Health and Social Care Alliance Scotland

Briefing on 'COVID-19 - A Framework for Decision Making and Further Information'
11 May 2020



Introduction

This briefing has been prepared in response to the Scottish Government's 'COVID-19: A Framework for Decision Making' document¹, and the associated 'Further Information' publication². The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes both publications and the opportunity to respond.

COVID-19 is a defining public health emergency for the 21st Century. The ALLIANCE recognises the strain that responding to the pandemic places on the Scottish Government, NHS, local authorities and Health and Social Care Partnerships, as well as the deep impact for people living with long term conditions, disabled people, unpaid carers and organisations that work for and with them. Given the importance of clear, concise and well drafted public messaging in this area, it is essential that guidance is correct from first publication, and that when necessary it is amended quickly. This briefing aims to provide constructive comment on the Framework and Further Information, and offers recommendations for future consideration.

Section 1 – Scotland's Approach

We welcome the Scottish Government's transparent approach in publishing the Framework, and its reflection of human rights, equality, and social justice values. The role of social care, however, remains under-appreciated in the principles of the approach. Whilst recognising that NHS capacity is a priority, if social care – from local authorities, the private sector, and third sector providers – is stretched beyond its capacity, and local authorities continue to cap social care services, this will have a profound impact on the lives of people living with long term conditions, disabled people and unpaid carers, and also create significant issues for the NHS. Further iterations of the Framework should recognise the inherent link between health and social care, and the key role social care has in any national response to and recovery from COVID-19.

¹ https://www.gov.scot/publications/coronavirus-covid-19-framework-decision-making/

² https://www.gov.scot/publications/coronavirus-covid-19-framework-decision-making-further-information/

We believe that the Framework would be strengthened with better recognition that COVID-19 will not have the same impact on everyone and that it is already disproportionately affecting some individuals and groups within society.³ Some people are having to shoulder significant additional responsibility – for example, unpaid carers.

We are concerned that consultation via an online tool, without accessible formats, leaves some people living with long term conditions unable to respond. We note, in particular, research produced by Inclusion Scotland⁴ and early findings from the Scottish Commission for Learning Disability (SCLD) survey on disabled people's limited access to the internet, and the inaccessibility of the COVID-19 information and the consultations about it. We welcome the new £5m Connecting Scotland programme, aiming to offer internet connections, training and support, and a laptop or tablet to people not already online during the COVID-19 pandemic⁵ and hope that this will reach disabled people. Further work should, however, also be planned to directly engage and consult with disabled people on the Framework.

Accessible and inclusive versions of the Framework, including Easy Read, British Sign Language and other languages, should be produced to allow for people with various communications needs to respond.

Section 3 – Preparing for transition

We welcome the Scottish Government's stated principles in relation to future transition from lockdown. The impact of transition must focus on those most likely to be disadvantaged, including (but not limited to) disabled people, people living with long term conditions and unpaid carers. We, therefore, believe that the follow areas are key to the decision-making process:

- Mainstreaming and embedding equalities and human rights in practice as well as principle – this will mean doing things differently.
- Ensuring people and organisations are actively involved in meaningful decisionmaking (with independent support to do so if required). This goes beyond engagement and consultation to the active co-production of solutions and decisions.
- Independent ongoing monitoring and scrutiny to ensure accountability and routes for redress if things go wrong.
- Transparency in decision-making.
- Fairness and non-discrimination.

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³ https://www.improvementservice.org.uk/ data/assets/pdf file/0013/16402/Poverty-inequality-and-COVID19-briefing.pdf

⁴ Inclusion Scotland, 'Coronavirus Update for Members of the Scottish Parliament' (21 April 2020).

⁵ https://www.gov.scot/news/getting-people-online/

Section 4 – Framework for Decisions

We welcome the acknowledgement of the different impacts that will be felt by people as we aim to ease lockdown. Further detail is needed on the principle that "we will protect those most at risk and protect human rights" and how this will be operationalised. More clarity is particularly required on the involvement and participation of disabled people, people who live with long term conditions and unpaid carers.

We would welcome more detail on what is considered "evidence" in the context of this Framework. Qualitative evidence (disaggregated) is as important as statistical data and scientific research. We welcome announcements elsewhere about new research, e.g. the impact of COVID-19 in relation to ethnicity and gender, and the impacts on people with lived experience of mental health problems. There are already a range of data gaps emerging around the impact of COVID-19, including in relation to health and care; it is particularly important that all relevant research and policy making takes an equalities approach to avoid these gaps in future.

Section 5 – Options for Easing or Imposing Restrictions

In easing or imposing restrictions, thought should be given to the distinction made between blanket social marketing and public messaging, and involving people directly impacted by COVID-19 in meaningful decision-making about person centred, equalities focused and rights based responses to COVID-19. The ALLIANCE would like to see the production and sharing of clear, transparent and accessible evidence and examples of how equalities and human rights have been central to decision-making so far. For example, we would welcome information on how Equality Impact Assessments and Equality and Human Rights Impact Assessments are being used, and by whom. Guidelines and decision-making frameworks should contain concrete commitments to embedding human rights within these processes, with specific detail on how this is to be achieved.

Changes to advice about visiting other households

The 'Framework – Further Information' document⁶ states that under suggestions regarding visiting other households that "this change would not apply to people currently in the 'Shielded' group", and that "we recognise that this will become increasingly challenging as advice changes for other people. We are committed to an honest conversation with our citizens who are shielding and with their families about the support they need, the evidence about the risks they face, and maintaining a quality of life while shielding". Whilst we welcome acknowledgement of the different

⁶ https://www.gov.scot/publications/coronavirus-covid-19-framework-decision-making-further-information/

experiences of people in the shielding group, further detail is needed, especially around the provision of additional support and care as shielding is extended, the impact on people's mental and physical health, and the equality impacts of blanket advice to everyone who is shielding (and who are not a homogenous group). Guidance is also needed on how, and if, this measure will be monitored for people who are in the shielding group but who wish to take a considered risk.

Resuming care and support

Both the Scottish Government and Health and Social Care Partnerships across the country are required to balance the prioritisation given to the resumption of services. They must tackle the difficult task of ensuring that people can access the support they require as quickly as possible, while also ensuring that services are not overwhelmed with immediate requests for support.

We believe that clarity is required over the priority with which health and social care services which have been suspended will return. We recognise that elective procedures and screening services need to return as quickly as possible. However, further consideration should be given to the relaxation of social care eligibility criteria and assessments.

We are concerned that some areas have increased their eligibility criteria for accessing Self-directed Support (SDS), and that for many people social care packages have already been reduced and/or stopped. For example, Dumfries and Galloway Health and Social Care Partnership have stated that "care will be provided at the minimum level required to keep people safe" and Glasgow Health and Social Care Partnership has stated that "all services continue to focus on urgent and priority care needs". The BBC reported that the number of social care clients fell by over 2,000 in the period January to April 2020. The ALLIANCE believes that it is imperative to the wellbeing of disabled people, people living with long term conditions, and unpaid carers that narrowed social care eligibility criteria should be relaxed. As soon as it is clinically safe to do so, support should be resumed at – as a minimum – the level it was at before the pandemic began. Furthermore, people whose assessments were cancelled due to COVID-19 should be considered for appropriate support as soon as possible, to minimise the disproportionate and negative impact on them.

We welcome the commitment to provide care "for those who need it, whether infected by the virus or not", and the revision in the 'Further Information' Framework

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⁷ https://supportdg.dumgal.gov.uk/article/20810/Care-at-Home-services

⁸ https://glasgowcity.hscp.scot/sites/default/files/publications/Glasgow%20City%20HSCP%20COVID-19%20Briefing%20-%20Staff%20-%203%20April%202020 0.pdf

⁹ https://www.bbc.co.uk/news/uk-scotland-52415302

to ensure that both "our NHS and Care services are not overwhelmed" (rather than just NHS, as per the initial Framework document). However, the Framework and associated documentation needs to contain a broader acknowledgement of the role of the third sector and unpaid carers in providing social care – and further detail on how they are to be supported during a time of unprecedented strain.

The ALLIANCE also believes that greater consideration is required of evidence suggesting that there will be more people with respiratory long term conditions than ever before, as a direct result of COVID-19. This is particularly important given that one of the Scottish Government's National Performance Framework National Outcomes is for people in Scotland to "live longer, healthier lives", with a National Performance Indicator to "reduce premature mortality" (deaths from all causes in those aged under 75). The Scottish Health Survey 2018 (revised 2020) highlighted respiratory conditions as a key area for concern, with 17% of adults reporting asthma diagnoses, and significantly higher rates of chronic obstructive pulmonary disease (COPD) among adults living in the most deprived areas of Scotland (8%) compared with those living in the least deprived areas (2%). Prior to COVID-19, COPD was a major cause of death in Scotland; the pandemic is likely to increase both the number of people living with COPD and associated long term conditions, and have a disproportionate and negative impact upon people living in the most deprived areas of Scotland.

The Scottish Government must plan to work closely with people with lived experience of these conditions and the organisations that work for and with them in planning future health services and social care support. This includes amending the Respiratory Care Action Plan for Scotland to account for a potential rise in demand for community-based support as a result of COVID-19, and advice on how statutory services should respond. It should also acknowledge the disproportionate demand on such services from people living in the most deprived areas of Scotland, and support should be funded accordingly.

We believe that the Framework could also be strengthened by the inclusion of good examples of how health and social care support and services are already adapting to different ways of working. The ALLIANCE's Community in Action series¹¹ has been sharing the work of Scotland's third sector as it responds to the pandemic and adjusts its health and social care support accordingly. **Inclusion of similar examples in the Framework could allow for a clearer picture of how support and services which are currently suspended could return.**

¹⁰ https://www.gov.scot/publications/scottish-health-survey-2018-volume-1-main-report/pages/68/

¹¹ https://www.alliance-scotland.org.uk/blog/case studies/

Options for allowing pupils to return to school

We believe more detail should be provided on the provisions being made for children and young people who are in the shielding group, or who have Special Educational Needs, on how they will get the same support when their classmates return to school.

Section 7 - Renew: Living with the Virus

The Framework contains welcome commitments towards renewal and plans for the future after COVID-19, including "building a fairer and more sustainable economy and society". **The ALLIANCE believes that the following areas should be priorities:**

- Taking a human rights based approach to fiscal matters, ensuring that future budgets, allocation and spend respect, protect and fulfil people's rights.
- Greater funding and support for unpaid carers, including increasing Carers Allowance.
- The suspension and review, with a view towards full removal, of social care charges for people who use social care (including collection of arrears and debt for previous care charges).
- Providing more detail on how local authorities, Health and Social Care
 Partnerships and social care providers will be accountable for the decisions they
 make during this period.
- Ensure any cuts to care provision are properly monitored, and input sought from people with lived experience, following PANEL principles.¹²
- Ensuring specific, inclusive and accessible communications for and with people who access support and unpaid carers. This should not solely focus on blanket communications to the whole population.
- Ensuring that any changes to the regulations, advice, or guidance, include detailed information and transparency of process on how any changes will affect disabled people, people living with long term conditions, and unpaid carers.
- Responding to changing eligibility criteria on social care support across different local authorities and Health and Social Care Partnerships.
- Consulting disabled people, people living with long term conditions, and unpaid
 carers about the implications of using the powers of the Coronavirus 2020 Act on
 disabled people, carer support and the impact it will have on those who continue
 to provide and need support during the pandemic. Extend these consultations to
 any changes to Framework for Decision Making or alterations to public advice.
- Ensure the incorporation of international human rights and stronger use of equalities provisions through all decision making processes, Guidance, and

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¹² https://www.scottishhumanrights.com/rights-in-practice/human-rights-based-approach/.

Frameworks. The ALLIANCE recommends greater detail in the Framework on equalities and human rights, including laws, principles, and their practical application.

Contact

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About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 2,900 national and local third sector organisations, associates in the statutory and private sectors and individuals. Many NHS Boards, Health and Social Care Partnerships and Medical Practices are associate members.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.