

Health and Social Care Alliance Scotland (the ALLIANCE)

Universal Periodic Review Shadow Report

30 March 2022



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 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, Libraries and Access Panels are also 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.

Contact

Gillian McElroy, Policy and Information Officer

gillian.mcelroy@alliance-scotland.org.uk

Rob Gowans, Policy and Public Affairs Manager

rob.gowans@alliance-scotland.org.uk

0141 404 0231

www.alliance-scotland.org.uk

[@ALLIANCE Scot](https://twitter.com/ALLIANCE_Scot)

COVID-19

Communication

1. People experienced confusing, limited and interrupted communication at all levels in health and social care settings: between services, for people who access services, and at the national public health messaging level.¹ A lack of tailored approaches throughout health and social care interactions meant that public health messaging was often confusing, inaccessible and contradictory. For example, written communication was often too ambiguous and lacked clarity on key information.
2. It is imperative that people have good quality, accessible and inclusive information in the right language and in a format that is understood. During COVID-19, accessibility issues were often delayed meaning people were not fully informed on a universal, equitable basis. This raises key concerns about people who experience communication or language barriers being indirectly discriminated against.
3. COVID-19 restrictions had a significant impact on tactile communication. For example, for people living with dementia touch is often the only means of communicating, particularly during the later stages. During COVID-19, many tactile activities were stopped. A lack of positive communication can cause rapid deterioration of people's health and wellbeing.
4. There is a lack of provision of translators in health services, and a lack of specialists to address communication and language barriers including BSL/English Interpreters, deafblind tactile communicators, guide communicators for vision loss and electronic notetaking for deafened/hard of hearing.

Digital exclusion

5. Digital support available during COVID-19 was not suitable for all, meaning some people have become further excluded. For example, the introduction of new technologies and apps (e.g. NHS Track and Trace) and video consulting at GP surgeries has created additional communication barriers for people with sensory loss and autistic people.

Social care

6. COVID-19 has had a significant impact on the social care sector, and on the rights of people accessing care and support, and unpaid carers. Some key issues are highlighted below:
 - At the outset of the pandemic some local authorities increased eligibility criteria for social care, and social care packages were being reduced or withdrawn leaving people in difficult and distressing situations.² Although emergency legislation allowed for an easing of health and social care

assessment duties, this did not apply to eligibility criteria or existing social care and carer support.³

- Some local authorities in Scotland suspended or altered statutory complaints procedures, raising concerns about the application of human rights, transparency and accountability in public services, and the impact on those that access social care.
- It is unclear how decisions have been made about which social care day services were being reopened during the gradual remobilising of social care day services. This has impacted adults with learning disabilities, people with dementia, children and young people, and rural facilities.⁴
- There are key human rights considerations about the impact of COVID-19 on care homes in Scotland. These include: the correlation between care home deaths and hospital discharges; whether decisions around visiting rights were reasonable, proportionate and in line with human rights; and whether there was adequate testing of care home residents and staff.

Education

7. During COVID-19, ALLIANCE members, PAMIS and Contact indicated that children and young people with profound and multiple learning disabilities had limited access to education whilst restrictions have eased for others.
8. Disabled children and young people have not received specialist educators, or access to specialist equipment and socialising outside of the classroom, impacting educational attainment. For people with sensory loss, touch is also a big part of development, and has been impacted due to social distancing measures.

Mental health

9. During COVID-19, the mental health and wellbeing of disabled people, people living with long term conditions, and unpaid carers has been disproportionately impacted:
 - People affected by deafness and other communication barriers were assessed by phone with no adjustments. Communication and language adjustments must be routinely available to ensure consistent, person-centred care and support.
 - Disabled people are more likely to have experienced anxiety about their physical health, as well as feelings of loneliness and struggling with their mental health during COVID-19.⁵ Research by Glasgow Disability Alliance notes that many disabled people experienced barriers to accessing support

for their mental health, and referrals to GDA's Wellbeing Service increased at the outset of the pandemic.⁶

- Inclusion Scotland found that people were experiencing stress, fear, and anxiety during COVID-19, with many losing access to health services and support for both physical and mental health during the pandemic.⁷ This was particularly acute for people with lived experience of mental health problems, disabled people living alone, or with limited access to digital communication.⁸
- Unpaid carers have provided full time, ongoing care throughout lockdown, often without access to support and respite.⁹ Carers Trust Scotland indicated that 50% of unpaid carers surveyed described their mental health as "worse than before the pandemic", and 34% described it as "much worse".¹⁰
- Disabled women are more likely than men to have sought support for their mental health over the course of the pandemic, or increased the support they are receiving for their mental health.¹¹ Midwifery and health visitor services were initially stopped then restricted, with an impact on maternal and infant health.
- People with learning disabilities, communication and language barriers have faced issues around capacity to make decisions affecting their lives.

Children and young people

10. The pandemic has severely impacted children and young people's mental health, and CAMHS has had limited capacity. Children living in poverty have also been disproportionately impacted by the pandemic, particularly in areas such as food insecurity, where food closures meant that they missed out on free school meals.
11. In relation to Article 12 of the UNCRC, children's perspectives and experiences have not been properly taken into account throughout the pandemic.¹² Children's rights charity, Together, has compiled a list of recommendations to address current challenges to children's rights during the pandemic.¹³

Social care

12. ALLIANCE members have repeatedly shared experiences that social care does not work for many people and families across Scotland:
 - Some people are not receiving adequate, person centred support (e.g. reductions in support, budget cuts, challenges in getting their support needs assessed) with an ensuing impact on human rights and the quality of life/mental wellbeing for people accessing support and unpaid carers.¹⁴

- People have experienced poor communication and relationships with social work professionals, raising concerns about decision making and autonomy; if people’s opinions are not recorded and acknowledged during assessments, then they cannot be said to control or choose their support.¹⁵
- There is inconsistency in the approach to charging for social care in Scotland.¹⁶ ALLIANCE members have described local authority applications for care charges to be complicated.¹⁷

Women’s experiences of social care

13. Social care is vital to society but continues to be undervalued, with low pay and poor terms and conditions. There are long term, ongoing problems with recruitment and retention in the sector, and we often hear of people leaving the sector to do less demanding jobs for similar or better rates of pay.
14. Around 85% of the social care workforce in Scotland identify as female, and around 70% of unpaid care is carried out by women. Issues relating to social care (including workforce issues) are therefore highly gendered. Failure to address these issues will exacerbate the inequality in women’s working conditions and Scotland’s gender pay gap.
15. Unpaid carers receive inadequate financial support, and there is a lack of awareness among unpaid carers about the wider support that is available (e.g. access to Self-directed Support, respite support). Unpaid carers have explained that information about access to social care support, financial support and respite support is often not “forthcoming”.¹⁸

Black and minority ethnic people’s experiences of social care

16. Black and minority ethnic people face barriers to enjoying equitable access to culturally appropriate social care.¹⁹ There are specific issues around stigma, racism, a lack of cultural awareness, and issues with transparency and accessibility in terms of social work processes and paperwork.²⁰

Data

17. There is a lack of detailed, accessible data about social care and who accesses social care. A recent report states that a lack of good quality social care data led to a late response to the care home crisis in Scotland during COVID-19.²¹ Compared to the NHS, a lack of reporting and available data reflects the “relative invisibility of adult social care”.²² This is due to issues such as different reporting periods for social care data across local authorities, and some authorities either not tracking or unable to share disaggregated data.²³
18. There is a need for local and national public bodies to improve systematic and robust disaggregated data gathering and intersectional analysis. This should

explicitly include gender disaggregated data, which distinguishes between the experiences of women as users of social care, and women who are unpaid carers.²⁴ This should include disaggregation by all protected characteristics and socio-economic information like household income and Scottish Index of Multiple Deprivation (SIMD) indicators²⁵. This is essential to ensure that the rights and needs of specific population groups are adequately upheld and considered in public services. Additionally, a lack of adequate data sharing processes are preventing the ambition of health and social care integration.

Impact of EU withdrawal

19. The UK's withdrawal from the European Union (EU) has impacted social care organisations, worsening their ability to fill vacancies. Employed staff and volunteers from across the world are a vital part of the social care workforce in the UK.²⁶ The eligibility criteria for a Health and Care Worker Visa means that social care providers will struggle to recruit international staff, exacerbating existing staff shortages and adding to the pressures already faced by the sector. The uncertainty of the future is a deterrent to recruiting in the sector, and the implications of these challenges will be borne by those accessing care and support.

Other issues

Environmental

20. Disabled people are adversely affected by climate change, but often feel overlooked or excluded in conversations about climate change, and actions to address climate change can create additional barriers for disabled people and people living with long term conditions.²⁷ We need to ensure that disabled people, people living with long term conditions and unpaid carers are involved in climate change discussions, particularly as new legislation and policies are introduced to respond to the climate change emergency.

Adequate standard of living, poverty and social security

21. Although the Scottish Government has made some positive steps to increase the take up of social security payments, there is still a large amount unclaimed. There is also no reliable estimate of the levels of take up for disability benefits, and anecdotal evidence suggests there is significant under-claiming.

22. Personal Independence Payment (PIP) has a very poor level of accuracy of decision making, with a high level of decisions overturned by mandatory reconsideration and appeal. Although this is being replaced by the devolved Adult Disability Payment, with improvements to the assessment and administrative processes, many of the rules and eligibility criteria from PIP are duplicated, so it may not fully address the issues experienced by recipients.

Positive developments in human rights protection

23. There is a growing focus on human rights in Scotland, and a commitment to embedding social, cultural, and environmental rights alongside the civil and political rights contained in the European Convention on Human Rights. Some examples are listed below:

- **The Scottish Sensory Hub.**²⁸ A connecting bridge between the Scottish Government, third sector and individuals with sensory loss. Adopting a human rights based approach, the Hub has three areas of focus: communication, information and mobility and the social model of disability.
- **Health and Social Care Standards: my support, my life.**²⁹ Human rights based, outcomes-focused standards, developed in consultation with people with lived experience.
- **Social Security (Scotland) Act 2018.**³⁰ Acknowledges that access to social security is a human right, essential to the realisation of other human rights.³¹ The Act includes an explicit provision for a right to advocacy for individuals accessing social security under section 10.³²
- **Expansion of free personal care.**³³ Made free personal care available to those under the age of 65 for the first time.
- **Health and Care (Staffing) (Scotland) Act 2019.**³⁴ Strives to drive improvement and assurance in nursing and midwifery, by ensuring appropriate staffing in the NHS.
- **Scotland's second National Action Plan for Human Rights (SNAP2).** SNAP2 will take practical actions to improve the realisation of human rights, and enable Scotland to better fulfil its international human rights obligations. SNAP2 will also provide a practical mechanism to implement recommendations of the National Taskforce on Human Rights Leadership.³⁵
- **Community Links Workers** provide a vital role in supporting people and signposting to support. The ALLIANCE's Links Worker Programme³⁶ has a direct link to the right to health and aims to mitigate the impact of the social determinants of health for people that live in areas of high socio-economic deprivation.
- **Lived Experience Groups.** A growing number of groups and panels comprised of rights holders are being convened to inform and influence policy and practice. Some examples include the People Led Policy Panel,³⁷ the Social covenant steering group,³⁸ and the lived experience panel of the

References

- ¹ The ALLIANCE, 'Health, Wellbeing and the COVID-19 Pandemic Final Report'. Available at: <https://www.alliance-scotland.org.uk/blog/resources/health-wellbeing-and-the-covid-19-pandemic-final-report/>
- ² The ALLIANCE, 'Social care and COVID-19 emergency powers' (1 July 2020). Available at: <https://www.alliance-scotland.org.uk/blog/news/social-care-and-covid-19-emergency-powers/>; The ALLIANCE, 'ALLIANCE policy briefing on COVID-19 social care assessment guidance' (5 May 2020). Available at: <https://www.alliance-scotland.org.uk/blog/resources/alliance-briefing-paper-on-covid-19-social-care-guidance/>
- ³ 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.
- ⁴ The ALLIANCE, 'Reopening social care day services during COVID-19' (16 June 2020). Available at: <https://www.alliance-scotland.org.uk/blog/news/reopening-social-care-day-services-during-covid-19/>
- ⁵ Scottish Government, 'The Impact of COVID-19 on wellbeing in Scotland: Ipsos MORI report' (12 March 2021). Available at: <https://www.gov.scot/publications/impact-covid-19-wellbeing-scotland-work-finances-neighbourhood-support-personal-wellbeing-behaviour-changes/pages/7/>
- ⁶ Glasgow Disability Alliance, 'Supercharged: A Human Catastrophe. Inequalities, Participation and Human Rights before, during and beyond COVID19' (August 2020). Available at: https://gda.scot/app/uploads/2020/09/GDAa_Supercharged-Covid-19Report.pdf
- ⁷ Inclusion Scotland, 'Rights At Risk: Covid-19, disabled people and emergency planning in Scotland' (October 2020). Available at: <https://inclusionScotland.org/wp-content/uploads/2021/05/Rights-At-Risk-Main-Report.pdf>
- ⁸ *Ibid.*
- ⁹ The ALLIANCE, 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'. Available at: <https://www.alliance-scotland.org.uk/people-and-networks/people-at-the-centre-engagement-programme>
- ¹⁰ Carers Trust Scotland, 'COVID-19 in Scotland: The impact on unpaid carers and carer service support workers', p.10. Available at: <https://carers.org/downloads/scotland-pdfs/covid-19-in-scotland.pdf>
- ¹¹ Close the Gap and Engender, *Joint Briefing on the Impact of COVID-19 on Women's Employment, Financial Security, and Mental Health*. Available at: <https://www.engender.org.uk/content/publications/Close-the-Gap-and-Engender-Joint-briefing-on-the-impact-of-Covid-19-on-young-women.pdf>
- ¹² Julie Spray, *Are we being inclusive enough of children in our pandemic response?* Available at: <https://thespinoff.co.nz/society/24-11-2021/are-we-being-inclusive-enough-of-children-in-our-pandemic-response>
- ¹³ Together, *Briefings and research*. Available at: <https://www.togetherscotland.org.uk/about-childrens-rights/coronavirus/briefings-and-research/>
- ¹⁴ The ALLIANCE, *My Support My Choice – People's Experiences of Self-Directed Support and Social Care in Scotland – Reports* (pp.53-57). Available at: <https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/>.
- ¹⁵ *Ibid.*, p.69-70.
- ¹⁶ Social Work (Scotland) Act 1968, s.87. Available at: <https://www.legislation.gov.uk/ukpga/1968/49/section/87> ; *Mental Health (Care and Treatment) (Scotland) Act 2003*, s.28. Available at: <https://www.legislation.gov.uk/asp/2003/13/section/28>
- ¹⁷ The ALLIANCE, *Adult Social Care Review – People at the Centre*. Available at: <https://www.alliance-scotland.org.uk/people-and-networks/social-care-review-people-at-the-centre/>
- ¹⁸ *Ibid.*
- ¹⁹ The ALLIANCE, *My Support My Choice: Black and Minority Ethnic Peoples' Experiences of Self-Directed Support and Social Care in Scotland* (December 2020). Available at: <https://www.alliance-scotland.org.uk/wp-content/uploads/2020/12/ALLIANCE-SDSS-MSMC-Black-and-Minority-Ethnic-Report-Dec-2020.pdf>
- ²⁰ *Ibid.*, pp.72 – 75.

-
- ²¹ Professor Bruce Guthrie, The University of Edinburgh, '*Navigating blindfold in a blizzard: the invisibility of social care in routine data*'. Available at: https://www.ed.ac.uk/files/atoms/files/acrc_briefing_1_social_care_data.pdf
- ²² *Ibid.*
- ²³ Public Health Scotland, '*Insights in social care: statistics for Scotland*' (29 September 2020). Available at: <https://beta.isdscotland.org/find-publications-and-data/health-and-social-care/social-and-community-care/insights-in-social-care-statistics-for-scotland/>
- ²⁴ The ALLIANCE, '*My Support My Choice – Women's Experiences of Self-Directed Support and Social Care in Scotland – Reports*' (December 2020). Available at: <https://www.alliance-scotland.org.uk/wp-content/uploads/2020/12/ALLIANCE-SDSS-MSMC-Women-Report-Dec-2020.pdf>
- ²⁵ Scottish Government, '*Scottish Index of Multiple Deprivation 2020*'. Available at https://www.gov.scot/collections/scottish-index-of-multiple-deprivation-2020/?utm_source=redirect&utm_medium=shorturl&utm_campaign=simd
- ²⁶ Scottish Government, '*The Contribution of Non-UK EU Workers in the Social Care Workforce in Scotland, June 2018*' (June 2018). Available at: <https://www.gov.scot/publications/contribution-non-uk-eu-workers-social-care-workforce-scotland/documents/>
- ²⁷ The ALLIANCE, '*Consultation response – single-use plastic items*' (17 December 2020). Available at: <https://www.alliance-scotland.org.uk/blog/resources/consultation-response-single-use-plastic-items/>
- ²⁸ The ALLIANCE, '*The Scottish Sensory Hub*'. Available at: <https://www.alliance-scotland.org.uk/policy-into-practice/sensory-impairment/about-us/>
- ²⁹ Scottish Government, '*Health and Social Care Standards: my support, my life*'. Available at: <https://www.gov.scot/publications/health-social-care-standards-support-life/documents/>
- ³⁰ '*Social Security (Scotland) Act 2018*'. Available at: <https://www.legislation.gov.uk/asp/2018/9/section/1/enacted>
- ³¹ '*Social Security (Scotland) Act 2018, s.1(1)(b)*'. Available at: <https://www.legislation.gov.uk/asp/2018/9/section/1/enacted>
- ³² '*Social Security (Scotland) Act 2018, s.10*'. Available at: <https://www.legislation.gov.uk/asp/2018/9/part/1/crossheading/advocacy/2019-01-21>
- ³³ The Community Care (Personal Care and Nursing Care) (Scotland) Amendment (No.2) Regulations 2018 - <https://www.legislation.gov.uk/sdsi/2018/9780111038925/contents>
- ³⁴ <https://www.legislation.gov.uk/asp/2019/6/contents/enacted>
- ³⁵ Scotland's National Action Plan for Human Rights, SNAP2. Available at: <http://www.snaprights.info/snap-2>
- ³⁶ The ALLIANCE, '*Links Worker Programme*'. Available at: <https://www.alliance-scotland.org.uk/in-the-community/national-link-programme/>
- ³⁷ Inclusion Scotland, '*People-Led Policy Panel (Adult Social Care Support)*'. Available at: <https://inclusionScotland.org/disabled-people-become-a-leader/people-led-policy-panel/>; Scottish Government, '*Adult social care reform: people-led policy panel*'. Available at: <https://www.gov.scot/groups/adult-social-care-reform-people-led-policy-panel/>
- ³⁸ Scottish Government, '*Social Covenant Steering Group*'. Available at: <https://www.gov.scot/groups/social-covenant-steering-group/>
- ³⁹ SAMH, '*National Suicide Prevention: Lived Experience Panels Expression of Interest*'. Available at: <https://www.samh.org.uk/national-suicide-prevention-lived-experience-panel>