

Supporting people with chronic conditions

The Association of Directors of Social Services (ADSS) Cymru is the professional and strategic leadership organisation for social services in Wales and is composed of statutory directors of social services, the All-Wales Heads of Children’s Service (AWHOCs), the All-Wales Adult Service Heads (AWASH) and tier three managers who support them in delivering statutory responsibilities: a group which consists of over 300 social services leaders across the 22 local authorities in Wales.

The role of ADSS Cymru is to represent the collective, authoritative voice of senior social care leaders who support vulnerable adults and children, their families, and communities, on a range of national and regional issues in relation to social care policy, practice, and resourcing. It is the only national body that articulates the view of those professionals who lead our social care services.

As a member-led organisation, ADSS Cymru is committed to using the wealth of its members’ experience and expertise. We work in partnership with a wide range of partners and stakeholders to influence the important strategic decisions around the development of health, social care, and public service delivery. Ultimately, our aim is to benefit the people our services support and the people who work within those services.

General Comment

ADSS Cymru welcomes the opportunity to contribute to the Health and Social Care Committee’s inquiry into supporting people with chronic conditions. A key driver within both the *Parliamentary Review of Health and Social Care in Wales* and *A Healthier Wales*, was that a medical/clinical model of health, and a separate system of social care, is not a model for delivering high quality, person-centred care fit for the future. Moreover, the expectation in both documents, whether that is the focus on the ‘Quadruple Aim’ in the Parliamentary Review or on the set of ‘Once for Wales’ design principles in a Healthier Wales, is that the most significant opportunity to create a system fit for the future is if we shift the balance of our health and care system towards earlier detection and intervention, which is designed to prevent illness and prolong independence. By doing this and ensuring people have a greater stake in managing their own health and wellbeing in the process, we will have a more sustainable and resilient health and care system, as well as improved public health outcomes for the citizens of Wales.

Lifestyles and people’s expectations of wanting to do and achieve more in life has continued to progress and evolve. People with complex health conditions, physical disability or impairment, are living longer because medicine is doing so much more to allow them to live and experience good quality of life. Coupled with this is the fact that technology is also transforming the way we live, allowing diagnostics, treatment and monitoring to take place

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away from clinical settings and into hubs in the community and even into people's own homes. Treating people in hospitals when they are symptomatic is only a small part of a modern health and social care system. Keeping people well, independent and resilient at home, in their community, is an outcome a fully integrated health and social system must strive to achieve.

What is the role of social care in supporting people with chronic conditions?

As leaders in social care, we know the sector plays a crucial role in supporting both children and adults with chronic health conditions, by providing a range of services that aim to enhance their overall well-being, independence, and quality of life. Some of the ways in which social care supports individuals with chronic health conditions, includes:

1. **Assessment and Care Planning:** Social care professionals assess the strengths, capabilities and needs of individuals with chronic health conditions to develop personalised care plans. These plans take into account the specific challenges posed by the condition and outline the support required, such as assistance with personal care, mobility, medication management, and emotional support.
2. **Personal Care:** Social care providers offer assistance with daily activities such as bathing, dressing, meal preparation, and managing medication. This support helps individuals with chronic health conditions maintain their personal hygiene, nutrition, and medication adherence.
3. **Coordination of Care:** Social care professionals communicate and collaborate with healthcare providers, community third sector organisations, and other relevant stakeholders to ensure a coordinated and holistic approach to care. They help individuals navigate the healthcare system, manage appointments, and coordinate different aspects of their care to promote continuity and effectiveness.
4. **Emotional and Psychological Support:** Living with a chronic health condition can be emotionally challenging. Social care workers provide emotional support, counselling, and personal empathy to help individuals cope with the psychological impact of their condition. They may also facilitate support groups or connect individuals with appropriate mental health services.
5. **Socialisation and Community Integration:** Social isolation is a common issue for individuals with chronic health conditions. Social care services offer a range of day opportunity activities and support groups to encourage socialisation and combat

loneliness. They may also help individuals connect with local community resources and organisations that cater to their specific needs.

6. **Support for Carers and Family Members:** Social care recognises the important role of unpaid carers and family members in supporting individuals with chronic health conditions. They assess individual need and provide guidance, respite care, and training for unpaid carers to ensure they have the necessary skills and knowledge to provide effective care while also addressing their own well-being.
7. **Advocacy, Information and Advice:** Social care professionals can act as advocates for individuals with chronic health conditions, helping them access appropriate healthcare services, benefits, and support systems. They provide information and guidance on available resources, rights, and entitlements, empowering individuals to make informed decisions about their care.
8. **Housing and Accommodation Support:** Social care services can work collaboratively with colleagues in other local government departments, to assist individuals in finding suitable housing options that accommodate their specific needs, such as accessible housing or supported living arrangements. They may also provide support with home modifications or assistive technology to promote independent living.

All these elements focus on enabling people to live and, in some circumstances, die well, with their chronic conditions.

New models of care have been developed which recognise the complexities of managing care where there is overlap between the wider community, the health care system and provider organisations, for example, the Expert Patient Programme. These new models indicate a shift away from the idea of chronically ill people as passive recipients of care, towards active engagement, in partnership with health and social care professionals, in managing their own personal care needs.

This partnership, ideally, involves collaborative care and self-management education because for effective person-centred care to be established, individuals should be able to discuss their own ideas about self-care actions, including lifestyle management, in an open and thorough way. If they are unable to achieve that independently, then they should be enabled to have these What Matters conversations through the supported advocacy.

Crucial to enabling personalised, self-managed care, is the need for individuals to have information from the point of diagnosis. It is important that the individual, and where appropriate, their unpaid carers and family members, have active participation during those

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initial encounters with health and care practitioners. For self-care needs to be addressed, opportunities for individuals to talk about their diet, routines and lifestyle management, need to be incorporated into the encounter. Care plans can help to facilitate this discussion. However, what is vitally important to support individuals with their self-care management is the recognition of the value of the person's knowledge and experiences.

Supporting a child with chronic health conditions

It is essential that we understand the daily lived experiences of a child to inform care planning. Whilst the voice of the child is important in developing self-managed care support, in the context of their age and stage of development, the voice of the carer is also crucial. Managing the physical and emotional needs of a child with a long-term health condition can be highly demanding for unpaid parent carers, particularly for older parents, who may have health issues of their own and parent carers who have other children they have a caring responsibility for. Young carers also play an important role in supporting siblings with chronic health conditions which can have a significant impact of their health and wellbeing.

Children with common chronic health conditions are twice as likely to suffer from emotional problems or disturbed behaviour especially if their condition affects their brain. There are also specific challenges for children who have suffered neglectful childhoods. These children are more frequently diagnosed with chronic conditions linked to poor parental care. Many will also have other behavioural needs as a result of attachment issues and traumatic experiences they have faced.

There is an increasing recognition that some long-term conditions caused by neglect and abuse, such as Foetal Alcohol Syndrome, are under diagnosed. Such health conditions can be difficult to diagnose, and it can be impossible to predict their long-term impact or what support might be needed in the future. Under diagnosis can be a barrier to children and their carers accessing the right support at the right time.

Children with long-term health conditions often need daily on-going medication and monitoring. Their condition can lead to them being away from school for long periods of time which can result in their learning being delayed.

At school and around other children, a child might feel that their condition makes them different to others and as a result develop anxieties about their condition and compromise their mental health. They might have fewer opportunities to learn everyday skills and to develop their interests and hobbies. Some children have barriers to engaging in treatment or care due to their traumatic experiences. As they move into adolescence, their behaviour can become unpredictable and unsafe, which leaves them at risk to complications of not taking medication or following treatment. Moreover, not accessing diagnosis and treatment in a

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timely way can increase their likelihood of involvement with the criminal justice system, which can have a detrimental impact in their future adult life. Therefore, it is crucial that a multi-Disciplinary approach is undertaken between health and social care professionals so that the child and their parent-carer/guardian feel supported.

Identification of key themes for the Committee to explore

ADSS Cymru believes that the inquiry needs to examine a number of key themes and factors in its work to ascertain whether the mechanisms that are in place to support both children and adults with chronic conditions are robust, sufficient and operate well in practice.

Understanding the myriad of complexities that are at play is crucial. Chronic diseases, including cardiovascular disease, cancer, chronic respiratory diseases and metabolic syndrome (hypertension, diabetes, dyslipidaemia) have been on the increase in the UK over recent decades and result in a substantial economic and social burden.

Added to this is the exponential rise of people with chronic mental ill-health and poor mental well-being. This has been exacerbated following the impact of the COVID-19 pandemic. The knock-on impact to society is that for many of our children, we have seen an increase in traumatic stress, leading to more behaviours that challenge and for our young people, the taking of greater lifestyle risks, like substance misuse. For adults, particularly older adults, we are seeing higher levels of substance use disorders, emanating from the impact of the abuse of alcohol, as well as a wide range of social and prescription drugs.

These factors not only directly contribute to additional demand in the system, which has been considerably outstripping the supply of health and care support that can be provided but they also provide health and social care professionals with complex scenarios that need to be overcome with resolutions broader than just lifestyle advice and signposting.

What are the barriers to optimised levels of support?

COVID-19 Impact

The COVID-19 pandemic has brought into sharp focus not just the essential value that social care plays to society but also the myriad of challenges that currently face the whole social care sector in Wales.

It is widely accepted that key areas of social service functions are experiencing challenges in a system that is facing unprecedented levels of complexity and demand. This, combined with fundamental workforce shortages, has exposed an already fragile situation. The reasons for this include:

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- Pent up demand suppressed during the COVID-19 pandemic and periods of Lockdown causing significant pressures on systems and escalations in need when demand is not met in a timely preventative manner.
- Increased complexity and frailty in older people from reduced prevention, medical care, increased waiting lists and a greater level of community isolation
- Pressures in the primary care system restricting access to key healthcare professionals and timely diagnostics that can reduce the escalation of healthcare need through early intervention
- A vicious cycle of delay and deconditioning/decompensation in hospital because of delays and shortages in key healthcare roles to ensure timely discharge
- Exhaustion across the social care workforce with more frequent early retirements and people leaving the sector to pursue other careers
- Increased wages and competition from sectors such as retail and hospitality
- Difficulty in recruiting and retaining social workers – particularly in children’s services - in sufficient numbers across the sector and systemic challenges in working with agencies both in terms of cost and competence.

Specifically in children’s services, we have seen not just an increased demand for services but the sheer complexity of those support needs, particularly in mental health and emotional well-being, is vast. These issues are now being further exacerbated by the cost-of-living crisis, which is placing extreme pressure on individual and family finances. We are already seeing the associated increases in poverty, unemployment, isolation, domestic abuse, family breakdown, anti-social behaviour and homelessness. These issues make it very difficult to effectively support and manage the needs of children with chronic conditions. The consequence is that more children, young people, and parents will require more services across the spectrum of need.

Financial Pressures

The Welsh Government have identified that the health and social care system is under significant pressure. Whilst we welcomed the increased uplift of £165m, accompanied with the recurrent provision of £70m for the Real Living Wage in the Government’s 2023-24 budget, it is evident that very difficult choices will have to be made in relation to continued service provision.

We know from survey work undertaken in the autumn of 2022 by the Welsh Local Government Association (WLGA) in collaboration with our members and the Society of Welsh Treasurers (SWT), that forecasts indicate that social care across Wales is facing a considerable financial challenge in 2023-24 and 2024-25. The pressure in both adults’ and children’s

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services includes the challenge of recruitment and retention of staff with this issue also affecting commissioned services from providers.

Local authorities are projecting an estimated total cumulative pressure for social services of £407.8m for 2023-24 and 2024-25. Within this overall social services total, the estimated total commissioning cost and demand pressures are £288.4m, with a pay inflation pressure totalling £75.8m for the two years.

Summary of Social Services Pressure 2023-24 and 2024-25

	2023-24 £000s	2024-25 £000s	Total £000s
Pay inflation pressures	51,858	23,918	75,776
Non pay inflation pressures	20,712	12,423	33,135
Fees/charges inflation	(2,677)	(2,192)	(4,869)
Commissioning cost pressures - Adults	86,939	55,201	142,140
Commissioning cost pressures - Children's	14,066	10,449	24,515
Demand related pressures - Adults	35,980	29,462	65,442
Demand related pressures - Children's	37,235	19,104	56,339
Reduction in specific grants	5,914	1,646	7,560
Local priorities	4,418	1,651	6,069
Other	1,699	0	1,699
Overall Total	256,144	151,662	407,806

Source: WLGA/SWT Survey September 2022

Further detail and commentary on our financial concerns can be found in our response to the Senedd's Finance Committee scrutiny of the Welsh Government's Budget of 2023-24.

However, it is clear that with wider concerns about NHS financial pressures due to waiting list demand, acute care demand and the increases in day-to-day running costs due to inflation, energy increases etc., a whole systems change is required. We need to move away from dealing with acute need to the effective management of chronic conditions in the community – in its broadest sense. There needs to be a focus on early access to health and social care professionals, so that timely diagnosis can be made, leading to the right size package of care and support being put in place quickly. Essentially, right time, right place, right professional at pace.

Workforce

The impact that the COVID-19 pandemic has had on the social care workforce has been wide-ranging and profound. The lustre of public support during the pandemic has long since faded and the workforce that remains feel exhausted, unappreciated and are questioning their long-term future in the sector. The issue of workforce recruitment and retention is widely regarded as an unprecedented, existential crisis for the whole social care sector; a crisis which has the

potential to hinder and undermined the sector's renewal and lead to suboptimal outcomes for individuals with chronic conditions.

This is not just a crisis facing in-house service provision, but it is also impacting independent commissioned provision as well. For example, there is a lack of capacity to undertake assessments to provide packages of care that are needed and there is a lack of Occupational Therapists and other multi-Disciplinary professionals to support people to live well and independently in the community.

Social care departments within local government have maintained a constant recruitment programme across Wales which has seen some success, but the market remains very volatile for both qualified and unqualified positions. Moreover, the resilience of the current workforce supporting children's services is also of significant concern. The challenges include:

- Difficulties in recruiting qualified childcare social workers - a recurrent theme over many years but this has markedly worsened
- Difficulties in finding quality agency social workers and ever-increasing agency fee levels
- A lack of both educational psychologists and mental health practitioners
- Competition between local authorities and other statutory services for key social worker roles
- Newly qualified social workers having to take on incredibly complex caseloads because of a lack of team capacity
- Significant pressures in respect of high levels of unexpected absence and staff sickness; none of which could have been predicted or planned for.
- Social workers stepping down from the profession into non-professional roles due the immense strain – consequently adding to the strain on the remaining workforce
- Staff that remain in the system becoming increasingly fatigued, both emotionally and physically.

The consequential impact of this capacity shortfall is an increase in agency related costs, which has added further financial pressure to local authority budgets, and we have seen a greater burden of responsibility and expectation fall on the shoulders of unpaid carers.

We believe workforce pressures in health and social care need to be examined as part of this inquiry because it is hampering the system's ability to deliver high-quality, integrated, person-centred support to individuals with a chronic condition.

Seamless Integration - the relationship between health and social care

The relationship between the NHS and social care is an important one when it comes to helping an individual manage their chronic condition. Without well planned care and the right interventions by the right professionals at the right time, people's conditions can quickly become destabilised. The consequence is often the individual experiencing acute need and requiring significant intervention to rebalance both physical health and mental wellbeing. Such episodes can severely damage people's confidence to live independently. This then creates a knock-on effect on so many other health and social care services already under intense pressure.

At the same time, a lack of capacity and resources in health also has implications for local authorities. For example, a lack of resources to progress individuals with a high level of complex needs where consideration of Continuing Health Care (CHC) is required; some of these packages are £150k to £250k per annum. There is a similar situation in children's services, where there are an increased number of children with complex care needs in need of assessment for Children and Young People's Continuing Care (CYPCC). Local authorities have reported that health boards' capacity to assess and arrange provision for these children and young people means that local authorities continue to have to meet their needs, requiring the use of specialist children looked after placements. We believe that operational delivery and governance functions around CHC and CYPCC needs to be examined in this inquiry because we believe it is damaging partnership relationships and ultimately, hampering care outcomes for individuals with chronic conditions, even for those in receipt of end of life care.

A significant investment into social care is required to help resolve some of these issues, but it is essential that social care is not just seen as a service simply there to support the NHS. There is a need to recognise the value social care has in its own right. However, where the NHS and social care work well together, there is potential to keep people well and reduce demand on secondary health services. There is also evidence that interventions like reablement have the potential to prolong people's ability to live at home and reduce or even remove the need for care. However, greater clarity on joint funding arrangements and their governance is required to ensure that people are front and centre of service provision not budgets.

Social care is also essential because it links to a wide range of other services that can support people's wellbeing such as work, housing, social interaction and a good environment. Ultimately, the greatest impact on health and wellbeing is in addressing the wider determinants of health and ensuring that local government has the power, flexibility and resources to fulfil its core purpose of ensuring that all our residents have the opportunities to have the best start in life, to live well and age well.

Conclusion

The inquiry Terms of Reference rightly point out the complex nature of supporting people with chronic conditions. The perspective of social care leaders post-pandemic is that we need to refocus on the key principles in the Social Services and Well-being (Wales) Act 2014 and in A Healthier Wales. That means statutory providers and associated partners concentrating solely on the individual to deliver, high-quality, strengths-based and seamless care and support. However, we need a health and care system that moves away from acute, symptomatic, reactive care to one based on earlier detection and intervention. Only by ensuring that people see the right professional, at the right place, at the right time, we will see improved self-management of personal health and well-being, as well a health and social care system more resilient and able to provide that support.