

SHCA response to DHSC's Mental Health Strategy call for evidence

Introduction

This document sets out the Specialised Healthcare Alliance (SHCA) response to the Department of Health and Social Care's (DHSC) [call for evidence](#) on a new cross-governmental Mental Health Strategy for England. The SHCA's response has been guided by our work-to-date looking at the unmet mental health need of people living with rare and complex conditions, including:

- *Rare diseases, common inequalities: Bringing rare diseases into the health inequalities agenda (2023)*
- *SHCA survey: unmet mental health needs of people living with a rare or complex condition (2024)*
- *Are you okay? Rare diseases and mental health – A case study report (2025)*

You can find our response to the call for evidence below (and the context for each question as set out by DHSC). Please note that each response is limited to 300 words and we have decided to respond to a select number of questions based on those of most relevance to SHCA members.

Draft response

Hospital to community

“Effective partnership working at a community level is essential for the provision of person-centred care. These partnerships address the broad range of factors which can influence a person’s mental health recovery, such as:

- *physical health*
- *employment*
- *housing*
- *addiction*
- *social care*

We are piloting [6 community-based mental health centres](#) across England to understand how services can better work together at a local level to improve people’s outcomes. We would like to hear practical insights that support wider transformation of mental health care in communities.

We welcome practical examples and evidence on how mental health services can work more effectively across:

- *the wider NHS, including new neighbourhood health centres*
- *services to support people with co-occurring mental health and neurodevelopmental conditions*
- *different sectors, including education, employers, local authorities and the voluntary, community and social enterprise (VCSE) sector”*

DHSC question

How can mental health services work more effectively across these areas? Please provide examples of cross-sector pathways in practice. (Optional, maximum 300 words)

SHCA response

People living with rare and complex conditions experience challenges that impact their mental wellbeing, including the diagnostic journey, uncertainty, treatment burden and disease progression. The SHCA’s 2024 survey into unmet mental health need for people living with rare and complex conditions found 57% of those surveyed felt isolated or alone, with 76% not receiving support quickly enough.

Given the significant impact of living with a rare or complex condition on mental health and the number of different services that some will access in their lifetimes, mental health support must be integrated across the health system. Mental health support should be routinely embedded within specialised care pathways rather than treated as a separate concern.

Our members consistently report that psychological support is rarely offered proactively and that when support is given, it can fall short of the specific needs of people living with rare or complex conditions. Mental health assessments and specialist support should therefore be available at key points throughout the care pathway, including during the diagnostic process, at point of diagnosis, major treatment decisions, and periods of deterioration.

The voluntary, community and social enterprise (VCSE) sector is a critical partner for the NHS. Many charities supporting people with rare and complex conditions provide peer

support, practical advice and emotional support that individuals cannot access elsewhere. However, these services are under significant strain from growing demand; our 2024 survey revealed 91% of charities providing mental health support for people living with rare diseases have been under increased strain since COVID-19, and 48% described this pressure as “unsustainable”. Services delivered by charities should complement, rather than replace, NHS provision.

The mental health strategy should recognise the increased mental health impact of living with a rare or complex condition and commit to improving access to integrated psychological support through specialist care pathways.

“We welcome views or evidence on what further support, in addition to NHS services, should be provided for people with severe and enduring mental illness to:

- help them stay well*
- maintain participation in education, work and community life*
- avoid crisis and/or hospital admission*
- reduce length of stay in inpatient units”*

DHSC question

What further support should be provided for people with severe and enduring mental illness? (Optional, maximum 300 words)

SHCA response

The experiences of people living with rare and complex conditions highlight the importance of holistic, person-centred support. Access to psychological support alone is unlikely to be sufficient if individuals continue to face significant inequalities as detailed in our 2023 report ‘Rare diseases, common inequalities: bringing rare diseases into the health inequalities agenda’.

Peer support can play an important role in helping people connect to their communities and reduce isolation; the SHCA’s 2024 survey on unmet mental health needs found that 90% of respondents said peer support was particularly important but only 60% described it as accessible. NHS services should work more closely with charities and community organisations to connect people with appropriate support networks.

Families and carers must also be recognised as an integral part of support. Caring responsibilities can have a profound impact on mental health and wellbeing, which in turn can impact on their ability to care. Yet, support for carers remains inconsistent and inadequate; 84% of those surveyed in our 2024 survey described availability of mental health support for the family, parent or carers of people living with a rare or complex condition as poor. Mental health services should proactively offer information, counselling and peer support to families and carers, particularly during periods of crisis or transition.

Finally, mental health support should be trauma-informed. Many people with long-term physical health conditions have experienced medical trauma, repeated interventions and uncertainty that can have lasting consequences for mental health. For people with rare and complex conditions, services should recognise these experiences and ensure that support is tailored to individual circumstances rather than relying solely on generic interventions.

The mental health strategy should commit to ensuring that people living with rare and complex conditions, and their families/carers, have access to person-centred support that is trauma-informed and specific to their needs.

DHSC question

What are the main barriers to continuity of care across transitions between hospital and community services, and between different levels of care, including child to adult services? Please provide examples from either side of the transition and outline how these barriers could be effectively addressed. (Optional, maximum 300 words)

SHCA response

A major barrier to continuity of care is the fragmentation that exists between physical health services, mental health services, community services and the voluntary sector. Individuals living with rare and complex conditions frequently report having to navigate multiple systems independently, repeating their story to different professionals and coordinating their own care.

The CONCORD study – a major review of the coordination of care of people with rare diseases funded by the National Institute for Health Research (NIHR) – found that, for the majority of people with rare diseases, their care is not well coordinated and this has a negative impact on all aspects of their lives, including their physical, mental and financial wellbeing. Without good coordination of care, the burden falls on the patient, further compounding the stress of having a rare disease.

For people living with rare and complex conditions, transitions can be particularly challenging. The move from paediatric to adult services is accompanied by the loss of established relationships with healthcare professionals, reduced coordination between services and difficulties accessing professionals with expertise in specific conditions. SHCA members have described this transition as a “minefield”, with adult services not always equipped to understand the condition or its wider psychological impact.

When asked how to improve mental health support for children living with a rare or complex condition, 83% of those surveyed said more support with the transition from paediatric to adult care services is needed, given the significant disruption and impact it can have on people living with rare and complex conditions.

Named workers or dedicated care coordinators can play an important role in supporting people through periods of change and improving coordination of care.

The mental health strategy should recognise the importance of coordination of care for people living with rare and complex conditions for their mental health.

Sickness to prevention

“The incidence and severity of mental health conditions has risen in recent decades, with young adults in particular now reporting substantially poorer mental health. Data from NHS England’s [Survey of mental health and wellbeing, England 2023 to 2024](#) stated that 25.8% of young people are estimated to have a common mental health condition, up from 17.5% in 2007.

Many of the solutions to mental health problems involve education, employment, housing and participation in community life. Therefore, if prevention is to be effective, we need to think beyond the realms of clinical care and across the life course.

We are especially interested in how we can identify distress earlier and support people to maintain participation in education and work. Preventative approaches include:

- *primary prevention - stopping mental health problems before they start*
- *secondary prevention - supporting those at higher risk of experiencing mental health problems*
- *tertiary prevention - helping people living with mental health problems to stay well*

We encourage examples of good practice within and beyond the health system, including in work and education settings where people with a co-occurring mental health and neurodevelopmental condition may particularly benefit.”

DHSC question

Which preventative approaches have the strongest evidence for reducing incidence or severity of mental health problems and promoting good mental health? (Optional, maximum 300 words)

SHCA response

For people living with rare and complex conditions, prevention often means identifying psychological distress early and providing support before individuals reach crisis point.

One of the most effective preventative approaches is the proactive integration of mental health support within and throughout physical healthcare pathways. Many individuals experience heightened vulnerability to anxiety, depression, trauma and social isolation throughout the diagnostic process, following diagnosis, during treatment, or when facing uncertainty about the future. Routine psychological assessment and timely access to support can help address difficulties before they become more severe. Mental health care must be integrated at every stage of the rare disease journey – not just at diagnosis – and made accessible without requiring relentless self-advocacy, and this support must extend to parents, siblings, and carers as part of whole-family care.

Peer support is another valuable preventative intervention. People living with rare and complex conditions frequently report feeling isolated and misunderstood. Peer support groups offer a space to connect, particularly for those who are newly diagnosed, and could be integrated more closely into healthcare settings within the NHS. Services should therefore work closely with patient organisations and community groups to ensure that individuals are aware of and able to access appropriate support.

The mental health strategy should prioritise early intervention by embedding routine mental wellbeing check-ins, proactive psychological support throughout specialised care pathways, and connecting people to peer support, rather than waiting until people reach crisis point.

DHSC question

How can services better support the 'missing middle' - those with sustained needs (that affect their participation in community life, for example, in education or work) who may not meet the criteria for NHS mental health services? Please provide examples. (Optional, maximum 300 words)

SHCA response

People living with rare and complex conditions illustrate the challenges faced by the 'missing middle'. Many experience ongoing anxiety, uncertainty, isolation or psychological distress that affects their day-to-day lives without meeting the threshold for specialist NHS mental health services. At the same time, they often have regular contact with healthcare professionals through their physical care, creating opportunities for earlier intervention.

Services should adopt a 'make every contact count' approach to mental wellbeing, ensuring that healthcare professionals across all settings – including in both specialist and non-specialist services – are equipped to routinely check-in with patients' mental health, recognise signs of distress and confidently signpost or refer people to appropriate support. Importantly, these conversations should not be limited to the point of diagnosis as mental health needs can emerge or change throughout a person's journey. Regular, proactive check-ins should therefore become a routine part of care.

Our case study report also highlights the importance of improving healthcare professionals' understanding of the psychological impact of living with a rare or complex condition. Participants consistently described feeling misunderstood, with generic mental health support often failing to recognise the realities of managing a rare or complex condition. Greater awareness and empathy among healthcare professionals would help create a more supportive care pathway, where people feel heard, validated and supported before their needs escalate.

By embedding mental wellbeing into routine physical healthcare, services can identify unmet need earlier, improve continuity of support and reduce the number of people who fall into the 'missing middle'.

The mental health strategy should adopt a 'make every contact count' approach to mental wellbeing, ensuring that healthcare professionals across all settings are equipped to identify mental health needs of people living with rare and complex conditions and connect people to appropriate support before their needs escalate.

Factors enabling good practice

Too often, we hear that services are hindered by administrative barriers that prevent innovative, integrated and person-centred care. We are interested in the underlying enablers of good practice around the country, and the role national government can play in creating the conditions for reformed models of mental health support. We are particularly interested to understand how access can be improved, for example through therapeutic support for certain groups such as women and girls subject to violence and/or child sexual abuse.

DHSC question

What commissioning, funding and oversight or accountability arrangements (nationally and locally) best support safe and integrated mental health services that improve outcomes across mental health, participation in work, education and community life, and social functioning? Please provide examples. (Optional, maximum 300 words)

SHCA response

With Integrated Care Boards (ICBs) having taken on commissioning responsibility for some specialised services and their emerging position as strategic commissioners, ICBs will have an increasingly important role to play in bringing together NHS organisations, local authorities and the VCSE sector to provide holistic care for people with rare and complex conditions. Commissioners should ensure that mental health support is embedded within specialised care pathways where evidence demonstrates unmet need, including for people living with rare and complex conditions and their families.

Funding models should also recognise the contribution of charities and patient organisations. These organisations provide valuable peer support, information and emotional support, yet many are under increasing pressure as individuals turn to them when NHS services are inaccessible. Sustainable partnership arrangements and appropriate funding mechanisms would enable closer collaboration while ensuring that statutory services remain responsible for delivering specialist mental health care.

The mental health strategy should require commissioners to embed mental health support within specialised care pathways and strengthen partnerships with the voluntary sector, ensuring charities complement rather than replace NHS mental health services.

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