Hospice UK’s submission to the Welsh Government’s consultation on draft regulations to support the implementation of the Mental Capacity (Amendment) Act 2019 and the Liberty Protection Safeguards

July 2022

Hospice UK’s responses to the questions in this consultation can be found below. More information on this consultation, including the draft regulations, can be found here. Information, on the UK-wide consultation, including the draft Mental Capacity Act 2005 (MCA) Code of Practice and LPS regulations, can be found here.

The Mental Capacity (Deprivation of Liberty: Training and Criteria for Approval as an Approved Mental Capacity Professional) (Wales) Regulations 2022

- Do you agree with the arrangements for the approval of the AMCP?

Somewhat Agree.

We support the arrangements for the initial approval of AMCPs but have some concerns around continuing approval and how to ensure consistency in the skills and abilities of AMPCs across Wales. For example, AMCPs must prove to the local authority that they have carried out their functions as an AMCP to an appropriate standard but it is currently unclear how local authorities will define what an ‘appropriate’ standard is and assess the performance of AMCPs. Similarly, there is no clarification on which factors can form the basis of a decision to exempt an individual from further training. Furthermore, annual AMCP refresher training is likely to vary significantly due to it only requiring approval at a local authority level. To ensure consistency, there needs to be clear training guidance from Government as well as a national framework for local authorities to use to assess the performance of their AMCP.

- There are three main types of training that will be provided for AMCPs: conversion training; initial training; and further training. Do you agree with the overall approach being taken to providing training for AMCPs?

Somewhat Agree.

We welcome the commitment to separate training for active BIAs and new AMCPs without a BIA background and that this training will be approved by Social Care Wales. However, as set out above, we are concerned that further training only needs to be approved by a local authority and the possibility that this leads to significant variation in the skills and abilities of AMCPs across Wales.

The approach taken to training AMCPs in Wales could also be improved upon by including a requirement for all training for new AMCPs, and refresher training, to imbue an understanding of the role liberty protection safeguards play in relation to palliative and end of life care and how a hospice environment may impact the LPS process.

It is also important to note that the palliative and end of life care sector is experiencing a staffing crisis, whilst facing significant demand for its services, due to a high number of undiagnosed conditions during the pandemic, which have resulted in complex palliative care needs, and Wales’ ageing and increasing
population. Palliative and end of life care professionals across Wales will struggle to find the capacity to take part in LPS training due to the pressures their services are currently facing.

Hospice UK would be happy to discuss measures to help ease the hospice staffing crisis and the importance of a consideration of future palliative care need within workforce planning with Welsh Government officials, as this is a key barrier to the successful implementation of the LPS.

- With specific reference to further training do you agree with:
  a) the proposed requirement to carry out 18 hours of further training each year?

Somewhat Agree

b) the content of further training being non-accredited and approved by either Social Care Wales or a local authority in Wales?

Somewhat Disagree

As set out above, we are concerned that allowing individual local authorities to approve further training will lead to a lack of consistency in the training provided to AMCPs and the delivery of the liberty protection safeguards in Wales.

Furthermore, whilst we agree in principle with the requirement for AMCPs to undertake an additional 18 hours of training each year we believe there will be significant challenges around implementing this. Hospices, which are typically small community-rooted organisations, primarily funded by charitable donations, will struggle to relinquish the staff capacity for AMCP training. On average, one third of adult hospice and one fifth of children’s hospice funding is from statutory sources and the instability of their funding creates pressures on staff and volunteer time. Hospices and other small independent providers will require Government support to enable their staff to dedicate time to AMCP training.

It is also hugely important that training for new AMCPs, and refresher training, includes information on how the LPS system will take place when the person deprived of their liberty has palliative and end of life care needs and on the process within a hospice context.

- Do you agree the draft Regulations should enable local authorities to work together with their partners to put in place regional or national arrangements for the approval of AMCPs?

Somewhat Agree.

The draft regulations do provide flexibility for local authorities, responsible bodies and other partners to create local and national systems for the approval of AMCPs. However, this also means that there is no clear system of governance or measures to ensure that AMCPs work to the same standards across Wales.

We suggest that guidance be published alongside the draft regulations outlining how local authorities can put in place regional arrangements for the approval of AMCPs through their exiting Regional Partnership Board and Public Services Board structures. Furthermore, this should detail how hospices and other third sector partners in palliative and end of life care are involved in this process.

The Mental Capacity (Deprivation of Liberty: Monitoring and Reporting) (Wales) Regulations 2022

- Do you agree that the draft Regulations on monitoring and reporting are clear and sufficient?
Somewhat Disagree.

We are pleased to read that there will be a Monitoring and Reporting Strategy informed by consultation with stakeholders. It is hugely important that Hospices Cymru, a group of all the hospices across Wales, is included in this consultation process and that the strategy considers, and responds to, the specific challenges hospices will have with providing the information on LPS implementation that Monitoring Bodies will require.

The most significant challenge we have identified with the draft Regulations on monitoring and reporting is that around the designation of Health Inspectorate Wales (HIW) and Care Inspectorate Wales (CIW) as Monitoring Bodies. Currently, some hospices, such as City Hospice in Cardiff, fall outside the CIW and HIW regulatory regime and other hospice services are only partially regulated by these bodies. This is a long-standing issue which Hospice UK and Hospices Cymru are working to resolve in the longer-term. However, in the short term, clarity is needed on whether hospice services that fall outside of existing HIW and CIW regulation will be able to have their implementation of the LPS process monitored by these bodies.

Typically, around one third of adult hospice and one fifth of children’s hospice funding is provided by the Government, with hospices having to make up the shortfall through bake sales, marathons and other fundraising endeavours. The lack of a sustainable funding model for hospices makes it challenging for them to invest in innovation and reforms that benefit the wider system, such as data collection. Recent research by the Nuffield Trust found that many hospices do not routinely capture information about patients, including ethnicity and other protected characteristics due to limited resources. For this reason, hospices will need significant support from Government, Responsible Bodies and/or Monitoring Bodies to collect any data that the LPS Monitoring and Reporting Strategy requires.

The strategy should also recognise the strain that multiple requests for data can have on small independent health and care providers, such as hospices, and encourage Responsible Bodies to align their requests for information with the timescales of other data requests these organisations have to submit. Any resource demands on hospices associated with collecting data should also be recognised in the Workforce Plan and Training Framework and statutory funding hospice contracts.

**Broader consultation questions regarding the implementation of the LPS in Wales**

- As part of the RIA, we have included proposed data items for the LPS National Minimum Data Set – which is currently being developed. Do you agree with the data items included in the draft LPS National Minimum Data Set for Wales?

Reporting data to Responsible Bodies is a key area where small independent hospices will struggle to implement the LPS process and require extensive support from the Welsh Government. A recent report by the Nuffield Trust revealed systemic challenges in collecting data across the hospice sector, which are driven by capacity and resource constraints, and a lack of agreed definitions and standards for hospice activity.

Many hospices do not have the infrastructure in place to collect the National Minimum Data Set data and will need support from Government to improve their data collection and handling. Furthermore, hospice statutory funding contracts and national workforce planning must recognise the resource demands associated with collecting the National Minimum Data Set data. Responsible bodies should seek to make it easier and less time consuming for small organisations, such as hospices, to collect this data by aligning their requests with other requests for data and information these organisations receive from their local systems and utilising terms and data sets that are commonly used across the health and care system.
We have issued a draft Children’s Rights Impact Assessment (CRIA) for consultation alongside the draft Regulations for Wales and the draft Regulatory Impact Assessment. Do you agree with our assessment of the impacts of the LPS Regulations on children’s rights set out in the CRIA?

The extension of the LPS process to the home and its associated scrutiny will be very challenging for the families of young people. There is also the potential that families of young people may not see a situation as a deprivation of liberty or that they might create barriers to health and care professionals carrying out the LPS process, for example, by refusing entry to their home. We are therefore pleased to read that supporting materials will be developed for young people, their families and the appropriate person to share information on the LPS process.

Difficulties may also arise around assessments of young people performed by staff who do not have a personal relationship with the child or palliative care experience. Assessors within the social work profession could also provoke fear in the families of young people, making them worried that their child could be taken away. These challenging scenarios need to be recognised and addressed within training for health and care professionals on the LPS, training for AMCPs and central resources/guidance on the LPS process produced by Welsh Government.

Welsh Government is currently engaging separately on a Workforce Plan and Training Framework – and a summary of this is included in the RIA. Do you agree that the LPS Workforce Plan and Training Framework will promote and embed person centred planning?

Neither Agree nor Disagree.

We are concerned that hospices in Wales will not be able to effectively train their staff in the new LPS process or have the capacity to deliver it due to significant workforce shortages. The palliative and end of life care sector is facing chronic workforce shortages and demand for its services remains higher than ever. This demand is driven by the numerous conditions that went undiagnosed or treated during the pandemic, increasing the need and complexity of palliative and end of life care, as well as the UK’s ageing and increasing population.

A Hospice UK survey of UK hospices, conducted in Spring 2021, found a 11% vacancy rate in community-based nursing roles and 7% vacancy rate in hospice-based nursing roles in adult hospices (with 16% vacancy rates for hospice-based nursing associate and community-based healthcare assistant roles). These vacancies are representative of what is affordable within current funding rather than the level of staffing actually required to meet population need. Furthermore, since this data was collected, the staffing situation in hospices across the UK has become much worse.

These reforms also focus on incorporating LPS thinking as early as possible in existing care planning, disproportionately increasing the workload of the community-based workforce. Unfortunately, this is where the palliative and end of life care sector is most under strain. There have been over 100,000 additional deaths at home across the UK since the beginning of the pandemic. In Wales alone, there have been over 5000 deaths at home in 2022 so far, making up 30% of all recorded deaths. This has rapidly increased the need for palliative and end of life care in people’s own homes.

Mental capacity also fluctuates enormously at end of life, which means the specialist palliative and end of life care workforce will need to ensure new capacity assessments, medical assessments and necessary & proportionate assessments are all undertaken when they complete the LPS process for a patient in their care, which will be very time consuming. The high pressure on the health and care workforce, and in particular the palliative and end of life care workforce, as well as the capacity demands
of the LPS process make the Workforce Plan and Training Framework crucial to the successful implementation of the LPS process within palliative and end of life care sector.

It is also vital that the Plan and Training Framework is informed by the needs of non-NHS health and care providers implementing the LPS process, such as hospices. We are pleased to see a mention within the draft explanatory memorandum of the importance of understanding the number of people supported by independent hospital services, including building-based hospice services, in mapping the workforce needs associated with future LPS demand. This assessment of the potential demand for LPS authorisations must also look at projected future demand, rather than just present demand, and consider the rising need for palliative and end of life care over the coming years and any likely associated increase in LPS authorisations.

Work to understand the number of people supported by hospices should not solely assess the workforce needs associated with undertaking the LPS process in hospice in-patient units, but also examine need in the community, where 90% of hospice care for adults in Wales is provided. Assessments of future demand for LPS authorisations should also account for the expectation that patient preference for palliative care in the community is set to continue and palliative care and care at home capacity will need to double by 2040 to meet projected demand. Furthermore, clarification is needed on whether hospice services that sit outside of CIW and HIW regulation will be included in these assessments.

The majority of hospices are small, community-rooted, primarily charitably funded organisations with limited resource. Therefore, they will need significant Government support to implement the Workforce Plan and Training Framework and ensure their staff are trained in the LPS process and their role within this. Only one third of adult hospice and one fifth of children’s hospice funding is from the Government and therefore the sector will require more support than most to develop and roll-out training specific to the hospice and palliative and end of life care sector. At a minimum, Welsh Government must ensure that the Framework and any training resources are not overly focused on the LPS within NHS services and sufficiently support the independent and charitable sector.

Whilst hospices will need support with implementing the LPS process, they are also valuable asset to upskilling their colleagues across the health and care system. Hospices and other specialist palliative and end of life care providers have significant expertise in supporting the people they care for with Advance Care Planning. This expertise should be harnessed by Social Care Wales and local authorities when devising and delivering training in person centred-planning.

Finally, we would like to emphasise the importance of ensuring a Quality Improvement approach is taken when developing all training on the LPS process to enable it to continue to improve and develop as it is rolled-out.