express our appreciation of the considerable amount of thoughtful and constructive dialogue that has clearly taken place.
If you would like to share your views with us or learn more about My Home Life please feel free to get in touch:

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