Health and Social Care Alliance Scotland (the ALLIANCE)

Response to the Scottish Government's question set for stakeholder organisations on shielding - next steps

12 June 2020

Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to respond to the Scottish Government email dated 5 June 2020 with the subject 'Shielding - next steps - question set for stakeholder organisations'.

As we know, COVID-19 does not have the same impact on everyone and it is already disproportionately affecting some individuals and groups within society – including people with learning disabilities, women, and unpaid carers.[1] The ALLIANCE has outlined our concerns about this disproportionate impact in several briefings and our responses to both the COVID-19 and Equality and Human Rights Committee's inquiries.[2] We believe that this disproportionate impact should be clearly acknowledged and specifically addressed in Scotland's approach to decision making – including the development of plans for people who are shielding and their families, centred on their lived experience.

1. Please briefly describe how your organisation's work is connected with Shielding. (i.e. are you involved with one or more of the specific clinical categories? Or a specific demographic of people within the shielded group? What kinds of support do you provide?)

The ALLIANCE is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of nearly 3,000 national and local third sector organisations, associates in the statutory and private sectors, people living with long term conditions, disabled people and unpaid carers – including members who are shielding.

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[1] https://www.improvementservice.org.uk/__data/assets/pdf_file/0013/16402/Poverty-inequality-and-COVID19-briefing.pdf

[2] https://www.alliance-scotland.org.uk/blog/news/refining-or-reducing-lockdown-arrangements-during-covid-19/; https://www.alliance-scotland.org.uk/blog/news/social-care-assessment-covid-19-human-rights-concerns/; https://www.alliance-scotland.org.uk/blog/news/the-alliance-comments-on-draft-covid-19-clinical-and-ethical-guidance/; https://www.alliance-scotland.org.uk/blog/news/engage-disabled-people-in-decision-making-about-easing-lockdown/; https://www.alliance-scotland.org.uk/blog/news/equalities-impact-of-covid-19-must-be-assessed/.

The ALLIANCE employs 31 Community Links Practitioners (CLPs), who are based within GP surgeries across Glasgow. The Links Worker Programme[3] aims to mitigate the impact of the social determinants of health for people that live in areas of high socio-economic deprivation (top 15% SIMD).

During COVID-19, Deep End GP practices[4] have referred people on the shielding list to the ALLIANCE's CLPs for help accessing support services, including mental health support, food boxes/food banks, prescription delivery, telephone befriending, homelessness and addiction services. CLPs have also arranged support for people who have been told to shield upon leaving hospital, assisted people applying for State entitlements (including housing support and Universal Credit), and maintained regular telephone contact with people in their practice on the shielding list. CLPs have also assisted people who were not originally on the CMO's shielding list but were concerned about risks to their health from COVID-19 due to long term conditions, advocating for their names to be added to the list. As such, the ALLIANCE's work involves a wide variety of individuals who are affected by shielding.

2. Do you have any data or information about the sociodemographic make-up of your shielding client group? (We are particularly interested in numbers of people likely to return to work; numbers of shielding children or families with children in the household; numbers of people living alone; numbers who may rely on carers for support.)

The shielded groups the ALLIANCE works with are wide and varied in terms of age, ethnicity, gender, circumstances, and family sizes. While the demographics of individual Deep End GP practices vary, CLPs report that most of the shielding people they work with are elderly (over 70 years old), not in employment, and living alone. Others have been furloughed (with a corresponding drop in household income), provide unpaid care for disabled children or family members, or are unlikely to return to work (often due to caring responsibilities and/or disabilities or ill health).

Some individuals working with CLPs do not have any family or friends and may have just moved into the area or country. Most live with multiple long term conditions; they have been asked to shield due to one condition (e.g. COPD), but also live with other illnesses or conditions (e.g. cancer) which further impact on their health. Our CLPs report that a high proportion of shielding people who contact them struggle to access available services, and many do not have easy access to the internet.

CLPs particularly highlight the need to support shielding people with lived experience of mental health problems, elderly people, people with learning disabilities, blind and

[3] https://www.alliance-scotland.org.uk/in-the-community/national-link-programme/
[4] https://www.gla.ac.uk/researchinstitutes/healthwellbeing/research/generalpractice/deepend/

partially sighted people, people who are Deaf or hard of hearing, and those with limited literacy in English (including people for whom English is an additional language).

3. What challenges are your client group likely to be experiencing as a result of shielding (physical health, mental health, wider social and economic challenges, etc.)?

Many people living with long term conditions, disabled people and unpaid carers are experiencing significant challenges from COVID-19, both in terms of higher hospitalisation and mortality rates, and in terms of socio-economic impact and reduced support during lockdown and social distancing arrangements.[5]

Those people who have been asked to shield, and particularly shielding people who are on lower incomes, are experiencing significant negative impacts in terms of loneliness, more reported mental health problems, lower rates of physical activity (with associated health complications), and – within the wider household – reduced income, as household members are not able to work in front-line or public-facing jobs because of the risks to the person/s shielding, or have been furloughed. Many people's social care support has been withdrawn or reduced during COVID-19, with an ensuing impact on their health and wellbeing, and that of people providing unpaid care.

People registered as patients at Deep End GP practices live in areas of very high socio-economic deprivation, with the associated higher incidence of health inequalities; as such, most people CLPs work with who are shielding have extremely low incomes and live in poverty. Many report that the 7-10 day wait for Scottish Government food parcels to arrive after the initial request is processed is too long, and shielding people are reliant on emergency parcels from the third sector to be able to eat during that interim period. ALLIANCE member organisations have shared information about their work to help tackle food insecurity in our Community in Action series.[6] The Poverty and Inequality Commission has recently reported concerns from frontline providers that they still might not be reaching everyone in need, and looking forward that there may be increased demand but less funding available.[7]

The additional fuel costs for those shielding at home are also a concern for many people, and Citizens Advice Scotland has noted the affordability and practical issues

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[5] https://www.povertyalliance.org/wp-content/uploads/2020/04/Covid-19-and-national-organisations-PA-briefing-22-April.pdf; https://www.bmj.com/content/369/bmj.m1557; https://www.bbc.co.uk/news/uk-scotland-52637581.
[6] https://www.alliance-scotland.org.uk/blog/case_studies/
[7] https://povertyinequality.scot/wp-content/uploads/2020/06/Food-insecurity-SPIRU-final-report-June.pdf

faced by people who are shielding.[8] The links between fuel poverty and long term conditions, disability and poor health and wellbeing are well known; cold, damp housing can exacerbate existing health conditions (e.g. diabetes and musculoskeletal pain), and cause and exacerbate symptoms of others (e.g. asthma).[9] People require reliable access to energy in order to stay warm and dry, keep medication refrigerated and follow dietary plans.

During COVID-19, some people rely on CLPs to help them apply for support or follow up on delayed food parcels, prescription deliveries, or other support services, as they have no credit to call the relevant helplines, are elderly, or lack the confidence to do so themselves. A high proportion of shielding people our CLPs work with experience digital exclusion.

CLPs also report that changes to PIP and other State entitlement assessments being completed over the phone has led to higher rates of shielding people from their practices being refused access to entitlements – particularly people with mental health problems who struggle to speak on the phone. Others report that shielding people have been sanctioned during COVID-19 after struggling to receive clear communication from the DWP (including the loss of Carer's Allowance). People engaged with addiction services also report that they have received inconsistent support.

Women are also likely to be more impacted by the indirect consequences of shielding than men: they make up the majority of workers in industries most seriously affected by lockdown measures (retail, hospitality), and are more likely than men to have caring responsibilities, both as unpaid carers and in providing household labour and childcare while schools and nurseries remain closed or only partially open. These factors are in addition to the number of women who are also shielding based on their own health. The United Nations, *The Lancet*, Close the Gap and Engender have noted the disproportionate impact that COVID-19 is having on women and girls.[10] For those people who are shielding with children, CLPs report that children have missed and are missing social and cognitive developmental milestones, which is likely to have significant negative impacts on their educational outcomes and overall health.

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[8] https://www.cas.org.uk/news/covid-19-impact-energy-bills-and-fuel-poverty
[9] https://www.alliance-scotland.org.uk/wp-content/uploads/2018/11/ALLIANCE-response-Call-for-evidence-on-the-Fuel-Poverty-Target-Definition-and-Strategy-Scotland-Bill.pdf
[10] https://www.ohchr.org/EN/NewsEvents/Pages/COVID19Guidance.aspx; https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)30823-0/fulltext; https://www.closethegap.org.uk/content/resources/Disproportionate-Disruption---The-impact-of-COVID-19-on-womens-labour-market-equality.pdf; https://www.engender.org.uk/content/publications/Engender-Briefing---Women-and-COVID-19.pdf.

There has been an estimated increase of 392,000 unpaid carers in Scotland as a result of COVID-19, bringing the total to 1.1 million.[11] Carers UK has reported the potentially devastating psychological, financial and practical impact that COVID-19, and responses to it, are having on unpaid carers.[12] COVID-19 has an unequal impact on Black and minority ethnic groups, including amongst health and care professionals.[13] MECOPP has identified that some Black and minority ethnic unpaid carers may have additional challenges in accessing information and services, which can be worsened without a carer's assessment in place or access to adequate social care packages for service users.

Research from the Women's Budget Group indicated that COVID-19 is having a disproportionately negative impact on Black and minority ethnic people's access to health and social are support. Over 50% of Black and minority ethnic women surveyed reported that they were "not sure where to turn for help" during COVID-19.[14] Similar concerns about Black and minority ethnic people's limited access to support were raised by CLPs. CLPs also report that Black and minority ethnic people who require access to interpreters have had reduced access to translation and interpretation services – which in turn is likely to exacerbate existing health inequalities among those population groups.

The ALLIANCE is also concerned that, despite announcements of additional resources from the Scottish Government,[15] some Local Authorities/Health and Social Care Partnerships have increased their eligibility criteria for social care and that social care packages have been reduced and/or stopped, sometimes with little or no notice, leaving people in distressing situations. For example:

- Dumfries and Galloway Health and Social Care Partnership stated that "care will be provided at the minimum level required to keep people safe".[16]
- Glasgow Health and Social Care Partnership stated that "all services continue to focus on urgent and priority care needs".[17]

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[11] https://www.carersuk.org/scotland/news/covid-19-pandemic-392-000-become-unpaid-carers-in-scotland-in-a-matter-of-weeks
[12] http://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf
[13] https://www.icnarc.org/DataServices/Attachments/Download/76a7364b-4b76-ea11-9124-00505601089b; https://www.bbc.co.uk/news/uk-52219070; https://www.crer.scot/single-post/2020/04/20/Are-we-really-all-equal-in-the-eyes-of-COVID-19; https://www.ifs.org.uk/inequality/chapter/are-some-ethnic-groups-more-vulnerable-to-covid-19-than-others/; https://www.theguardian.com/society/2020/apr/10/uk-coronavirus-deaths-bame-doctors-bma; https://www.crer.scot/single-post/2020/04/20/Are-we-really-all-equal-in-the-eyes-of-COVID-19.
[14] https://wbg.org.uk/analysis/bame-women-and-covid-19/
[15] https://www.gov.scot/publications/coronavirus-covid-19-update-health-secretary-statement-parliament-28-april-2020/
[16] https://supportdg.dumgal.gov.uk/article/20810/Care-at-Home-services
[17] https://glasgowcity.hscp.scot/sites/default/files/publications/COVID-19%20Glasgow%20City%20HSCP%20Briefing%20-%20Staff%20-%207%20May%202020.pdf

- The BBC reported that the number of social care clients fell by over 2,000 in the period January to April 2020.[18]
- Research by Inclusion Scotland and Glasgow Disability Alliance indicates that social care packages have been reduced and stopped.[19]

UK and Scottish COVID-19 emergency legislation allows for an easing of health and social care assessment duties, but not eligibility criteria or existing social care and carer support.[20] Over 230,000 individuals and families (1/24 of the Scottish population) access social care, and for many disabled people and people living with long term conditions it is essential for their rights to independent living and equal participation in society.

In terms of longer term challenges, the ALLIANCE believes that greater attention should be given to evidence suggesting that there will be more people with respiratory, neurocognitive, heart, mental ill-health, and other long term conditions than ever before as a direct result of COVID-19.[21] 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%).[22] 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.

4. What support needs do you think your client group will have as lockdown eases?

The ALLIANCE believes that many people living with long term conditions, disabled people and unpaid carers will be unequally affected as lockdown eases for some parts of Scotland's population, and that these people will require additional support. We propose a range of recommendations for how the Scottish Government and public bodies can seek to mitigate these impacts, including breaking down barriers in access to information and participation in decision making, and ensuring that equalities, human rights and the needs of those people most likely to be disadvantaged are at the forefront of any post-lockdown considerations. There is an

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[18] https://www.bbc.co.uk/news/uk-scotland-52415302
[19] https://inclusionscotland.org/covid-19-evidence-survey/; http://gda.scot//content/publications/GDAs-Covid-Resilience-Interim-report-27April_alt-text.pdf
[20] Sections 16 and 17 of the Coronavirus Act 2020 ('the 2020 Act') "allow for an easing of health and social care assessment duties in relation to adult social care, carer support and children's services in Scotland." These powers were "switched on" by the passing of the "Coronavirus Act 2020 (Commencement No. 1) (Scotland) Regulations 2020/121" on 5 April 2020.
[21] https://www.vox.com/2020/5/8/21251899/coronavirus-long-term-effects-symptoms
[22] https://www.gov.scot/publications/scottish-health-survey-2018-volume-1-main-report/pages/68/

urgent need for sustained investment in health and social care support services in areas of deprivation going forward – particularly mental health support, housing support, addiction services, and access to respite.

It is imperative for people's rights and wellbeing that narrowed social care eligibility criteria should be relaxed and that social care support should be resumed at – as a minimum – the level it was at before the pandemic began. Packages must be reinstated to at least the level prior to COVID-19, and assessments centred on people's outcomes should be prioritised for people who are expected to continue to shield – often without adequate support arrangements in place or with additional demands upon unpaid carers. The ALLIANCE also asks for greater transparency and scrutiny of changes to social care, including information on the criteria and tools used by public bodies in this decision making, and what measures are being taken to ensure ongoing monitoring.

The National Carer Organisations have produced a discussion paper outlining some of the measures that should be implemented to support unpaid carers and those they support as lockdown restrictions are eased.[23] This includes key principles that unpaid carers and those they care for must be at the heart of decision making and that carers' rights must be reinstated and reinforced. Other recommendations cover issues relating to information, service provision, social care, practical and financial assistance, employment and education.

The Scottish Government and local health and care bodies must plan to work closely with disabled people, people living with long term conditions, unpaid carers and the organisations that work for and with them in planning future health and social care services, both while people continue to shield, and as plans are developed on how all parts of the population can emerge from lockdown arrangements. This includes amending the Respiratory Care Action Plan for Scotland to account for a potential rise in demand for community-based support due to 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.

People living with long term conditions, disabled people and unpaid carers will not all experience relaxations to elements of the current lockdown arrangements in the same way as the wider general population. It is important to recognise, as the Scottish Government 'Framework – Further Information' document does, and recent announcements on shielding by the Cabinet Secretary and First Minister acknowledged, that such steps in effect increase further the level of sacrifice that people in the shielded category are being asked to make, relative to the rest of the

[23] https://www.carersuk.org/scotland/policy/policy-library?task=download&file=policy_file&id=7108

population. This may have an impact on the mental health of people within the shielded category, and as such people should be provided with the psychological and practical support they require to comply with the instructions whilst minimising any negative impact on their health and wellbeing as far as possible. We are aware that there are many research projects underway exploring the impact of COVID-19 and mitigation factors on people's mental health – it is important that sufficient resources are invested in practical measures to support people, and that disabled people, people with long term conditions and unpaid carers have equitable access.

The ALLIANCE appreciates the complexity involved in developing population level guidance that balances clinical risk of COVID-19 with the other negative risks associated with mitigation measures. It is important to recognise that the shielded category is not a homogenous group, and there may be circumstances (for example near end of life) where people included within this category may wish to make an informed decision as to the level of risk they are willing to exercise. We believe that people who are most at risk from the virus should be supported by clinicians, CLPs, and social care practitioners to have compassionate conversations about how the shielding guidance applies to their own individual circumstances.

The ALLIANCE welcomes the Scottish Government's stated principles in relation to future transition from lockdown for people who are shielding. The impact of transition must focus on equalities, human rights and those most likely to be disadvantaged, including (but not limited to) disabled people, people living with long term conditions and unpaid carers. The ALLIANCE believes that the following are key to the transition from lockdown decision making process, including in relation to people who are shielding:

- Mainstreaming and embedding equalities and human rights in practice as well as principle – this will mean doing things differently, for example carrying out Equality and Human Rights Impact Assessments before steps are taken, and designing action based on the results
- Taking a human rights based approach to financial decision making, including resource allocation, budgets and expenditure.[24]
- Ensuring people and organisations are actively involved in meaningful decision making, with independent support to do so if required. This goes beyond engagement and consultation to co-production of solutions and decisions.
- Providing 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 but tailored advice for groups

[24] https://www.alliance-scotland.org.uk/blog/news/covid-19-public-finances-and-human-rights/

such as people living with long term conditions and disabled people. Communications should be available in multiple languages and formats.

- Ensuring any changes – particularly cuts – to health and care provision are properly monitored, and input sought from people with lived experience, following human rights based PANEL Principles.[25]
- Independent monitoring and oversight to ensure accountability and routes for redress if things go wrong.
- Transparency, fairness and non-discrimination in decision making.

5. Do you think your shielding client group would welcome increased flexibility in the shielding guidance so that they could better decide for themselves which measures to follow?

Yes.

Many of the shielding people the ALLIANCE works with indicate that they would welcome increased flexibility and agency; people report that the current arrangements have led them to feel as if they have lost all control over their lives, with increased loneliness, uncertainty, and mental health pressures. However, while for many people more flexibility would be welcome, inconsistent messaging could increase anxiety for other people who are shielding – who have already expressed considerable confusion and alarm over what activities they can undertake.

The ALLIANCE believes that it is essential that suitably tailored communications about changes to shielding guidance are shared clearly and consistently with all population groups, including plans for cascading information to every part of the community in appropriate languages and accessible formats. One CLP relayed their perspective on initial information dissemination as follows:

> "At the start of lockdown […] there was a lag in information being distributed and understood by every part of the community. The groups who had not received the appropriate guidance were then accused of not acting in accordance with measures laid out and then parts of the wider community were able to easily target them. It became very confusing for parts of the community who experience racism and discrimination when social distancing measures took effect and they were unaware of these measure and why they were being asked to stay back – it was perceived by some that this was another attack on them until the information was more widely shared and understood."

[25] https://www.scottishhumanrights.com/rights-in-practice/human-rights-based-approach/.

Contact

If you would like to discuss any of the topics raised within this briefing, or to request any further information, please 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 nearly 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

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.