Health and Social Care Committee Inquiry: Department’s White Paper on Health and Social Care

Written Evidence submitted by Sue Ryder

Executive Summary

Across the UK, Sue Ryder has six hospices and associated community palliative care services, one standalone community palliative care service and four specialist neurological centres. We offer Online Bereavement Support nationally, in addition to that provided by our family support teams in our hospices.

Sue Ryder believes that the policy intentions behind the White Paper are largely positive but it must be noted that an enormous amount of preparatory work and relationship building is needed to make collaboration work effectively and as many other commentators have said, much of this cannot be legislated for. Coupled with huge backlogs in the health and social care system and massive strains across every element of the system due to the Covid-19 pandemic, there is a risk that many of the benefits that are hoped to be achieved will not be felt for some time.

Integration

- The overall move towards integration and horizontal collaboration is welcomed by Sue Ryder. For this to be achieved, it is vital that the new statutory ICS bodies are fully accountable and there is genuine partnership between the ICS NHS body and the ICS health and care partnership. This is a significant opportunity for organisations involved in the ICS partnership to shape service provision and delivery, so time and energy must be spent on ensuring the governance and structures allow this to happen.

- Attention is needed to ensure the new ICS health and care partnership is truly representative, with patient voice embedded in all levels of decision-making. Patient groups and voluntary sector providers like ourselves have high levels of expertise relating to specialised services, and should be treated as equal partners to the NHS. We believe the ICS health and care partnership should be backed by a formal duty to collaborate to ensure this happens.

- Whilst the NHS and its partners should have some flexibility to deliver joined-up care informed by local priorities, there should be a national standard to ensure that all areas of health, social care and voluntary groups are represented, reflecting the needs of the local population they serve.

- The removal of some procurement rules means there is a risk that high-quality voluntary sector providers like ourselves, that are well-placed to meet local needs, are excluded as they are not aware of opportunities to collaborate in areas they do not already operate in. Early and ongoing meaningful engagement with local communities is key to ensuring patient populations have ongoing dialogue in shaping the services that meet their needs.
ICS health and care partnerships are expected to embed provider collaborative leadership arrangements amongst specialist service providers. Yet it’s unclear whether specialist service providers such as ourselves should engage at a place, regional or national level. Without more detail on how collaborative commissioning will work in practice, there is a risk that ICSs will simply become enlarged CCGs.

Greater flexibility at a local level is helpful in terms of population health but does risk geographical variation in care. This can be positive so long as health outcomes are achieved and people do not feel they are subject to a postcode lottery of services. Yet this risk is heightened for rare diseases such as many neurological conditions since their patient populations are too small for a ‘needs-based’ formula of commissioning of care. Therefore, further accountability and safeguarding are needed to ensure minimum national standards are met across the country.

The proposals may help provide more joined-up care across specialised and local services, and the expansion of patient choice rights is welcome. Having said that, with patients sometimes sent across the country for a specialised procedure, the proposals risks budget and accountability disputes between places and trusts. What’s more, considerable expertise is needed to commission care for rare diseases, again requiring a national approach with clear oversight.

It is important to remember that regulation and restructuring alone is not enough to engender integration and collaboration – cultural change is also needed. Whilst the proposals would remove barriers to better integration, ultimately the level of change on the ground will depend on the quality of local relationships – risking further regional variation. There is also a risk of dominance within the ICS partnership by larger providers, which would result in a loss of community and/or population responsiveness currently met by smaller providers and providers from the voluntary sector.

Additionally, the proposals come at a time when the NHS is severely overstretched and there is a danger that more reforms pose disruption, distract from the backlog of treatment, and fail to address the health inequalities laid bare by the pandemic. Whilst legislative changes are an opportunity to progress the integration agenda and bed in new ways of working adopted during the pandemic, in implementing these proposals the health and care system must not be overburdened.

Funding and commissioning

- Defined mechanisms need to be established for the delegation of specialised commissioning budgets to ICS bodies. In particular, safeguards need to be in place to guarantee existing levels of spending on specialised services. Questions remain on how funding for existing services will be allocated to meet population needs. Smaller providers such as ours need urgent clarity on funding allocation or our services will be at risk, impacting people’s care and lives.

- Covid-19 has shone a light on the inequitable basis of the funding model for specialist palliative care. We are grateful that the government partly offset the drop in income we and other independent palliative care providers have experienced as a result of the pandemic, in the form of emergency stand-alone funding. However, a long-term funding
uplift is needed to place the sector on a sustainable footing so we can continue to provide its much-needed services, as part of the wider health and care system.

- The white paper represents an opportunity to review how funding is allocated, alongside how services are commissioned. It is clear that our services are valued and absolutely critical to good quality care, yet for historical reasons the sector relies on the goodwill of the public to fund most of the specialist palliative care we provide. As a result, funding agreements with commissioners merely assist in keeping us afloat rather than strategically plan to meet the current and future needs of local populations.

- In the NHS Long Term Plan, hospices are cited as an example of best-practice personalised care. With the white paper building on and realising the Long Term Plan, and demand for palliative care projected to increase from 245,000 patients in the coming year to 379,000 by the end of the decade¹, hospice funding needs to now be addressed. Without a government commitment to significantly increase levels of statutory funding to cover clinical costs for palliative care services, there is a genuine and serious risk of services being withdrawn and patients and their families losing out on the specialist, holistic support that hospices offer.

- A commitment to fund 70% of total palliative care costs is the minimum required to ensure the sustainability of the hospice sector and these vital services in the medium term. This would cost the government a total of £663m per year. The alternative is likely to be hospice closures, resulting in the overstretched NHS having to provide end-of-life care services at a total cost of £834m per year for the government.

Additional powers for the Secretary of State

- We welcome the attempt to improve the political accountability of the Secretary of State for the performance of the health service. However, along with many others, we believe more detail is needed on the scope, circumstances and oversight of the proposed additional powers for the Secretary of State, and how the government is held to account by Parliament.

- Additional powers should be used to ensure consistency in the development of national frameworks. At present, policies such as NHS RightCare Pathways are not statutory so local systems are not compelled to develop them. This significantly impacts patient populations, especially people with neurological conditions, so further thought must be given to how people who are often left behind by the commissioning process are now brought back into the system so that their needs are met.

Workforce

- Regrettably, the white paper does not address current chronic workforce shortages. In addition, the proposed duty on the Secretary of State to publish a report on workforce planning once every Parliament is too infrequent. Plans should also include firm targets and the Secretary of State should be held accountable for meeting these.

¹ ‘Modelling demand and costs for palliative care services in England’, London Economics, 2021
To read the full report, visit: sueryder.org/hospicefunding
Ultimately, there is an overall lack of strategic, integrated, long-term workforce planning. An overarching approach encompassing all of the health and care system is needed; planning for one part of the system in isolation can actually create more problems for the NHS in the future if social care services and other providers collapse.

Implications for social care

- The white paper fails to address the urgent need for reforms to adult social care in England. We do welcome the stronger central oversight and data collection of adult social care but the pressing need for action on social care cannot be overstated and the government must bring forward its proposals this year. Real integration will never be realised without a long-term funding solution for adult social care.

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