Response to the Scottish Parliament Call for Evidence on the National Care Service Bill

General questions

- **The Policy Memorandum accompanying the Bill describes its purpose as being "to improve the quality and consistency of social work and social care services in Scotland". Will the Bill, as introduced, be successful in achieving this purpose? If not, why not?**

SPPC is responding to this consultation on the Bill from perspective "how will this improve/impact people's experiences towards the end of life?" Some might view this as too narrow a perspective but SPPC believes that this is a very good litmus test of the proposed legislation because:-

- People approaching the end of life are by far the biggest single group of people receiving social care
- As people approach the end of life they typically move between a range of services (health, social care, community, acute) which requires successful integration
- Social care towards the end of life consumes a large amount of social care funding
- The care which people wish for at the end of life is very individual and demands a person-centred rights-based approach to support dignity and wellbeing. It requires establishing "what matters to you", often in situations where people may have cognitive and communication difficulties and reduced agency
- Care towards the end of life is a near-universal need – we will all die
- Providers of care towards the end of life include NHS, Local Authorities, hospices, other Third sector and Independent sector organisations – a true test for the planning, commissioning, sustainable funding and multi-agency delivery of services

- There is scope for very significant improvement in care for people approaching the end of life.

The Bill has the potential to contribute to improving the quality and consistency of social work and social care services in Scotland. However, a great deal will depend on the detail which the Bill suggests will be developed and included in secondary legislation. Key conditions for improving social care are outwith the scope of the Bill (including the secondary legislation) – most critically the level of funding available to sustain and develop social care services. In addition workforce shortages need to be addressed. There are positive workforce proposals in the Bill. These need to be complemented by additional funding and an enabling UK policy on immigration.

- **Is the Bill the best way to improve the quality and consistency of social work and social care services? If not, what alternative approach should be taken?**

The Bill is primarily about enabling new high level structures and lines of accountability. At best structural changes may be necessary but not sufficient. If real progress is to be made then there is a need to ensure that the well-documented factors which have limited the effectiveness of IJBs are addressed and not simply replicated in the new Community Health and Social Care Boards (CHSCBs). There is a need to consider how to ensure: collaborative leadership; strategic capacity; continuity in senior roles; budgeting and planning which is integrated, long term and focussed on outcomes.

- **Are there any specific aspects of the Bill which you disagree with or that you would like to see amended?**

We would like to see the Bill and subsequent secondary legislation appropriately reflect the fact that people approaching the end of life are the biggest single group needing social care support. Social care, as part of palliative and end of life care, plays a vital role in optimising wellbeing for many people towards the end of life:

- In an average week around 60,000 people receive over 700,000 hours of care at home. Well over half of these are frail elderly people .

- At 31 March 2021, there were nearly 33,353 older people living in a care home. The percentage of long stay residents living with dementia (either medically or nonmedically diagnosed) in a care home for older people is over 60% .
- The vast majority of people in care homes for older people have palliative care needs. The majority of people living in care homes for older people are in their last year of life. Around 20% of deaths in Scotland take place in care homes.
- The next 20 years will see a steady increase in the number of people dying in Scotland each year. By 2040 it is projected that 65,757 people in Scotland will die each year, a 16% increase on 2016. It is expected that on average people will die at an older age – including a 59% increase in deaths of people aged 85+, who will account for 45% of all deaths (up from 33% in 2016). Complexity of need will increase as more people approach the end of life with multimorbidity. This will lead to increased need for palliative care, including social care.
- Individuals' use of health and social care services generally increases sharply with proximity to death, with profound implications for the planning and efficient allocation of scarce resources.

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We appreciate that this is a high-level framework Bill and would not be appropriate to include lots of specific detail about particular conditions, circumstances or demographics of the many different people who need social care.

However, the founding principles of the National Care Service must be clear that in Scotland we continue to 'care' for people even when there is no 'cure' for what ails them. As they stand, the current draft principles are not clear on this, and some of the language used does not easily encompass the provision of care for people who are approaching the end of their life. Examples that particularly stand out are:

1a ii) "enables people to thrive and fulfil their potential"

and

1c “services provided by the National Care Service are to be centred around early interventions that prevent or delay the development of care needs and reduce care needs that already exist”

Most people come to a stage in their life when, with the best support in the world, their care needs cannot be ‘reduced’ and they cannot be described as ‘thriving’ – we must be clear that the NCS will continue to care past this point. To ‘centre’ services primarily around ‘preventing’ and ‘delaying’ and ‘reducing’ care needs cuts out a huge population of the older people who rely on social care.

We propose the insertion of an addition principle such as:

‘Services provided by the NCS will include care and support for people whose health is in irreversible decline through illness or old age and for whom the end of life is approaching.’

Other principles could be amended to be clearer about this, for example:

1c – ‘services provided by the NCS are to be centred around interventions that prevent or delay the development of care needs, reduce care needs that already exist where possible, and support those whose health is in irreversible decline through illness or old age’

A clear and high level incorporation such as this within the principles will help to ensure that this domain is not overlooked during the development of secondary legislation and subsequent implementation.

SPPC believes that end of life should be threaded through all levels of the legislation – beginning with the principles of the NCS, in guidance around strategic planning, in the Charter and should also be an important parameter in decisions around which services to transfer to CHSCBs.

Some might argue that amending the principles is unnecessary and that care for people at the end of life doesn’t need clear and explicit mention. However, language is important. Our experience is that despite being an inevitable and universal phase the end of life is repeatedly omitted in policy and planning. In the current legislation for example, the Scottish Government has published 4 substantial evidence papers in relation to the NCS: Scotland’s

Health and Demographic Profile; People Who Access Adult Social Care and Unpaid Carers; Social Care Support and Service Provision; Social Care and Caring Experiences. None of these evidence papers consider the demographics of dying or palliative care and end of life care.

- **Is there anything additional you would like to see included in the Bill and is anything missing?**

See previous section.

- **The Scottish Government proposes that the details of many aspects of the proposed National Care Service will be outlined in future secondary legislation rather than being included in the Bill itself. Do you have any comments on this approach? Are there any aspects of the Bill where you would like to have seen more detail in the Bill itself?**

SPPC appreciates the intent of Scottish Government's approach is to ensure that people with lived experience of both needing and delivering social care are engaged in determining crucial details of the reforms.

This approach places a real onus on effective co-production. We have some concerns about the practical and ethical challenges of engaging typical users of social care at the end of life in co-production. We are also concerned about the challenges of engaging staff of provider organisations at a time of enormous service pressure. Hospices and other Third sector providers of care need to be involved, alongside statutory partners, in the co-production of detailed guidance (and eventually in strategic planning as part of the new arrangements). Realistic timescales need to be allowed for the co-production of complex detail.

To avoid errors/unintended consequences SPPC would like to see further wide consultation on draft secondary legislation. Adequate time must be allowed for stakeholders to consider and respond, even at the expense of delaying the passage of legislation.

- **The Bill proposes to give Scottish Ministers powers to transfer a broad range of social care, social work and community health functions to the**

National Care Service using future secondary legislation. Do you have any views about the services that may or may not be included in the National Care Service, either now or in the future?

At this stage in the development of the reforms we would wish lead responsibility for all adult palliative care to lie with the new Community Health and Social Care Boards (CHSCBs). This would include all adult specialist palliative care services such as hospices, NHS specialist palliative care units and hospital specialist palliative care teams. In addition Community Health and Social Care Boards should have responsibility for the generalist palliative care delivered by GPs, district nurses, care home staff, care at home staff and general hospital staff – these generalists deliver the bulk of formal palliative care.

The Bill (and Policy Memorandum) say very little about Community Health Services and how (whether) the new governance, accountability and improvement frameworks of the NCS will apply to these NHS services. It is unclear how the apparently dual lines of accountability to Scottish Ministers (for NHS and for National Care Service) will work in respect of services which integrate health care and social care.

Acute hospitals are the biggest single provider of end of life care (around half of all deaths occur in hospital, and 1 in 3 hospital beds is occupied by people in the last year of life). Hospital palliative care is a necessary and valuable component of good care towards the end of life. The relationship between CHSCBs and hospital palliative care is therefore really important, but there is the possibility of a lack of attention/focus by CHSCBs which see their primary focus as being on social care and community health. This is an issue within the current IJB set up.

In addition to formal services we would like CHSCBs to take a public health approach to palliative care, recognising that most care is provided by family, friends, colleagues and community members. CHSCBs can play a role in supporting work to build the capacity of individuals and communities to help each other through caring, dying and bereavement. CHSCBs can also play a role by designing and configuring services as "porous institutions" which are flexible enough to work with and alongside informal care.

- **Do you have any general comments on financial implications of the Bill and the proposed creation of a National Care Service for the long-term funding of social care, social work and community healthcare?**

There is a need for sustainable funding for hospices and other Third sector providers. Such funding needs to ensure a level playing field for recruitment and retention such that Third sector providers are able to compete with SG-funded pay awards and pensions.

Financial memorandum questions

- **Did you take part in any consultation exercise preceding the Bill and, if so, did you comment on the financial assumptions made?**

SPPC took part in the previous consultation, but we did not explicitly comment on the financial assumptions. However, we emphasised the need for an adequate level of funding.

- **If applicable, do you believe your comments on the financial assumptions have been accurately reflected in the financial memorandum (FM)?**
- **Did you have sufficient time to contribute to the consultation exercise?**
- **If the Bill has any financial implications for you or your organisation, do you believe that they have been accurately reflected in the FM? If not, please provide details.**
- **Do you consider that the estimated costs and savings set out in the FM are reasonable and accurate?**

SPPC doesn't have the capacity to assess the costs and savings in the Finance Memorandum. We note the recent analysis of the FM produced by the Fraser of Allander Institute. It is hard to assess what spending has already been committed in relation to social care reform announcements. Whilst there may be adequate funds to implement the very specific provisions of the Bill there will be a need for further additional spending in order to deliver the wider aspirations of the Bill.

We note the high inflation environment and the other cost pressures on providers (and commissioning organisations).

Questions on specific provisions

We welcome the provisions designed to promote information sharing in support of improved co-ordination and quality of care.

We welcome the provisions designed to improve access to short breaks for carers.

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