

VODG Consultation response Major Conditions Strategy July 2023

Earlier this year the government announced a <u>Major Conditions Strategy</u> aimed at 'tackling the major conditions which contribute to the burden of disease' namely cancer, cardiovascular diseases (stroke and diabetes), chronic respiratory diseases, dementia, mental ill health and musculoskeletal disorders.

The Voluntary Organisations Disability Group (VODG) response to the government's consultation on the Major Conditions Strategy.

July 2023

Our response

In response to this consultation, we call on the government to ensure its proposals genuinely involve, support and reflect the needs of disabled people, and address the current health inequalities they face.

Existing barriers

- We know that disabled people face vast inequality in regards to accessing health and social care and experience poor health and wellbeing outcomes because of it (ONS). This was bought into stark focus with the pandemic where 60% of those who died from COVID-19 were disabled (ONS). And we also know that people from minoritised ethnic communities had poorer outcomes than White British. For example, people with a learning disability from an Asian/Asian British background were three times more likely to die from COVID-19 than a white British person with a learning disability (University of Bristol / LeDer).
- Learning disability and autism are mentioned scarcely in the strategy, yet we
 know that people with learning disabilities face poor health outcomes, die
 earlier and many remain in settings that are not fit for their needs (<u>LeDer</u>).
 People with learning Disabilities were eight times more likely to die of COVID19 than the general population (BMJ).
- Access to support is a huge barrier for people with disabilities, made worse
 where intersectionality exists. Many people are trying to navigate a system
 that has not been designed with their needs in mind and does not
 communicate with them in the ways they need.

- The existing barriers lead to people experiencing discrimination and avoidable and premature health issues arising or not being treated at all. The worst of this was seen through the pandemic with the forced use of Do Not Resuscitate Orders being placed on disabled people without the necessary consent (CQC).
- There are many factors that contribute to the major health conditions outlined

 in terms of cause, quality of life and recovery, where applicable, which are
 largely overlooked by the strategy in favour of a medicalised approach to
 prevention.
- It is of limited benefit for the government to look at these conditions as solely health issues. They must instead be considered alongside social and economic determinants including loneliness, ageing, housing, household income, education, transport, access to green space and fresh air. It is essential for government, and its agencies, to strengthen it approach to adopting the social model of disability (<u>Disability Rights UK</u>).
- A life course approach to health and care planning and provision is essential.
 Currently children, young people and adults of all ages with a disability face
 significant barriers to good health and care and the services they need to
 access can often result in 'cliff edge' experiences at key transition points in
 their lives.
- Ageing in particular is given very little attention within the consultation but is a significant influence on a person's health and wellbeing, as well as the planning and system structures needed to meet people's needs.
- A whole systems approach is needed which goes beyond the NHS to include the voluntary, charity and social enterprise sector, local government, housing and other partners to ensure community provision is accessible, integrated and the benefits maximised for those in need of support.
- Any strategy that seeks to address the impact of major health conditions must equally consider the role social care plays any package of support required. Currently social care lacks the workforce and funding support it needs, having a direct impact on the capacity of the health service and people's health outcomes.

Addressing inequalities

- To address the inequalities people with disabilities face in regard to all health conditions, including the major conditions which are the focus of this consultation, person-centred support must be at the heart of service they receive.
- A truly person-centred system is built around the individual, rather than around their condition, as is the inference in the consultation.

- Government must commit to taking action that removes unnecessary duplication and confusion, allows people to access all of the support they need in a timely and integrated way, and reduces the stress that too many people experience when trying to navigate complex health systems.
- Person-centred support must be built on trust, respect, communication, involvement and choice.
- We welcome recent announcements to expand choice to patients, in regards to appointment times and locations, but this must be equally accessible to disabled people as to those without disabilities. Otherwise, initiatives designed to improve people's experience of the health service create a two-tier system.
- As the COVID-19 pandemic demonstrated, the intersectionality of disability
 with race negatively impacts a person's life chances. Therefore, extra effort
 is needed to ensure that disabled people, including those from Black,
 Asian and minority ethnic groups, are involved in the planning of the
 services they need; communicated with via means and in ways that is
 accessible; and the range of support on offer is properly understood.
- It is disappointing that the standalone Health Disparities White Paper was dropped. It would have provided essential focus to the detriment of disparity and the best ways to address it. Embedding the strategy within a major conditions focus, risks 'disparity' becoming a tick box exercise rather than the priority it should be. We hope that further work is undertaken to ensure that addressing health disparities are a cornerstone of any future data, research and delivery plans.
- Early intervention and prevention is key. We know that disabled people, particularly people with a learning disability are often unable to access early support. This must be addressed through training of care staff, nurses GPs and GP practice staff alongside improved data, which is used by GPs to follow up on things like annual health checks, screenings and targeted information campaigns.
- In addition to general training for all health staff around disability awareness, we support calls for the implementation of the Oliver McGowen Mandatory Training, across the NHS and social care sectors. However this roll out must be supported with additional financial resources to enable providers to fully embed and implement these new requirements.
- Third sector providers are essential partners in the experience of people's?
 long term health and wellbeing. Many of the services people value the most,
 including support in their own homes, adaptations and wellbeing advice, are
 delivered by the voluntary sector. Therefore, the stability of the sector,
 including funding and a long term plan for the social care workforce, is
 essential to the success of addressing people's experience and health
 outcomes.

- Although digital provision has a big part to play in health and wellbeing support, it is important to remember that not everyone is digitally connected or able to use the NHS app or access other digital solutions. Digital provision must not further disadvantage those already struggling to access the support they need. We recommend the NHS working with disabled people's organisations (DPOs) to ensure any new digital initiatives are shared, co-designed and communicated with disabled people, to limit the risk of further inequality of experience.
- The decision not to have a separate mental health strategy was disappointing. Given the stigma, access issues and lack of understanding already experienced by those experiencing mental ill health, it risks further demoting mental health provision as a priority, and medicalising solutions in a way that undoes years of progress towards more personalised, community-based provision. If mental health is to remain within the umbrella of 'major conditions' it must become truly integrated within the health service, not only in regard to the other major conditions listed in the strategy, but all health and care provision.
- Finally, we support the call on the government to "commit to ensuring that all people receive the care and support they need to live well, regardless of whether the conditions they live with are considered to be 'major'" (BGS).