

**Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)**

**This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)**

**HSC PSS 137**

**Ymateb gan: | Response from: Leonard Cheshire**

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## Question 1: Initial priorities identified by the Committee

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

### Q1. Which of the issues listed above do you think should be a priority, and why?

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

All the priorities identified by the Committee are worthy and appropriate, and indeed many are interdependent. In particular, a valued health and social care workforce, whose wellbeing needs were effectively addressed, and which was supported with effective organisational culture would be of immense benefit in enabling public health and prevention, access to Covid and non-covid rehabilitation services, access to services for long-term chronic conditions, etc. This makes it challenging to judge potential priorities issues against one another. Nevertheless, there are a number of specific issues which we would recommend that the Committee focusses on, as set out in our answer to question 2.

In terms of its ways of working, we would strongly recommend that the Committee actively and consistently seeks to enable and empower disabled people to participate, and have a voice, in all of its inquiries- regardless of whether they are explicitly related to disability. Leonard Cheshire (and we anticipate many other third sector organisations) would be very happy in assisting the Committee in this regard, not only through its own engagement with Committee inquiries, but also by assisting the Committee and its Members in engaging directly with disabled people through our own networks. The Committee may also want to consider the Measuring the Mountain (<http://www.mtm.wales/>) methodology which gathered people's stories (450+) of their experiences of using health and social care services, as well as hosting Citizens' Juries. We would recommend that this takes place over the whole five year term of the Committee. We would also welcome the Committee taking efforts to ensure that it hears from a wide diversity of witnesses over the course of its inquiries and evidence gathering.

We would also welcome the Committee undertaking post-legislative scrutiny at appropriate junctures. The Committee is uniquely positioned to follow up on previous Welsh Government commitments. For example, the Committee may wish to consider further scrutiny of the Welsh Government in relation to the Social Services and Well-being (Wales) Act 2014, following up on the findings of its predecessor that:

“For so many that we heard from, the Act has failed to have any meaningful impact on their lives. Problems with assessments, inappropriate services and inconsistent information and advice have resulted in carers telling us that they feel forgotten about, undervalued and desperate.”

In particular, the Committee may wish to consider how such legislation has been practically implemented during the course of the pandemic, and in the recovery from such.

## Question 2: Key priorities for the Sixth Senedd

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

- a) health services;
- b) social care and carers;
- c) COVID recovery?

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

a) Health services

Leonard Cheshire would welcome **an inquiry into the merits of integrating health and social care funding**. We believe a robust health service needs a robust social care system. The social care sector has warned that greater emphasis needs to be placed upon creating a holistic and cohesive service, that puts the person at the heart of their care plan. Leonard Cheshire believes that uniting the health and social care services and funding streams will lead to improved wellbeing in the community; minimised competition between the two sectors for adequate funding; fewer delayed hospital discharges; fewer inappropriate care assessments and packages; and streamlined services that prioritise patients' wellbeing alongside their health. This may be related to the Committee's potential priority of the health and social care workforce.

A particular aspect of an inquiry into the integration of health and social care funding would be the potential for increased transparency and communication between different services. For example, current where individuals have had a prolonged hospital stay before being placed in social care services social care assessments can be misleading or inflexible (e.g. a person is experiencing delayed discharge whilst funding is being agreed social v health funding ). Individuals also have different levels of support whether they have a health need or a social need and this leaves some individuals without adequate social support due to having funding from health and then the social need is not funded as a result. There are also many professionals in duplicated meetings discussing decision tools over who funds the individuals, time better spent on professionals working on other areas of work or focussing on outcomes for the individual rather than who funds their care and support in community or residential setting. This could be addressed through integration of funding, enabling a more streamlined assessment of the care an individual needs, uncomplicated by disagreements over whose funding will be utilised. This also reflects a particular concern of Leonard Cheshire's Swansea-based Disability and Inclusion panel, that social care practices are too focused on cost, and disregard individual need.

We would welcome a review on some of the current challenges of funding not being integrated and the benefits and efficiencies that could be created with full integration of funding. Improved tendering of services for health and social support rather than funding being given to LHB or LA for specific projects and services and this happens to frequently rather than being offered as a competitive process to third sector organisations.

#### b) Social care and carers

Leonard Cheshire would welcome **an inquiry into Wales' social care workforce**. Leonard Cheshire believes that Wales' social care workforce remains undervalued and understaffed. We believe that there is a desperate need to improve the profile of social care and retain staff whilst reducing shortages. Urgent intervention is needed to stabilise and improve prospects for the social care workforce in Wales. Partnership working has been vital during the last 18 months but can be problematic to maintain when short-term funding mechanisms prevail. We believe that the Committee could have particular impact in maintaining the profile of this issue. This may be related to the Committee's potential priority of the health and social care workforce.

This is not a unique issue to Wales- indeed the World Health Organisation has estimated a worldwide shortfall of 18 million health workers by 2030. Nevertheless, the fact remains that since 2009, funding for social care in Wales has been declining per capita, leading to inconsistency across services, poor staff retention and inadequate and delayed care packages. Social care is therefore in a funding crisis, and many of its services are at breaking point.

While the legislative framework in Wales positively focuses on early intervention and sustainability this needs to be reinforced with:

- adequate and substantive funding by the Welsh Government,
- a better understanding of what helps communities achieve well-being, and
- further consideration of how the Welsh Government can encourage social care organisations to work collaboratively.

Wales is due a social care revolution – one that is person-centred, properly funded and which celebrates its workforce. Staff turnover rates in Wales are still relatively high: calculated to be 13% in 2019, equating to 194 carers leaving the profession per year.

This also has a negative impact on individuals in receipt of social care, who cite relationships and continuity of carers as one of the most important elements of good quality social care. With such

a high turnover rate, and low retention levels, urgent intervention is needed to stabilise and improve prospects for the social care workforce in Wales.

The need for effective social care is undeniable. It is estimated that 500,000 adults aged 18+ will have a limited long-term illness in Wales by 2035, and 312,000 adults aged 65+ will be unable to manage at least one self-care activity on their own. To keep up with the increasing and persistent demand, the social care sector needs to be flexible, and adaptable to new changes and ways of working.

The impacts of Covid-19 have further demonstrated the need for greater clarity for the sector and increasing pressures on staff to meet demand.

We would also welcome the Committee undertaking an **inquiry into awareness of direct payments**. Since the mid-1990's, recipients of social care have been legally entitled to a choice about whether to receive funding in the form of direct payments (by which they can privately pay for care), or for funding to be channelled through local authorities. Both options have supporters and critics. However, many disabled people state that they are unaware that they even have a choice, removing an opportunity to exert control over their own lives.

In the financial year 2018-2019, 75,741 individuals aged 18 or over received social care services from their local authority. However, only 6,262 individuals utilised direct payments.

This indicates that approximately 69,479 individuals were not receiving direct payments as their preferred form of care, and that only 8.3% of disabled people in Wales used direct payments.

Leonard Cheshire would like to see Local Authorities offering more choice and options for the use of Direct Payments which can provide better support and more flexibility over their use. Programmes like Together as One offered by Leonard Cheshire is a blended approach to pooling, enabling individuals to have choice, control and more autonomy over how they use their direct payment, this in turn is breaking down the barriers and challenges to receiving a direct payment. Local authorities need to be more innovative in their approach to social support to increase uptake of direct payments and allow individuals to have a choice. We would urge the Committee to review what changes need to happen in the local authorities cultures for them to enable more uptake of direct payments.

### c) COVID recovery

We would welcome the Committee's consideration of **Mental Health Services** in the context of Covid recovery. Mental wellbeing amongst disabled people is currently in decline, and has worsened as a result of isolation and lockdown restrictions. The UN Office of the Commissioner for Human Rights identified that disabled people were one of the most adversely affected groups, with societal, environmental and attitudinal barriers being present. Disabled people are more likely to have been shielding and to have had a number of their rights eroded by residential health settings and legislative changes. The Mental Health Foundation found that a higher proportion of people with long term disabling health conditions reported having difficulty coping (26%) compared to the overall population (14%). They were also more likely to have been worried that the pandemic may make their existing mental health condition worse (46%)<sup>1</sup>. Furthermore, this group were more likely to be more anxious, panicked, afraid and lonely.

Unfortunately, during the pandemic several of the support lines and information support systems previously available have been suspended. This was presumably to reduce contact and direct worker capacity to coronavirus related work, and favoured methods of information-sharing that takes place online. However, for disabled people digital technology can be challenging, and often disabled people do not have access to the internet or devices they can use to access. Our view is that use of digital technology this should not remain the 'norm,' as we anticipate many people will wish to attend drop-in sessions and meetings.

A key finding from a survey conducted by Leonard Cheshire on the effects of Covid-19 on disabled people and their carers in Wales<sup>2</sup> was that disabled people did not feel they have adequate access to information during the pandemic. This led to fear and anxiety, particularly in relation to care and support packages. A member of our Citizens' Disability and Inclusion Panel in Swansea stated that: "a lot of disabled people often struggle with digital technology, so it can be difficult to get support when we need it."

We would also welcome the Committee's consideration of **the facilitation of physical activities in a post covid recovery**, especially for disabled people who have been inadvertently segregated from their communities. Sport Wales and Public Health Wales noted in '*Getting Wales Moving*' (2017) that "while many people would like to be more physically active, they often face substantial physical and social barriers in doing so."<sup>3</sup> Such barriers have only increased as a

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<sup>1</sup> Mental Health Foundation. 2020. Coronavirus: The divergence of mental health experiences during the pandemic. Link: <https://www.mentalhealth.org.uk/coronavirus/divergence-mental-health-experiences-during-pandemic>

<sup>2</sup> Leonard Cheshire. 2020. A survey to assess the effects of Covid-19 on disabled people and carers in the UK – Wales statistics. March 2020 – June 2020.

<sup>3</sup> A joint report by Sport Wales and Public Health Wales '*Getting Wales Moving*'. (2017) Link: <http://www.wales.nhs.uk/sitesplus/documents/888/Getting%20Wales%20Moving%20V1.pdf>

result of the pandemic. In particular, the Committee could consider the strategic role of the Welsh Government in enabling gyms and outdoor exercise equipment that cater to all.

Finally, it may be noted that in Leonard Cheshire's survey into the impacts of Covid-19 on disabled people, one of the key messages we identified was a fear of social care hours being cut due to shortages, and lack of funding. Disabled people in Wales should not have anxiety relating to their provision of social care: even less so during a global pandemic. If Wales is to align with the goal of 'a healthier Wales' as set out in the Well-being of Future Generations Act (2016), then prioritisation of social care needs to be addressed. This reinforces the need for an inquiry into Wales' social care workforce, as set out in our response to question 2b.

### Question 3: Any other issues

#### Q3. Are there any other issues you wish to draw to the Committee's attention?

Leonard Cheshire is particularly concerned that Covid-19 had steadily eroded of **the rights of disabled people** on a national and international scale. A number of our care services received letters from local GPs referencing Do Not Resuscitate orders for their service users. This caused a great deal of distress for the families, loved ones and carers who support these individuals on a daily basis. One of our Service Managers commented that:

*"We've had some residents who needed to go into hospital, but the response has been that because of the risk in hospital, that they should remain at the service. I have spoken to some really upset family members, where their GP had contacted them directly to look at putting DNRs in place for residents. This was not a nice conversation for family members to be having. It was really upsetting for me to hear the distress these families were experiencing."*

This is not an isolated incident. Through our continued engagement with the Disability Equality Forum, we have heard of other DNRs that have been issued to members of the public, both in care settings and in the community. This is a prime example of disabled people having decisions made about their health and wellbeing without including them in the discussion. It is imperative that disabled people have voice and choice in discussions around their health and care, and this fundamental right was eradicated when DNR orders were sent without their knowledge, nor their families' knowledge.

We believe this pandemic has afforded Wales with a prime opportunity to enshrine the UNCRPD in law. The Equality and Human Rights Commission has similarly recommended that *"The Welsh Government should build the CRPD into legislation in a similar way to the UNCRC, and use opportunities afforded by the Well-being of Future Generations Act to promote the CRPD."*

More generally, it may be noted that a wide range of factors impact on health and well-being, including housing, digital inclusion, transport and employment. Preventative care measures also include a diverse range of services including Disability Service Grants, Wheelchair provision, Mental health services, Hydrotherapy, Physiotherapy, Prevention Therapy, Supported social visits,

and Digital Inclusion and skills. We recognise that many of these factors go beyond the remit of this Committee. Nevertheless would recommend that the Health and Social Care Committee works with other Senedd committees, and relevant Cross-Party Groups, to consider health inequalities: both for the public in general and specifically for those with protected characteristic(s). In particular Senedd committees could examine the extent to which Government departments are working together to improve health and wellbeing outcomes across the population.

Finally, we would welcome all efforts that the Committee can make to being accessible in its work, including explicitly welcoming evidence being provided through varied means, such as video case studies. The Senedd Commission's guide to "[Getting involved with committees](#)" could usefully be refreshed in this regard.

### **About Leonard Cheshire**

We are Leonard Cheshire – supporting individuals to live, learn and work as independently as they choose, whatever their ability. Led by people with experience of disability, we are at the heart of local life – opening doors to opportunity, choice and support in communities around the globe.

Leonard Cheshire is one of the UK's largest voluntary sector providers of services for disabled people. We work in local communities to provide people with opportunity, choice and support. We have accommodation services – including supported living and registered care homes; and social, education and leisure services – including day support, community outreach services and respite support.