Nothing about us without us

Five principles for the next phase of the Covid-19 response

National Voices

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The Covid-19 crisis has been incredibly challenging for all of us. Leaders have had the unenviable task of having to make difficult decisions, with life and death consequences, in an unprecedented situation and with limited data. The stakes could not be higher. Meanwhile, all of us have had to live with the consequences of those decisions, including the loss of basic rights and freedoms. For more than 2 million people in the "extremely vulnerable" category, that has meant "shielding" through self-isolation within their households; many others considered "vulnerable" are self-isolating - seemingly indefinitely.

Until now, policymakers have been operating in crisis mode, as is necessary and understandable. But as the mists start to clear, and we shift from responding to an acute crisis into ongoing management, a transparent, accountable, and consensual approach is crucial. Nothing about us without us has never been more important, not least because, without it, trust is eroded, undermining long-term compliance with any new rules and recommendations, and in turn public health.

As a point of principle and accountability, decision makers must engage with those citizens most affected by both the virus and lockdown restrictions and understand how lives are lived by those who have `underlying conditions.´ We at National Voices, the leading coalition of health and care charities in England, have heard from hundreds of charities and people living with underlying conditions, and developed these five principles to underpin and test any policy change. They put people and their rights at the centre.

1. Actively engage with those most impacted by the change

People have a right to be consulted about changes that profoundly affect their lives. People most affected by service cuts, lockdown, self-isolation, and difficulties with accessing food and medicine, need to be heard and their experiences and concerns acted on. Policymakers must base their decisions on a deep understanding of how people and patients are affected. Proper coproduction must be the cornerstone of policy design and development as we are making decisions for the longer term.

2. Make everyone matter, leave no-one behind

Everyone matters – all lives, all people, in all circumstances. Whether your life is normally unaffected by health issues or you struggle every day with your ill health or disability – your life matters equally and needs to be weighed up the same in any Government policy. It is essential that decision makers signal that they want people living with ill health or disability to lead full lives and remain an active part of society. Even if some people need to live with more severe restrictions, we must take steps to ensure they are able to work, earn money, access clinical care and socialise. We must move through this crisis together, and leave no one behind.

3. Confront inequality head-on

We're all in the same storm, but we're not all in the same boat. Mortality and morbidity are higher for those living in poverty and working on the frontline. People from Black, Asian or minority ethnic backgrounds are disproportionately affected. Life in lockdown is harder for those living in overcrowded or insecure housing than it is for those in spacious homes with outside space. There has never been a more urgent moment to confront the social determinants of ill-health as we build back better. All policies to manage the next phase must recognise these stark inequalities, taking a proportionate universalist approach.

4. Recognise people, not categories, by strengthening personalised care

We need a personalised approach to how people want to live. Vulnerability should not mean blanket bans. Having a learning disability does not in itself mean people will have a short life expectancy or poor quality of life, people in care homes are not simply waiting to die. Not everyone over 70 privileges safety over family contact. The category of 'vulnerable' needs to be rethought and broadened beyond narrow clinical criteria to include more holistic circumstances that can make people vulnerable, such as domestic violence, poverty, disability or overcrowding. Personalised care is essential to safety and dignity.

5. Value health, care and support equally

People living with ill health or disability need more than medicine. They need care and support, connection and friendship. Social care, charities and communities are part of this vital, life enhancing fabric of life. The siloing, underfunding and neglect of social care, its workforce, users and purpose as a life enhancing public service has to end. Charities and communities need to be enabled to take part in the design and delivery of future care models. Any policy efforts to rebuild services need to actively address and dismantle barriers between sectors that only ever mattered to funders and regulators.

The future will be different. Let's make sure it will also be more compassionate and equal, with people's rights at its centre. The many people who died, who lost loved ones or whose lives have been made immeasurably more difficult deserve nothing less.

Notes

National Voices is the leading coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. We have more than 160 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people.

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