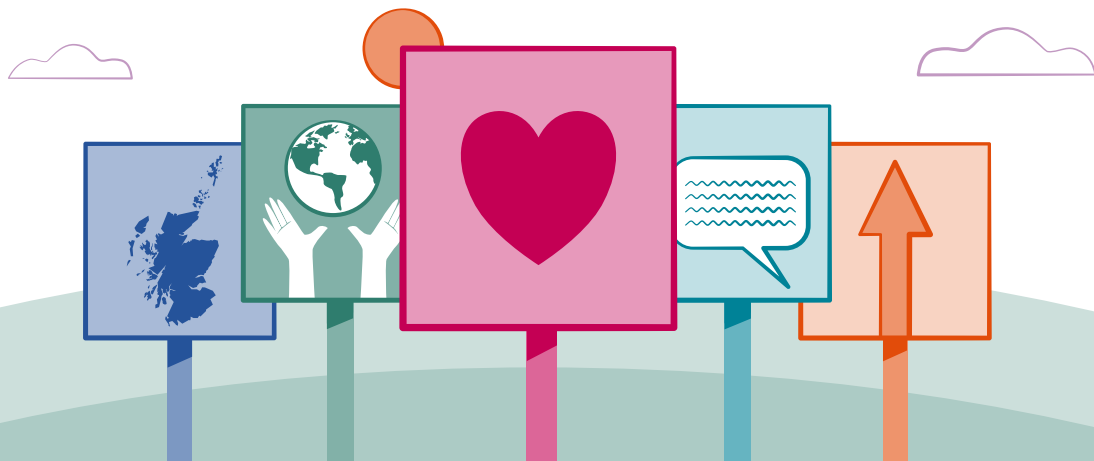


“ The opportunity is now ”

Human rights in health and social care in Scotland:

where we've been and the journey ahead



Barry Black, Paul Pearson and Dr. Jo Ferrie

Research conducted on behalf of the Health and Social Care Alliance Scotland (the ALLIANCE)

branchresearch.com

hello@branchresearch.com

branch
social research

Contents

Key terms	1
Introduction	2
Chapter one: literature review	3
Human rights based approaches	3
The PANEL principles	4
Incorporation legislation	5
Health inequality	6
Defining 'social care'	7
Social care in Scotland	7
Social care staff	8
Impact of EU withdrawal on staffing	9
Unpaid carers	10
Intersectional inequalities	10
The experience of disabled people	11
Detention and guardianship in healthcare	11
Impact of COVID-19	12
Measures	12
COVID-19 and care homes	13
Impact and information	13
Long Covid	14
Chapter two: research deep-dives	15
Example one: Self-directed Support	15
Example two: dignity in healthcare education	16

Chapter three: methodology	18
The selection and aims of case studies	18
Method	19
Participants	20
Analysis	21
Power	22
Chapter four: what next for human rights policy and health and social care in Scotland?	23
Unique and powerful legislation	24
Rhetoric and reality	27
Readiness	29
Inspection	30
Data improvements	31
Coherence of direction and the barriers in the policymaking process	32
Opportunity is now	34
Chapter five: learning from the 'pandemic experience'	35
Key current issues	36
Pandemic exacerbation of existing issues	37
Sector running on goodwill	39
Unpaid care	39
Charles' initial COVID-19 experience	41
Taking on unpaid care	42
Experience of the pandemic	43
Balance of rights	44
Working during COVID-19	46

Chapter six: human rights in healthcare education	50
The aim of the course	51
Use of PANEL	52
Barriers	53
Learnings	54
An interdisciplinary approach	55
Chapter seven: reflections and aspirations for Scotland’s National Action Plan for Human Rights (SNAP)	57
C-Change: SNAP1	58
Aspirations for SNAP2	61
Shape of SNAP2	61
Ownership	62
Cultural Change	63
Conclusion	65
Recommendations	66
References	67
Appendix One - Scottish Government Written Answers	72
Endnotes	79
About the ALLIANCE	82

Key terms

Duty bearer: A person or organisation with obligations to respect, protect and fulfil the human rights of rights holders. This includes State bodies and professionals employed by them such as the Scottish Government, local authorities, social workers, and healthcare professionals.

Economic, social and cultural rights: Recognised in international human rights treaties, these are the essential conditions needed to live a life of dignity and freedom. They include the rights to education, fair and just conditions of work, an adequate standard of living, the highest attainable standard of health and social security.

Human right defender: A person or organisation who works with and for other people whose rights are affected by a situation.

Realisation of rights: Where the State is required to progressively achieve the full realisation of rights over a period of time.

Rights holders: The Universal Declaration of Human Rights states that every individual is a rights holder. Rights holders are entitled to their full range of human rights without discrimination.

Introduction

Scotland is currently at a key moment in its human rights journey. Within the last session of the Scottish Parliament, the Bill to incorporate the United Nations Convention on the Rights of the Child (UNCRC) passed unanimously (before being referred back to the Scottish Government by the Supreme Court). It was also announced that the Scottish Government would — in this current session of Parliament — seek to incorporate four other covenants and treaties.

The International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the Convention on the Elimination of All Forms of Racial Discrimination (CERD), the Convention on the Rights of Persons with Disabilities (CRPD) are all envisaged to be fully incorporated into Scots law. The Scottish Government commitment also includes incorporation of rights not currently covered by specific international treaties — the right to a health environment and the rights of older and of LGBTI+ people.

These reforms — alongside the legislation to create a National Care Service — mean that health and social care services are experiencing incredible structural reform. The sector is experiencing this at a time when it is emerging from the disruption and pressure brought by COVID-19 — and now the cost of living crisis.

This research combines an overarching literature review and analysis of eleven elite interviews across four selected case studies:

- What next for human rights policy and health and social care in Scotland?
- Learning from the ‘pandemic experience’
- Human rights in healthcare education
- Reflection and aspirations for Scotland’s National Action Plan for Human Rights

It aims to capture some of the issues, barriers, aspirations, innovations and experiences of the health and social care sector in Scotland.

This report seeks to begin to unpack the questions and emerging issues which surround health, social care and human rights — what the sector has been through, where it is now, and where it is going.

Chapter one: literature review

The aim of this chapter is to introduce the concepts which are the focus of the research and to give context and background to the key issues which concern it.

Firstly, the chapter sets out what is meant by a 'human rights based approach' and the position of human rights in the policy landscape in Scotland. It then seeks to develop an understanding of inequalities in health and social care in Scotland, before defining social care and discussing some of the key issues which exist in the sector.

Intersectional inequalities in social care are then considered before an exploration of the role of the pandemic, and the issues which have emerged as a result and the experiences of it. This is followed by some 'deep dives' into research which forms the basis of some of the case studies.

Human rights based approaches

Human rights based approaches are increasingly being used within the public, private and third sectors alike. It is a means for people to 'name and claim' their human rights, and for organisations to acknowledge and meet their obligations, better serve those they have a duty towards and improve their services by putting people at the centre of decision making.¹ This approach, and human rights more widely, have received increased prominence as the Scottish Government has signalled its intention to introduce new human rights legislation that would see economic, social, and cultural rights (ESCR) incorporated into Scots law. This increased Government attention is further evidenced in increased funding to some third sector organisations to advance 'the realisation of human rights'.²

Economic, social, and cultural rights are the rights, freedoms, and entitlements that individuals — and communities — have and require to live full and dignified lives.³ They include but are not limited to rights to housing, health, education, food, and cultural identity. In essence, they are the 'everyday' rights of our lives.⁴

It is not just the role of States to ensure access to these rights; they can also be used as a conceptual framework for development, ensuring rights based approaches are inherent within services. Indeed, as many service providers receive some form of State funding, services have legal roots in their obligations to realise human rights. Doing so should ensure that services are built with human rights at their core, but also provide remedial action and intervention if rights are violated. These rights can be understood on a macro-level of State implementation, and on a more micro-level of organisations embedding rights based approaches to their work.

This approach furthermore can be employed from the perspective of the organisations that are responsible (duty bearers) for protecting, respecting, and fulfilling rights by opening up their practices to scrutiny and involving rights holders in decisions making, while also ensuring that they are then accountable for delivering against decisions made. This increase in accountability, in turn, helps to enable rights holders to seek redress when their rights are violated. It aims to set a framework whereby the rights holder is considered at every stage of service planning and creates mechanisms for redress and access to rights.

A human rights based approach often will require an analysis of the inequalities that exist between duty bearers and rights holders and uses the principle of non-discrimination to focus on those who are most marginalised.⁵ At the core of the approach, and this analysis, is planning services and interventions, which aim to rebalance power dynamics and put people at the centre of the services and decisions which impact upon them. This approach also enables employees to view themselves as rights holders in terms of their own lives and be able to frame the issues they face in both their personal and professional lives, as rights issues.

The PANEL principles

The Scottish Human Rights Commission have developed a set of five underlying principles which are key to applying a human rights based approach.⁶ Known as the 'PANEL principles' they are:

- **Participation:** people should be involved in decisions that affect their rights.
- **Accountability:** there should be monitoring of how people's rights are being affected, as well as remedies when things go wrong.
- **Non-discrimination and Equality:** all forms of discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritised.
- **Empowerment:** everyone should understand their rights, and be fully supported to take part in developing policy and practices which affect their lives.
- **Legality:** approaches should be grounded in the legal rights that are set out in domestic and international laws.

Incorporation legislation

In Scotland, the Government is currently seeking to incorporate into Scots law four UN human rights treaties: the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the Convention on the Elimination of All Forms of Racial Discrimination (CERD), and the Convention on the Rights of Persons with Disabilities (CRPD). The Scottish Parliament has also passed a Bill to incorporate the United Nations Convention on the Rights of the Child (UNCRC), but it was referred back to the Scottish Government by the Supreme Court.⁷

Incorporation goes beyond ratification and strengthens the ability to legally require access to rights and creates new obligations for public bodies in designing services and consulting on policy. The ambitious legislation is amongst the first of its kind, and, if written into law, would represent a sea-change towards how human rights are understood and upheld in Scotland. It represents a significant departure from the rhetoric and policy direction of the current UK Government.

Incorporation has the potential to have a significant impact on the provision of health and social care. Though it must be noted, that there already exists a strong statutory framework of human rights in health and social care in Scotland — and there has been for some time. Organisations such as the Care Inspectorate (the regulatory body in Scotland), for example, have begun using human rights based approaches in their inspections. However, organisations such as UNISON note that while the rhetoric is strong there is a gap between this, and practice:⁸



Social and economic policy in Scotland is littered with well-intentioned policies and plans such as promotion of a human rights approach. Despite statutory obligations and repeated Government commitments, human rights have yet to be fully incorporated into the law of Scotland. Human rights remain abstract, unenforceable and ineffective. In the absence of adequate staffing and resources it is care workers who seek to fill the human rights gap.

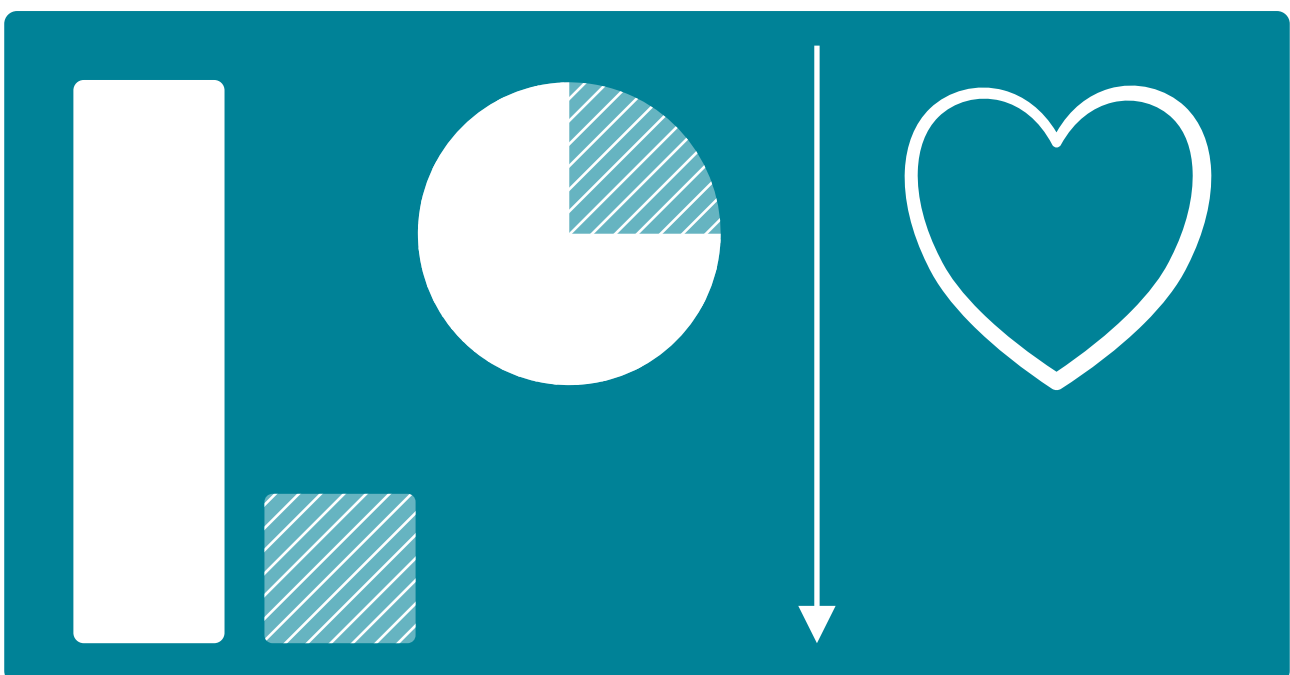
This suggests that there is still a significant gap between where the Government is signalling it intends to go, and where the state of play currently is. The intention of the incorporation legislation is to ensure that there is legality in seeking access to rights, and routes of redress when rights are not realised. The gap between current conditions and realisation highlighted in the care sector by UNISON, perhaps underlines the need for rapid incorporation.

Health inequality

Contemporary understanding of the concept of 'health inequality' stems from the Marmot Review of 2010,⁹ and broader understandings of health inequalities in seminal publications such as 'The Spirit Level'. The research sets out at its core that generally — once a country reaches a certain level of development — the higher its level of income inequality, the higher its level of health inequality. These measures include 'standard' metrics such as life expectancy and prevalence of disability but also rates of mental ill health and happiness. A key tenet of this understanding of health inequality that is of particular relevance to the current research is that more unequal societies have a lower rate of healthy life expectancy, which increases the need for social care and adds pressure to services. While issues such as obesity, smoking and alcohol rates and the lack of exercise, are the causes of poor health, Marmot concludes that inequalities in society are the 'causes of the causes'.¹⁰

'Health inequality' in Scotland is understood by public authorities as 'the unjust and avoidable differences in people's health across the population and between specific population groups'.¹¹ Public Health Scotland notes that their existence contradicts the principles of social justice and that the outcomes of health inequalities for individuals — namely ill-health — are outwith their control, and that they limit the chance to attain and live longer and healthier lives.

Indeed, Scotland has a staggering rate of health inequality. Life expectancy in the country has grown significantly since the 1980s, slowing in recent years, with the life expectancy gap between the richest and the poorest widening over the past five years.¹² Scotland has the lowest average life expectancy in the UK and is amongst the lowest in Western Europe. Of particular relevance to health and social care services is that people born in the most deprived areas of Scotland on average live 24 fewer years in 'good health' than those in the least deprived areas. There are also significant intersectional inequalities faced by underrepresented groups, for example disabled people in Scotland can expect to live substantially fewer years than the Scottish average.¹³ This is the context in which health and social care services are operating.



Defining 'social care'

'Social care' is a broad term that covers a wide range of services which are related to all forms of practical and personal support for those who need it.¹⁴ It is separate but intertwined (in a societal and organisational sense), with the primary healthcare services that are available on the NHS.

It includes, but is not strictly limited to:

- **Care homes:** residential settings where those in need of care will live and receive their support.
- **Residential care:** residential settings, where people live independently but receive a package of care.
- **Care-at-home:** where people will live in their own homes but be supported by social care staff according to their needs.
- **Unpaid care:** where people will receive the care they need from friends, but most often from, family.

The Scottish Government set out that the aim of social care support is to best enable people to live independently, be active citizens, participate and contribute to society whilst maintaining their dignity and human rights.

Social care in Scotland

Social care has seen incredible pressures in funding over the last decade, with cuts in three of the four UK nations (including in Scotland) evident over the last decade. In 2020-21, around 1 in 25 people in Scotland were reported as receiving some form of social care support.¹⁵ This is not to mention the pressure that was forced upon the sector by the COVID-19 pandemic. Around £5.2 billion was spent on social care in Scotland in 2019-20.¹⁶

Social care in Scotland is on the cusp of a significant period of reform. A period of consultation relating to the draft of a human rights incorporation legislation is imminent (as of August 2022), meanwhile plans have been published for a National Care Service (NCS). Stemming from a recommendation of the Independent Review of Adult Social Care,¹⁷ the NCS will aim — according to the Scottish Government — to 'have equality, dignity, and human rights at its heart. It will empower people to make the choices that are right for them'.¹⁸

This will involve legislation¹⁹ to transfer responsibility for social care from local authorities to a new, national service. This may include children’s social care, justice social work and some NHS services. It will establish ‘care boards’ responsible for the delivery of services. Within the general principles of the National Care Service (Scotland) Bill, it aims to introduce rights such as a ‘break for carers’ and guaranteed access to care home visitation (commonly known as ‘Anne’s Law’). Significant anticipation in the sector, and wider society, surrounds the Bill and aspirations of it as a vehicle to drive structural and meaningful change for staff and those in receipt of social care. The Bill has however received criticism. COSLA (the umbrella body for Scotland’s local authorities) have criticised the Bill, contending that the NCS could ‘threaten the delivery of vital services’ and that to move services away from Local Authority control could disempower those who rely on services.²⁰

Social care staff

Audit Scotland have set out stark warnings that there are ‘huge challenges’ facing the sustainability of social care. Key challenges include funding settlements and workforce planning. There are currently 209,690 people working in social care in Scotland (159,260 in full-time equivalent posts) — this represents 8% of the total employment in the country.²¹ This means that the sector is not only key to the health and wellbeing of Scottish society, but to the Scottish economy too. The profession is not well resourced and a ‘typical’ contract for someone providing frontline social care is precarious, has low pay and poor working conditions. It is important to also note in this context that around 84% of the workforce are women. Audit Scotland — using figures from the Scottish Social Services Council, the Care Inspectorate, Fair Work Convention and the Scottish Government — set out that:

20%

are not on permanent contracts

11%

are on zero hours contracts

13%

work over 50 hours a week

15%

work unpaid overtime

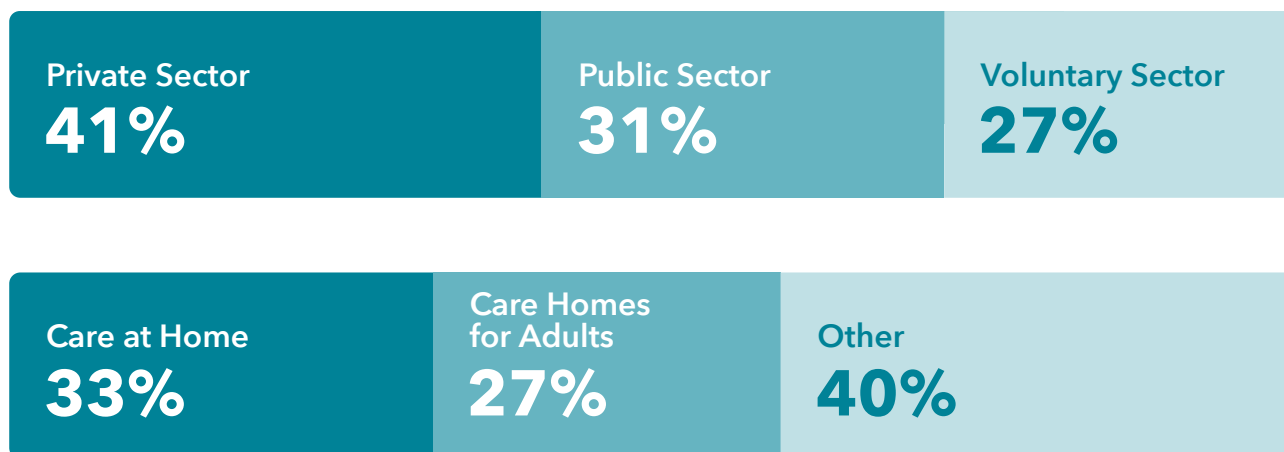
£9.79

is the average hourly pay (with pay generally poorer in the private settings, compared to public sector posts)

The result is that staff turnover and vacancies remain high. Though turnover and vacancy rates reduced during the pandemic (due to the twin-factors of a lack of economic opportunities to leave the sector, and an influx of workers from other sectors which faced restrictions on their activity), they have begun to increase since the relaxation of public health measures.

In December 2020, 36% of social care services in Scotland reported having vacancies, which is just over three times higher than the average across the country. The highest rates of vacancies were reported in housing support, care at home services, care homes for older people and care homes for adults (60%, 59%, 55% and 48% respectively). Experience from the UK sector as a whole shows that there is a large turnover of staff within the sector who move post-to-post or between organisations. In Scotland, private providers face a large turnover of staff as more secure and better paid roles in the public sector become available. As can be seen in table one, there is a fairly even split between the employment sectors, but with a skew towards the private sector.

Table one: Distribution of the paid workforce in Scotland?



Impact of EU withdrawal on staffing

Key concerns have been raised across the UK of the impact of Brexit on the sustainability of the sector. Acute staff challenges have been exacerbated by both the pandemic and the additional challenges of attracting staff following withdrawal from the European Union. In Scotland, 5.6% (or 9,830) of adult social care and childcare staff are EU nationals.²²

There is growing concern that Brexit has deterred EU staff from both joining and continuing in the sector. The emerging impact can be seen in research from the workforce in England which shows that between January - April 2019, 5.2% of all starters in social care were from outside the UK, compared to just 1.8% in January - April 2021.²³ Concern also exists around future plans for the UK's immigration system, which looks set to be points-based with a minimum income needed for visa entry. Current proposals are that a person must earn £25,600²⁴ — which is above the median salary of a frontline social care worker and will have a profound impact on the sector's ability to recruit.

Unpaid carers

There are around 800,000 unpaid carers in Scotland.²⁵ This overshadows the size of the paid workforce, and therefore means that most of the social care support in Scotland is carried out by this group. Audit Scotland set out that many unpaid carers are forced out of employment (reducing their personal income and in so doing, their taxable income) due to their caring responsibilities. Though unpaid carers were extended more rights under the Carers (Scotland) Act 2016, most are not aware, or are unable, to claim them. Carers Trust estimates the value of unpaid care to be £10.3 billion a year. They also estimate that three in five people will become carers at some point, and that one-in-ten is already providing some sort of caring role.

Carers Scotland research shows that 160,000 people a year take on a caring role and that 59% of carers are women. Of the 800,000 carers in Scotland, 56% are employed or self-employed. The main carers' benefit in Scotland is worth just £62.50 per week for a minimum of 35 hours work (though the Scottish Government have introduced supplement support), and half are experiencing some form of financial hardship and insecurity. 80% self-report their own health as being worse due to caring.²⁶

A study conducted by Carers UK on 'caring behind closed doors' during the COVID-19 pandemic revealed that in Scotland, 65% of carers were unable to take any breaks from their caring responsibilities and just over one-in-five said they had not been able to take as many breaks as they needed.²⁷ This has a clear impact on the ability for carers, and those they care for, to access respite and rehabilitation. The report concluded that there has been a significant impact on the mental health of carers — and those they care for — as a result. This 'caring behind closed doors' is critical to the understanding of health inequalities as it highlights situations where human rights are being upheld not by duty bearers, but by large numbers of individuals, many of whom have or can expect to be disabled and/or have long term health conditions and face intersectional inequality. It is unclear to what extent the caring which unpaid carers provide to protect and fulfil the human rights for those they care for, impacts negatively on their own capacity to realise their human rights.

Intersectional inequalities

It must be noted that there is not a neat separation between the workforce and unpaid carers; many individuals are both. This raises questions about the role of intersectionality in health and social care inequality within the existing literature. The Poverty and Inequality Commission have stated that a 'one size fits all' approach to narrowing inequalities leaves people behind, particularly where multiple inequalities intersect. Policymakers should instead seek to better understand who is served by existing policy interventions and public service provision models, and who they serve less well, with a focus on lowering barriers to accessing services and resources for particular groups.

The experience of disabled people

During the COVID-19 pandemic, 20% of disabled women surveyed reported that they had lost support from the government, a figure compounded by 42.9% of disabled women reporting that they had lost support from other people during the period.²⁸

Research from Inclusion Scotland sets out the reality that disabled people face when accessing services with nine-in-ten feeling that they were often treated unfairly due to their disability or impairment when accessing services.²⁹ Just over 80% noted that this feeling was due to the attitude of service providers, and 72% mentioned that the design of services was an issue. The report also sets out how lack of control over services impacted on their experience, alongside invasive questioning when accessing services. The non-discrimination and equality standard of the PANEL principles is not evident in such accounts.

There exists an issue, particularly with certain groups, of disabled people being viewed as a homogenous group whose needs are all the same. In 'A society fit for autistics',³⁰ the authors note that most participants experienced communication barriers. They included not being listened to or taken seriously, the use of ambiguous and imprecise language, and being misunderstood, including as a result of inappropriate expectations about body language and tone of voice.

Detention and guardianship in healthcare

The Mental Welfare Commission investigated detentions under the Mental Health (Care and Treatment) (Scotland) Act 2003 between 1 March 2020 and 28 February 2021.³¹ This study found that detentions increased by 9.1% during this time (in comparison to a five year average increase of 5% year on year). The lack of Mental Health Officer consent in emergency detentions during this period was also highlighted as a major concern, with consent present in 43.8% of cases, a drop of 7.8% when compared with the average from the previous five years. In addition, social circumstance reports dropped from previous years, another safeguarding process that appears as retrogressive, which in turn can be understood as a diminishing of access to human rights. Also of serious concern was an increase in detentions of visible minorities. This again highlights serious issues of multiple discrimination impacting on the human rights of disabled people in Scotland.

Research from People First also raised serious questions with regard to substitute decision making.³² This research published in 2017 showed evidence of an overwhelming tendency for guardianship applications relating to people with a learning disability being uniformly successful. This has created an environment where substitute decision making occurs across a wide range of decisions, dehumanising people as they are informed that they are not allowed to make decisions for themselves. While capacity has been contested legally, and some decisions may need advocates, the PANEL principle of participation should enable people to have involvement in all decisions. A focus on mental capacity (understood as capacity to make decisions independently), as opposed to that of people's ability to co-produce decisions, further entrenched this inequality. High legal costs for both applicants and the State are creating further barriers in these processes.

Of further concern is the ability of the State to ensure that guardianships are working as they should be. The monitoring of these guardianships is compromised by what appears to be a lack of resources of the regulatory body. There is no current mechanism for people to reject appointed guardians, which emphasises a gap between the recognition in law between disabled and non-disabled people. This leads to a situation where it is possible that a disabled person is placed in a guardianship arrangement that they do not want, and where, due to a lack of State redistribution of resources, their Guardianship can proceed free from regulatory oversight. These factors raise serious concerns as to whether all disabled people do in fact enjoy equal recognition before the law.

The Mental Welfare Commission studied in detail 10% of all discharges from hospitals to care homes from March to May 2020. 20 of these cases were considered 'clearly unlawful'. In addition, in 78 out of 267 cases that involved power of attorney, those working in the hospital discharge lacked full awareness of the powers held by attorneys and guardians. In order for this human right to be upheld, it is essential that all involved with these processes fully understand the legal rights of the people involved, and the responsibilities of themselves as duty bearers. The report also noted that the issues raised were not exclusively the result of the pandemic.

Impact of COVID-19

Measures

The impact of COVID-19 on health and social care has been profound. In primary healthcare, the biggest strain on services since the inception of the NHS was witnessed, with the cancellation of most routine procedures and unprecedented restrictions. So too for social care, with not only incredible measures taken to attempt to protect people accessing support and services, but also difficult restrictions such as the cancellation of all visitations in care home settings.

Within many of these decisions, was a departure of human rights being understood as indivisible, towards a reality where choices were made over which rights superseded others. For example, balancing the right to health with the right to private and family life. It brought about tensions in rights, which highlights the need for clear and embedded human rights approaches to bring more clarity in these emergency situations.

Indeed, research found that '[t]here [was] a stark lack of evidence of a human rights based approach to decision making throughout the period March – September 2020' from public authorities in Scotland and that '[h]uman rights are still assigned a subsidiary role in service and policy design when compared to duties under the Equality Act'.³³

Concern was also raised regarding the easing of complaints procedures in social care, the reduction in social care packages, the suspension of assessments and how long these processes have taken to be remobilised.

COVID-19 and care homes

While no part of the sector was unaffected, the situation in care homes was particularly acute. Concerns were raised about the provision of Personal Protective Equipment (PPE) for staff and the ability of staff to keep themselves, and therefore residents, safe. The suspension of visiting rights for families was also questioned, with doubts raised that the length of time those restrictions remained being 'reasonable and proportionate' to protect public health. As mentioned, this issue is sought to be remedied during the National Care Service legislation.

There have been over 3,600 deaths with the confirmed cause being COVID-19 in care homes since the beginning of the pandemic.³⁴ This rate of death was accelerated by the discharge from hospital to care homes of COVID-19 positive patients, as primary health care services in the NHS readied themselves for the wave of cases in 2020, with 338 patients discharged.³⁵ This move directly countered the later aim of the 'no visitor' rule to control the environment.

As early as July 2020, the Scottish Human Rights Commission raised concerns over the death rate in care homes, and the human rights implications which related to it. In particular, concerns were raised at the time over the use of Do Not Resuscitate orders (often without prior knowledge of the individual), PPE and the balance of obligations which the State was exercising.³⁶ It remains an issue of key concern and will undoubtedly be a strong focus of the Scottish COVID-19 Inquiry into the handling of the pandemic.³⁷ Discussing the impact of COVID-19 on social care more generally, UNISON have stated that:



The absence of human rights in social care is a major cause of avoidable infections and deaths during the ongoing pandemic. This has a profoundly disparate effect by gender, ethnic origin, age and disability.³⁸

Impact and information

ALLIANCE research found that those in receipt of social care experienced significant impacts on their mental and physical health and wellbeing during the period, disrupted — and reduced — access to services, and felt that their participation in decisions which impacted upon them was abandoned.³⁹

Scotland in Lockdown, a research project at the University of Glasgow, found that minority groups — including disabled people — found that inconsistent messaging from Government and public authorities contributed to their anxieties (both generally and regarding their healthcare), and that it was often confused with both too much and too little information available at different times.⁴⁰

It was also the case that the rapid move to digital only services and information projection increased the 'digital gap' that disabled communities and older people already experienced.

Long Covid

Long Covid refers to an emerging condition whereby people experience long term symptoms of COVID-19.⁴¹ This is normally understood as symptoms lasting over twelve weeks. While understanding of the condition is in its infancy and developing all the time, there is concern surrounding permanence of symptoms, with some terming it a 'mass disabling event'.⁴²

Long Covid could have profound impacts upon the future of health and social care in Scotland in two key ways:

- **Support:** with 3% of the UK population reporting symptoms of Long Covid, it is likely that the reliance of those affected on either unpaid or paid social care will continue to increase. Long Covid Scotland estimate that the number of individuals with the condition in Scotland to be around 150,000.⁴³ This has profound societal effects, not least in how the State responds to ensure the rights of this group to health, dignity and participation in decisions which impact them are realised.
- **Workforce:** health and social care staff are themselves among the estimated 150,000 individuals with Long Covid. Office of National Statistics (ONS) figures show that workers in social care are more likely to report Long Covid symptoms, with the impact of this on social care provision noted as a 'question to be addressed'.⁴⁴ That the workforce is made up of demographics more likely to report Long Covid — and higher exposure to the virus — there exists concerns in illness and disability within the workforce and what it means for those individuals and their families, and the workforce more generally.

What can be observed stemming from the pandemic is an ingraining and worsening of existing issues and inequalities within health and social care, and the raising of profound questions that stems from reflections on the period. These questions surround the way in which decisions are made, how best to protect service users and staff, and what 'reasonable and proportionate' means when it comes to deciding the supremacy of rights, particularly when they are seemingly at odds with each other in an emergency situation. The question remains how health and social care will adapt to operating post-pandemic, and what is its readiness for the period of significant reform that is underway.



Chapter two: research deep-dives

The aim of this chapter is to provide greater critical depth into issues and research of direct relevance to this research.

It first explores Self-directed Support (SDS) — a domestic social care policy which aims to improve participation and human rights realisation. Then, it considers research which aims to assess student nurses' understanding of human rights and how the conceptualisation of 'dignity' informs their professional practice.

Example one: Self-directed Support

Self-directed Support in Scotland is lauded as a mechanism of delivery of social care which increases the participation of those who are in receipt of it. It delivers greater autonomy of choice for the person who accesses social care and enhances greatly their role in being at the centre of their own care.⁴⁵

Introduced through a 2013 Act of Parliament, it aims to bring a greater realisation of rights by offering those in receipt of social care four 'options' for their care, as defined by Self Directed Support Scotland and the ALLIANCE:⁴⁶

- 1** A direct payment to the individual, who can use it in any way they choose as long as it secures the outcomes agreed between the person and their social worker as set out in their support plan.
- 2** When an individual chooses their support and provider but the local authority or a local organisation maintains control of the budget. In order to make an informed choice, individuals should be made aware of all the resources that are available to achieve their support plan.
- 3** When the budget and support is managed and provided by the local authority in coordination with the individual. The individual should still retain choice and control over the type of support they receive.
- 4** A mix of some or all of the first three options. This is suggested in 2013 Act Statutory Guidance to provide maximum flexibility and may be attractive to those who would like to experiment with direct payments.

In providing these options, SDS has aimed to increase involvement and participation in care, as well as increasing the information and choice that is provided to people about their own packages of care. Due to the process that exists between a person who accesses services and support (the rights holder), the Local Authority or Health and Social Care Partnership (the duty bearer), and providers of care, enhanced collaboration in care and provision of dignity in the process is a key aim. The Local Authority is also duty bound to provide support and advice in decision making over options being reached.

While SDS has been embedded for some time now, and its principles well regarded in enhancing choice and realisation and embedding a human rights based approach in social care,⁴⁷ it is not without issue. Much of the critique stems not from SDS itself, but its implementation, and particularly the different rates of implementation across Scotland's 32 local authorities.⁴⁸

Scottish Care research called for greater collaboration and human rights based approaches to implementation, spaces for dialogue surrounding the issues of implementation and further analysis of how much SDS has actually changed the delivery of social care.

For further information, Scottish Care produced a report on Self-directed Support and Human Rights, with an analysis using the PANEL principles: <https://scottishcare.org/wp-content/uploads/2019/11/A-Human-Rights-Based-Approach-to-SDS-for-Older-People.pdf>.

Example two: dignity in healthcare education

In research from 2017 focused on student nurses' perception of 'dignity' in the care of older people, Macaden and co-authors found that there was an equation among students of dignity with listening to patients, involving them in decision making and upholding their personal privacy.⁴⁹

The research was mixed methods in nature and involved an online survey with 303 undergraduate students at a Scottish university. Three focus groups were then held, with each involving a different group of students from each year of the three year course.

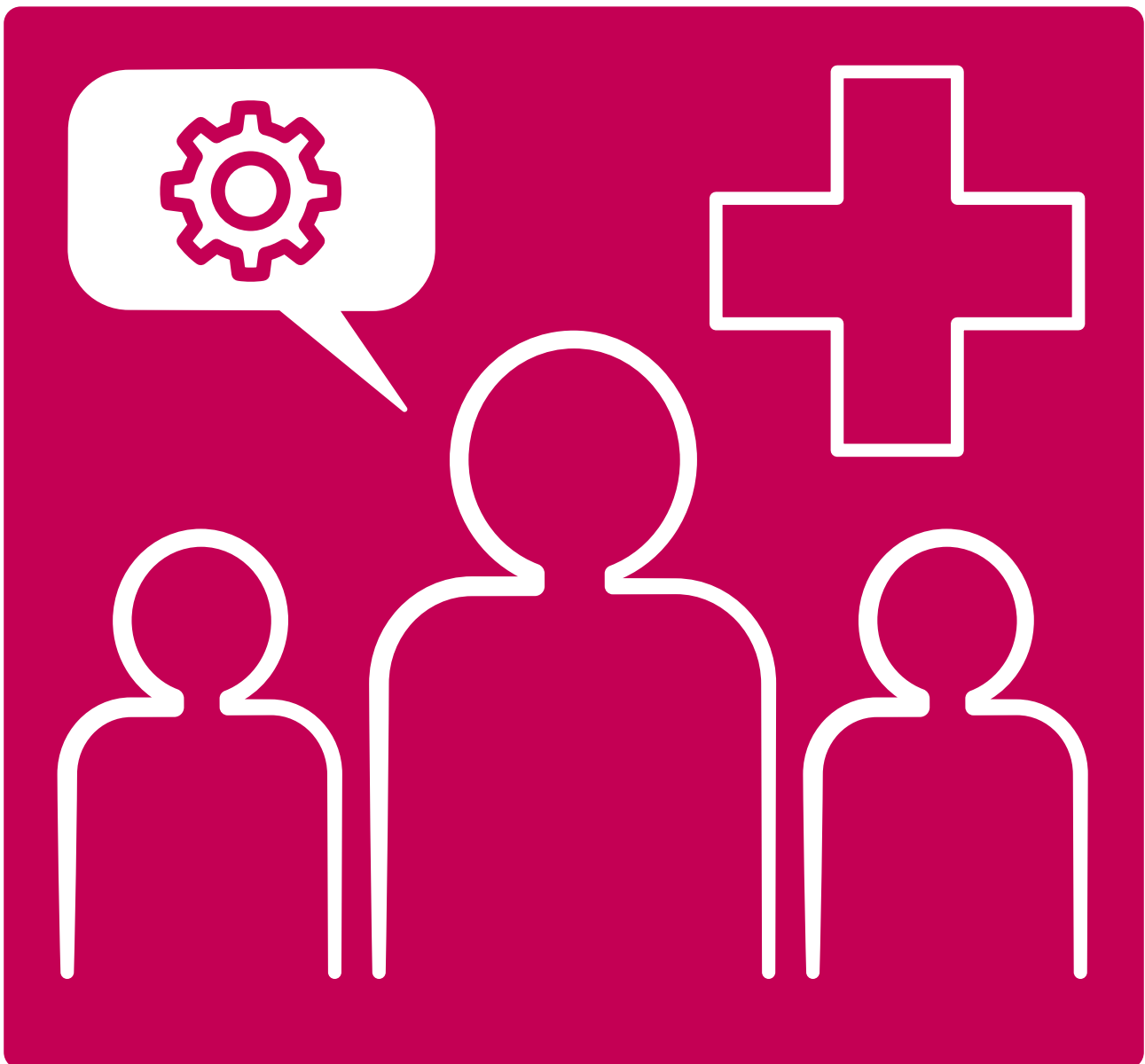
'The 'right to be heard', 'ability to make choices', 'having one's own identity' and 'being valued by other people' as well as being able to express options were among the top understandings of what 'dignity' constituted. Most students rejected that dignity was dependent upon social characteristics such as gender, culture or language. Students were asked to agree or disagree with five statements, with 'supporting patients to make decisions about their own care' being the most agreed with statement.

The study also notes that 'students attending focus groups were united in their views about the caring qualities such as compassion, understanding, empathy, enhancing self-esteem, making people feel valued and acknowledging individual preferences as factors that facilitated the promotion of dignity in the care of older adults'.⁵⁰ The research also found that while students had confidence in their perceptions of what practices could uphold dignity, they were less confident of theoretical understandings.

Crucially, four barriers to the promotion of dignity were identified:

- **Organisational:** these are related to culture, processes and resources.
- **Environmental:** these were factors such as a lack of communal space for mutual connections and ward layout which could be an inhibitor to privacy.
- **Professional:** these were issues such as time constraints.
- **Personal:** these centred on specific attitudes and traits held by individuals like communication skills, emotions (and emotional fatigue), attitudes and prejudice.

The researchers concluded that dignity education for healthcare professionals needs to inform more of the education that is received pre-registration, in particular so that there is time and space for more theoretical understandings and discussions of the concept, so that these can be reflected in their practice.



Chapter three: methodology

The selection and aims of case studies

The research team formed branch social research — a research collective — in 2020 to deliver social justice-oriented work with civil society. Given our political subjective positioning, we developed a research design that begins with objective engagement with the field of literature.

From this point, four case studies have been selected to interrogate the key issues which are raised within the previous literature, and which aim to develop understanding of the current role of human rights in health and social care in Scotland, and its future role.

The selection of case studies was concluded through a dual process whereby branch social research developed aims and scope of the case studies through assessment of the existing literature and identification of key emerging issues, which were then adapted in discussion with the ALLIANCE. These discussions centred around what would be of most use and interest to the sector.

1 What next for human rights policy and health and social care in Scotland?

The aim of this case study is to discuss issues surrounding health and social care with those with influence over human rights policy and legislation. The case study focuses upon how policymakers propose human rights legislation interacts with delivery of health and social care.

2 Learning from the 'pandemic experience'

The aim of this case study is to capture some of the experience that the paid workforce, unpaid carers, and those in receipt of care had during the course of the pandemic. It also seeks to gain insight into how the pandemic has affected the delivery and experience of care now, and how it may change this in the future.

3 Human rights in healthcare education

The aim of this case study is to explore emerging best practice at the University of the Highlands and Islands who have incorporated an 'Understanding Human Rights' module into a nursing degree program, focused on medical practitioners engaging with their practice through the lens of human rights.⁵¹

4

Reflections and aspirations for Scotland's National Action Plan for Human Rights (SNAP)

The aim of this case study was to reflect on progress made since the launch of SNAP, gain learning from one of the organisations which was involved in the process, and to look ahead and discuss the aspirations for SNAP 2 — which is in progress now at the time of writing (August 2022).

Method

Elite interviews were conducted using a range of participants who were identified as being knowledgeable about the areas within the case studies. A range of perspectives were also sought in agreeing the participants who would be approached.

The Scottish Government were invited to interview but requested to receive questions and provide answers in writing. Their answers have been included in Appendix One but have not been included as part of the analysis.

The intention of elite interviews is to speak to individuals — or individuals representing organisations — who are at the 'top' of a system, or who have deep and direct experience and knowledge of a subject.⁵² The aim is to gather a detailed knowledge of a subject area and are often used in research which may consider institutional knowledge and processes.⁵³

It should be noted that although the participants within this research are experts in the areas which they were interviewed about, it is a limited view and care should be made when making vast generalisations from the data. The case studies are reflective of the views of the individuals — and organisations — which participated.

All interviews were conducted online. All except one were conducted one-on-one. Dr. Elaine Webster and Dr. Leah Macaden conducted their interview together.

All individual participants are kept anonymous, except those in academia and politics (identity revealed with their consent). All participants were sent transcripts or draft sections where their data was used, with the opportunity to check data accuracy or withdraw any data.

Participants

In total, 11 participants gave their time to this research. Thanks to them for their time, their insight and critical engagement with the aims and objectives of this work.

Participant	Additional Information
A senior manager within the third sector	Professional experience in international and domestic human rights campaigning and policy.
Pam Duncan-Glancy MSP	An opposition MSP, and Scottish Labour's Shadow Cabinet Secretary for Social Justice and Social Security.
A senior official of UNISON trade union	A trade union which represents staff in the health and social care sector.
A senior manager at the Care Inspectorate	The regulatory body for social care.
Student nurse A	Attended a Scottish University not part of DigniSpace programme, had a placement in a hospital ward in 2021.
Student Nurse B	Attended the University of the Highlands and Islands, and a 'DigniSpace' student.
A person with Long Covid	Is in receipt of unpaid care, pseudonym is 'Charles'.

A staff member from MECOPP	Works with people from marginalised groups, noted that MECOPP do not speak on behalf of the communities, but can share evidence they have gathered with the communities.
Dr Elaine Webster	Senior Lecturer, Law School, University of Strathclyde.
Dr Leah Macaden	Senior Lecturer, Department of Nursing and Midwifery, University of the Highlands and Islands.
A member of C-Change	An organisation which champions Self-directed Support and works with communities to work inclusively towards human rights realisation.

Human rights is a growing area within Scottish civil society and government. The experts involved here often contributed to multiple case studies given their expertise and depth of understanding.

Analysis

All transcripts were uploaded to NVivo Qualitative Analysis Software, and a thematic analysis of each case study was performed to group themes within the intended case study. A second round of analysis was conducted on each interview to theme any data which may be relevant to other case studies.

Power

'Power' is a contested and highly politicised concept. In many definitions, it can be understood as a commodity which is used in relationships and conflict management within those relationships. Often relationships — both personal and 'wider' relationships (like with the State or society, for example) — involve power dynamics between those with power and those without.

While the four case studies are distinct and draw on a diverse range of data, an overarching theme of 'power' was evident throughout. The role of power in the dynamics was a key theme which linked across case studies and became an analytical frame for the research. Whether, how, and by whom power was held, used, gained, taken away, lost, considered and so on, was key to the experience of all participants.

Power imbalances and dynamics had an influence in every case study in the research: whether it was the relationship between the State and the population, between colleagues, those accessing a service and the service itself, family dynamics, or the hierarchical nature of work, power is at the core of relationships and current considerations of the human rights agenda in Scotland.

What characterised many interviews was the active campaigning and work being done to dismantle power imbalances. Thus, power was rarely acknowledged as a passive or unchallengeable imbalance. In many interviews the new human rights legislation was understood as having the potential to deliver a significant shift in who will hold the power to realise human rights, and how easily duty bearers will be held to account for delivering against their obligations.

To use the PANEL principles, empowerment is essentially about equipping service users and communities with the skills required to operate 'power'. This is needed for participation. In this way, participation is the active engagement with duty bearers to co-produce solutions and make decisions. Not so well articulated, but logical nonetheless then, is the idea that if empowerment and participation are truly achieved, then duty bearers and those working for service providers, must in practical and ideological ways, share their power. To put this another way, those with power currently, must operate with less, for a human rights based approach to work.



Chapter four: what next for human rights policy and health and social care in Scotland?

The aim of this case study was to discuss issues surrounding health and social care with those with influence over human rights. The case study focused on how policymakers propose human rights legislation interacts with delivery of health and social care.

Four interviews formed the basis of the analysis of this case study (though one other interview extract was also used):

- A senior manager in the third sector, with professional experience in international and domestic human rights campaigning and policy
- Pam Duncan-Glancy MSP, an opposition MSP, and Scottish Labour's Shadow Cabinet Secretary for Social Justice and Social Security
- A senior official of UNISON trade union
- A senior manager at the Care Inspectorate, the regulatory body



Unique and powerful legislation

A key theme which was threaded through nearly every interview throughout the project was anticipation of the future of human rights in Scotland. There was a strong sense that the incorporation legislation — that will incorporate the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the Convention on the Elimination of All Forms of Racial Discrimination (CERD), and the Convention on the Rights of Persons with Disabilities (CRPD) into Scots law — and which is expected to be passed in the Scottish Parliament this term (before the 2026 election) is an exciting and ambitious approach. As was succinctly described by one participant:



Scotland is on the verge of the incorporation of legislation that would create a unique human rights environment.

It was noted that the journey towards incorporation of international treaties into domestic law has been on the agenda, of the third sector particularly, for some time. With roots in the children's sector and the campaign to have the United Nations Convention on the Rights of the Child incorporated (which was passed by the Scottish Parliament unanimously in the previous session, but 'struck' down by the UK Supreme Court), it began a movement towards incorporation of a range of treaties which started with the First Minister of Scotland setting up an incorporation taskforce led by Professor Alan Miller, former and inaugural Chair of the Scottish Human Rights Commission:



We've also seen that emerging out of the National Taskforce, human rights leadership, into a broader incorporation agenda of other relevant treaties and conventions.

– Third sector participant

Pam Duncan-Glancy MSP, reflecting on the scale of change — and the scale of the challenge ahead — noted that there is still some way to go in the realisation of incorporation. Particularly, she noted that the process of the legislation through parliament may change its scope.

Of critical importance to this, she said, was:



Whether or not the Government decides to take a maximalist approach to incorporation. And whether they make incorporation like pinning jelly to a wall or whether they make it tangible, real, deliverable, accountable, participative. All the kind of things that we would expect from a human rights based approach.

The view that, just because incorporation legislation has been signalled, the campaign is not 'won' spread across participants. In many ways, participants felt that the 'real' campaign — to ensure the legislation is strong, workable and that it meets expectations — was beginning, and this was a strong theme within these interviews.

All participants did note that the intentions of the Scottish Government and their human rights agenda was positive, sincere and had the correct intentions. This was best summed up by opposition politician Pam Duncan-Glancy MSP, when reflecting on the 'human rights agenda' across the United Kingdom:



This current government does try and 'get it', and I genuinely believe they do try to 'get it' but I don't think they always get it right, but I think the intention is there in a way that I don't think it is in the current UK Government, for example.

Indeed, within the anticipation of the legislation was a strong belief that incorporation will bring with it significant changes to the functioning of public services, and fundamental shifts of power from the State and its services (duty bearers) to rights holders:



Ultimately they're putting in place something that, you know, means they're going to have to do things really, really differently from how they're doing it now.

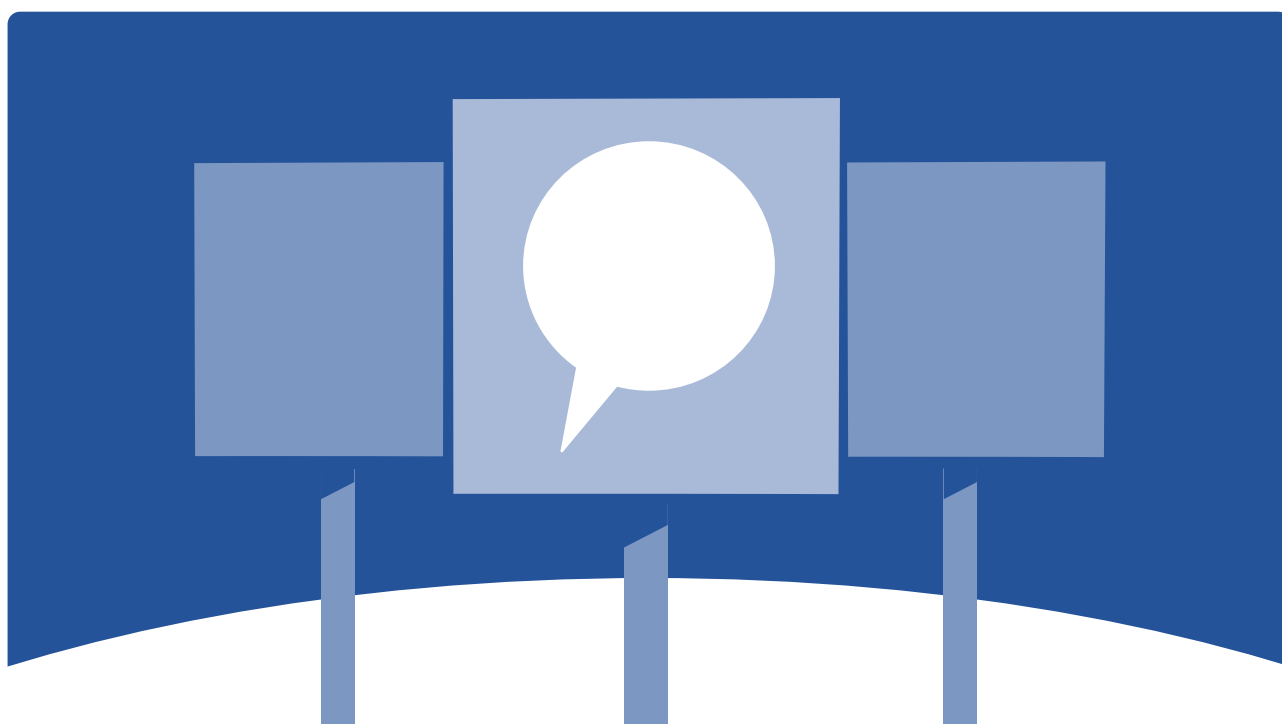
– Third sector participant



I don't know that they [Scottish Government] have made that leap to understand that, in particular for disabled people to call in human rights is going to mean tangible movements of money, probably movements of power and resource and is likely to result, if it's to be meaningful, in a redistribution of income and wealth.

- Pam Duncan-Glancy MSP

Pam Duncan-Glancy MSP also noted that while incorporation needs be about the extension of legal rights to individuals, it must also bring about a broader shift into service design and the participation of those using public services, and broader society, saying that 'it is about participation as an outcome, as well as a process.'



Rhetoric and reality

Underlying the theme of ambition of Scotland's intentions for incorporation was however, that often in Scotland the recent rhetoric around human rights does not meet the reality that is experienced. While this theme is expanded upon in chapter five, there was a strong sense of this theme within policy considerations too.

The third sector participant noted that 'there is an increasing use of rhetoric of rights, but without necessarily a very good, if any, understanding of where that comes from', and that more can be done now — ahead of legislation — to improve the realisation of rights:



It's actually the Scottish Government that has shown it can actually use the powers that are at its disposal to do things and make changes if it so wishes. It's not completely and utterly hamstrung.

– Third sector participant

MECOPP gave an example whereby a taxi company had cancelled a booking from a person who was using the service to access a health appointment when they realised the 'pick-up' point was an area where people from a particular ethnic group lived , saying:



You know, you can talk to people about 'this is your human right', 'This is a right that you have under the Equality Act', for example, but again, it's the difference between policy and practice - or law and practice. And, you know, there isn't a lot of confidence [about realisation].

Within the interviews there was a feeling that 'the State' — as a catch all term for public services and authorities — is still not fully aware of the magnitude of change which is coming, which is a concern given the UNCRC was intended to be incorporated into law by this point in time. Some questions were raised regarding the understanding of human rights among duty bearers with a 'competency gap' described.

Some concern was also raised about the limitations of incorporation in shifting the culture of public services, with the third sector participant stating: 'public bodies will do what they're legally obliged to do', and that:



Duty bearers don't like human rights...you know the clues in the name, that duty bearers have obligations and responsibilities.

As a practical example to rhetoric not matching reality, it was described that, too often the tangible human rights clauses are 'buried' in guidance and not part of primary legislation — thereby diluting or removing the legal recourse and redress — which is the point in incorporation:



The essential human rights - bits of some of that legislation, weren't actually part of the law, but they were part of guidance, which was either not justiciable or enforceable.

– Third sector participant

Of key importance to ensuring that rights are set out in primary legislation, and not just guidance, is that it is justiciability in seeking rights realisation that allows the power to shift from being skewed towards the duty bearer to the rights holder. Commenting on rights being placed in guidance, the third sector participant said:



It doesn't threaten or challenge the power imbalance in it. ...if you're going to put stuff into legislation that people can appeal stuff or whatever, it needs to be done in a rights based way as well.

The third sector participant concluded this point by stating the Government are aware of the expectation of rights being in primary legislation:



...they [the Scottish Government] have heard that actually there's a lot of things people want to put in the primary legislation, because that's the stuff we want to hold you to account on.

Building on this theme, the Care Inspectorate stated with regards to rhetoric matching reality that 'I think it is a journey that has started.'

Readiness

This emerged as a broader theme of 'readiness', where it was set out that more must be done to prepare services in health in social care for the new legislation, despite the integration of human rights principles into services taking place some time ago.

When asked their view on the level of preparedness in the sector for the National Care Service reform and incorporation legislation (despite its draft not yet having been published), the participant from the Care Inspectorate concluded that: 'I would say a lot of work, you know, needs to be done.' This was in terms of the services themselves, but also in the culture and process of the sector — such as the tendering and commissioning process and how human rights based approaches are embedded:



There's no front-end value in evaluation within the commissioning process...Are they going to win the contract on the basis that it's high quality, or they're going to lose it on the basis of price?

– Trade union participant

That human rights standards need more prominence within the commissioning and tendering process for services was a key theme which three interviews focused upon. A feeling also emerged that some duty bearers are further forward than others in preparing for what reforms may mean, and the shift in resources – but particularly the shift in power – that will need to occur:



Some of them get that. And the ones that get that are freaking out about it.

– Trade union participant

Inspection

One of the key drivers of change in the sector can be a shift in inspection to being based in human rights approaches and understandings. It was explained that:



The Care Inspectorate is looking and it's developing a quite practical implementation of human rights in the health and social care standards. [We] have tried to move from having quite prescriptive inputs and a description of quality...the new standards are trying to turn that definition of quality on its head, and to come at 'quality' from someone's lived direct experience of a care service.

While it was noted that the change of approach to inspection has developed changes in human rights approaches in social care, it was also highlighted that the sector has responded in a 'bottom up' way too, in embedding a human rights based approach in practice:

Researcher:



Has [providers] trying to implement a human rights based approach came from the fact that you're embedding standards as an inspector, or has it been a bit more bottom up than that in your experience?

Care Inspectorate participant:



Little bit more bottom up in that, of course the Scottish Government and the current Inspectorate are reflecting the increased expectations of human rights. And you know, we're not working in isolation and we're reflecting, you know, some of the increased expectations.

Expanding on this point, the Care Inspectorate participant described that the Social Care Standards — and the new inspection model — is attempting to ‘articulate’ rights, and that well-being, respect, and dignity are at their core. They argued that the inspection model is intended to be outcome focused, and about the practicalities of rights realisation.

The Care Inspectorate were also keen to stress the importance that they place on ‘user voice’ and that the role of participation, not only in service design, but in inspection was paramount. The intention, they contended, was to create an environment where services were ‘self-inspecting’ on a constant cycle using a human rights based approach. The empowerment of service users in this context is key to move the power during inspection from the inspectorate and the service to the service user.

This view of inspection was not shared by all participants, however. The UNISON official set out views of the workforce over the power they feel the Inspectorate hold, and how it is all encompassing. Expanding, the UNISON official also gave examples of situations where staff had waited, or have been waiting, ‘years’ for complaints handling processes, and has even driven people out of the profession. The differing views of the role of inspection gives some more insight into the theme of ‘rhetoric vs reality’, in that there is no settled view of stakeholders within the sector of how well processes are working, or how standards are being implemented. The trade union representative noted that the overall response of providers to embedding human rights based approaches to service design had been positive, and successful.

Data improvements

One of the key issues that allows a disagreement over policy intentions and reality of service delivery is fragmented and disparate data collection and publication in many areas of health and social care (but mainly in social care).

In talking about performing effective parliamentary scrutiny of the social care system, and ensuring that a policy intention of human rights realisation is met, Pam Duncan-Glancy MSP said:



I think to properly scrutinise whether or not we're doing human rights properly we need to understand and have data disaggregated on the basis of all the protected characteristics, so at a really basic level, and we need to know who our population is, where they work, if they work. Where they play, if they play. Where they rest, if they rest. Where they participate...

A theme in all interviews surrounded how data collection, consistency and publication needs to improve within the framework of the National Care Service — and hopes that the service being brought into a national body may allow opportunity for that. There was also a sense within the interviews with the third sector participant and UNISON that inspection processes and outcomes need to be made more transparent.

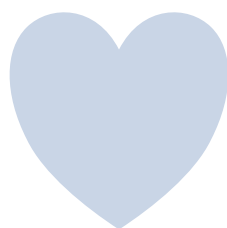
Coherence of direction and the barriers in the policymaking process

One of the potential barriers which was raised regarding the incorporation of human rights was the political and policymaking process in Scotland. The third sector participant maintained that policymaking in Scotland is not conducive to rights-realisation. That there is too much 'siloing' of issues and outcomes directed at, and dealing with, a specific policy outcome instead of approaches which allow realisation of rights:



Everything needs to be broken down into bite-size manageable pieces. 'So, we'll do Social Security here'. 'We'll do poverty there'. 'We'll do health and care here'. 'We'll do economic transformation there'... things end up becoming a bit fragmented.

For example — they said — in mental health, services are being reviewed to deal with the small numbers who require acute mental health support (and that it is of course correct to do) but that no focus on a general 'right to health' in the population and designing services to match that is present within such reviews. They also set out what they saw as an 'implementation gap' in general rights realisation.



That the Government is too wary of allowing the stakeholders into helping, constructing, and aiding the incorporation of legislation was also a noticeable theme. Some participants thought that the Government is too keen to 'own it [the incorporation agenda]' and suspicious of others being too close to the process, in case of losing power and control over it:



There's...a bit of a behaviour and attitude problem in the Scottish Government, that they need to be the ones that have got the answers and know how to do all this. And actually, they need to be a bit more modest and a bit more honest about the fact that they need more learning themselves, and that actually where that knowledge sits a lot of the time in Scotland now is in the third sector, in academia, and then they should be less suspicious about us having ulterior motives.

– Third sector participant

It was also stressed by more than one participant that learning must be taken from other countries which have incorporated treaties into law, and that attention must be paid to the challenges they faced in doing so — so that best practice can be adopted in Scotland from the beginning.

The third sector participant also set out their perspective that there is currently no cohesive Ministerial direction in the realisation of rights across Government — and that there is not full buy-in from the Cabinet:



They don't actually have to do huge amounts to look good internationally compared to the UK Government, but they've decided they want to champion this and progress it and all of this kind of stuff. It's not an ambition that's completely shared by the whole of the cabinet, that's the first thing and that's a problem...

...Some ministers are much more lukewarm on this than others. You know, people are off the record saying 'I'm doing this cause it's the [First Minister] wants me to do it'...the odd civil servant might actually be trying, working within the, to get their Minister more interested in that kind of thing. But that's just going, you know, that depends on personalities and personal interests and stuff like this.

Opportunity is now

So, while there is a broad coalition in Scotland on the rights agenda, there was a feeling that the current political momentum around the rights agenda and incorporation must be seized — and the opportunity realised — in the time of Nicola Sturgeon’s tenure as First Minister.

Pam Duncan-Glancy MSP set out the opportunities for the human rights agenda in health and social care which are imminent, but the scale of the challenge and the shifts in resources and power dynamics that will be required:



I think probably the most important thing I would say is that, if we're really serious in Scotland about making human rights real and using that as a tool to improve social care, there are two opportunities or mechanisms coming down the line.

There is the National Care Service, and there is the human rights incorporation.

But we have to get real about the fact that that will mean moving resources, people, systems, structures to places that they might not have been before and places that [Scottish Government] might not want them to go.

The third sector participant highlighted their experience within the sector, that there are some ‘bad actors’ who are opposed to the legislation ‘because it takes power away from them and they don't want that to happen’. Furthermore, they underlined that it is imperative to act now and legislate while there is a political opportunity to do so.

Chapter five: learning from the 'pandemic experience'

The aim of this case study was to capture some of the experience that the paid workforce, unpaid carers, and those in receipt of care had during the course of the pandemic. It also sought to gain insight into how the pandemic has affected the delivery and experience of care now, and how it may change this in the future.

Six interviews formed the basis of the analysis of this case study:

- A senior official of UNISON trade union
- A student nurse (A) who had a placement in a hospital ward in 2021
- Pam Duncan-Glancy MSP, an opposition MSP, and Scottish Labour's Shadow Cabinet Secretary for Social Justice and Social Security
- A person with Long Covid who is in receipt of unpaid care
- A senior manager at the Care Inspectorate, the regulatory body
- A staff member from MECOPP



Key current issues

These interviews started by asking participants what they felt the current key issues were in health and social care. This was in order to gain an insight into the sector now and assess in later discussion how these issues may have arisen or evolved during the course of the pandemic.

Pam Duncan-Glancy MSP set out what she thinks of the current state of the sector, and how she feels it does not meet the aspirations of the country. She also discussed recruitment issues, and how the terms and conditions and the pressures on services are making in an increasingly unattractive career option:



I don't think we are delivering the social care system that anyone would expect – or want – for the people of Scotland...the terms and conditions [for the paid workforce] aren't very good. In actual fact you're having to do more for less, and a lot of people are actually talking about the ways in which they're being asked to deliver care – it's not what they wanted to do in the first place. From a workforce point of view, I think it's a really, really difficult sector to recruit to.

On a similar theme, the UNISON official highlighted that for some in the sector the terms and conditions were not as good for them as other jobs, and that the sector was losing experienced and skilled staff to other sectors:



...but supermarkets are better paid. People may say 'I don't want to stack shelves but I'd spend less on petrol going to stack shelves. So, I might have stayed in here [the care sector], but I'll go and stack shelves.

Indeed, they described the key issue facing the workers they represent as 'fuel prices'. As the current (August 2022 is time of writing) cost of living crisis deepens and inflationary pressures increase, the trade union official described how the workforce is struggling to make ends meet with their terms and conditions. They raised the point that a petrol allowance or fuel subsidy would ease some of the pressures on staff — particularly care at home staff who use their own cars for travel between visits. For staff, they said, 'we've moved from the COVID-19 pandemic to the financial pandemic.'

MECOPP — an organisation which supports unpaid carers — said that ongoing communication remains a key issue in their work. Particularly as guidance and standards — for both public health measures, and the NCS and human rights incorporation process — are evolving:



Language and communication is a huge barrier, and it is an ongoing barrier. Part of that I think is linked to the age cohort where people are more likely to assume a caring responsibility. Also, to access information, and subsequently having knowledge of your rights and entitlements, being able to advocate for yourself, and to realise those rights and entitlements is severely compromised.

The MECOPP staff member highlighted the ongoing need to ensure that carers — and ‘people’ more generally — are not ‘left behind’ in the rights agenda due to barriers such as language or cultural difference. Talking about the Gypsy/Traveller stream of their work they noted that ‘there’s a general mistrust of services’ and realisation — or empowering people to participate and advocate — will only be possible if trusted relationships are built and the power dynamic between duty bearers and rights holders is challenged in structural and meaningful ways.

Pandemic exacerbation of existing issues

Within the interviews there was an overarching theme that though the pandemic has raised some new issues, its impact was to exacerbate the existing issues and inequalities which were present before 2020. The participant from MECOPP, for example, described the period as ‘supercharging existing inequalities’. Giving an example from MECOPP’s work with Gypsy/Travellers:



With the Gypsy/Traveller community, you know, there’s a high degree of self-employment. You know sole trader, small businesses, et cetera. And obviously people weren’t able to travel. Their ability to earn and provide for the families was again severely impacted.

The UNISON official, and Pam Duncan-Glancy MSP, stressed that issues which were understood about the structure of work in social care pre-pandemic — high staff turnover, stress, low pay, precarity and so on, remain — and have been exacerbated. There was a general feeling of non-support from Government and employers, particularly in how the workforce have been treated since the pandemic. A general scene of chaotic, precarious and erratic working patterns was described, due to high staff turnover, and rates of sickness, particularly from stress and COVID-19:



For those people who stay in care, it's now a much more intense experience. So that's longer working hours, more frequent requests to work additional hours in an existing day, or to double up on cover for people to take additional visits. If it's a care-at-home [staff member], or if it's a mobile worker, they need to work on days off. But also, there is disruption to previously rota-ed shifts, because the supervisors are under pressure because they can't fill shifts.

– UNISON official

MECOPP described the residual effects of the period, where communities that needed quite intense support had that support lost in the emergency response that was needed to COVID-19, or had the support changed to less accessible means:



So, even before the pandemic, people needed a lot of support and encouragement to access services. Then you know – for the last two years – a lot of services shut down. So even where you were receiving a service, you lost it. Or, you know, people were moving almost to an emergency footing, which is understandable. But again, it made it much more difficult to get any support.

For some communities, or people receiving care – particularly those who were older – the move to online or telephone support services 'was not optimum' and a lot of work was needed to even get services up and functional. Across interviews, there was a concern that some who accessed services pre-pandemic, but then disengaged, will not re-engage.

The trade union representative described what they termed 'a perfect storm' that is currently being experienced. They argued that while policy discussions around human rights and the NCS are dealing with the 'macroeconomics of care', the staff in the sector are concerned with the 'micro-economy' of their own lives.

Sector running on goodwill

The UNISON official explained that staff are 'running on empty', and that the only thing keeping the sector afloat is the goodwill and passion staff have for the job. Noting that wages, workload, conditions and stress are push factors for most, but that the care they have for care is for now, keeping the workforce 'on the job'. They said, 'that might be infinite, it may be able to continue like that forever' but that if there is a point at which that goodwill runs out and '[people say] 'I can't do this anymore', and if that cascades, we have a major, major problem. And we have a major economic problem'.

The trade union representative starkly set out that the impact of working in the care sector through the pandemic, into the current conditions, has left the entire sector in a precarious position, particularly given the wholesale reform process that is underway:



We're dangerously close to exhausting our human compassion component of the care sector.

The message within the data was that the sector is only being 'propped up' by the love, care and sense of duty that staff have towards their jobs — and if that goes it may never come back. It is likely that their efforts mean that they are undermining their own individual human rights. For some, the only power they feel they have within the system to deal with the issues is to consider leaving altogether. It is not a position of strength from which to launch serious and structural reform.

Unpaid care

This theme was also present in discussions around unpaid carers — and the stress and burnout they are experiencing. It was noted that this group faces even larger challenges around participation and has an even worse power dynamic with the State than the paid workforce. This is largely down to much of their work being 'unseen' and that many people do not realise they are 'unpaid carers'. Thus, there is a paradox where their work is invisible, yet vital.

From the perspective of a legislator, Pam Duncan-Glancy MSP, concluded that:



We have an over reliance on unpaid care, and I think that is having a detrimental impact on particularly women across Scotland. I think that's got worse over the pandemic, and I don't think we can quantify how bad that is, because I don't think we are collecting the right data.

Another theme within the interviews for this case study was that although in policy terms, the workforce and unpaid carers are often discussed as separate groups many paid carer staff are unpaid carers in their personal lives — and that the toll it is taking is extreme:



So, you have that intensification and disruption of family life, which then disrupts their own care commitments. In our experience, many social care workers are already care committed in that they're both paid and unpaid carers.

– UNISON official

This reality was the case for the mother of a person with Long Covid – 'Charles' – who was a nurse and an unpaid carer for a family member before the pandemic, before also becoming an unpaid carer for Charles during the pandemic.



Charles' initial COVID-19 experience

Describing the initial experience of COVID-19, Charles said:



So, I caught COVID-19 in March 2020. I was one of the first people I knew who got it...I was feeling, you know, dozens of symptoms. Almost a new one every hour – it was like an advent calendar of new symptoms'

In total, I spent about five weeks very unwell living by myself...nobody was allowed in to help me...my girlfriend who lives in a different city, she wasn't able to come and visit, because there was travel restrictions and, obviously, she couldn't come in and I didn't want to spread it to anyone else.

I was in pure survival mode, and I was really depressed. I was not really communicating very much with my girlfriend, which was very worrying for her.

My mum came to the door, you know - distanced - spoke to me, and after, she said that she cried the entire drive home. She lives twenty minutes away from me. And because, she just genuinely had never seen me as bad physically but also mentally...she called me up and basically said 'you come back home.

Initially, Charles was against the idea, because the public health restrictions at the time did not allow for it, and they did not want to accept the need of receiving unpaid care from their parent.

Taking on unpaid care

Charles was forced to reassess the situation as his symptoms continued and as few healthcare professionals were aware, or had gathered experience of, Long Covid at that point:



And I was like I'll just do it, and I said to [parents] 'I'll stay here for a couple of weeks, I'm sure that's all it takes for me to get better...two and a half years later, I still need either my parents or my girlfriend's care to look after me...I have to live, either with my parents or with my girlfriend.

And although they discussed that their condition has improved, they noted that multiple health issues are still being experienced, such as issues with skin, breathlessness, extreme fatigue, cognitive tiredness ('brain fog'), among others.

Charles explained the toll his care can take on family relations:



I basically feel very supported, very loved and very looked after by my family. I do know, sometimes it's frustrating for them...within unpaid care, sometimes the carers feel it, they just have to expect to just soak everything up all the time, and no matter the cost, no matter their own sacrifice. And then, when they get frustrated, it's very easy to see the person you're caring for as not being grateful or like not appreciating the carers needs enough. I guess nobody really talks about [what] those aspects of unpaid care is like - the frustrations and the negatives - because we don't want us to find fault in the people who love and care for us.

Charles also set out the issues that they have had accessing any State support — particularly financial — where their application for Personal Independence Payment (PIP) was initially refused by the Department for Work and Pensions (DWP). This means they cannot contribute to the financial running of the family home as they would like to. This particular point came up within a broader discussion on the impact on Charles' right to family life.

The need for receipt of care also bears heavily upon plans for the future, and for his relationship, and the power dynamics that have to be considered:



So, the only option really for us as a couple going forward is to move in together in the city where she lives, and the amount of fear and caution that I have exhibited because I know I will be putting all of my care needs onto one person.

A key theme within the interview with Charles was the identification that there is a need for a social change in attitudes to human rights and ‘reasonable adjustments’. They set out that fatigue is still a major symptom, and that sitting can only be done for a short period of time, before lying down is required. They described examples where a request for a camp bed has been knocked back by organisations – including the DWP. They said, ‘you know, if you lie down in a public place, it's seen as something's gone wrong.’

They used this example to highlight a core point — that human rights are universal. Describing the insertion of an ‘armrest bar’ to a bench to deter rough sleeping, Charles explained that this impacts on him also, as by not being able to rest in public his participation in public life is severely restricted.

Experience of the pandemic

A theme which was sustained throughout the interviews was the questions raised during the pandemic regarding rights; their balance, which rights take precedence, the process for deciding that, and the power in aiding or impeding realisation of rights. Most acutely, this was raised in relation to the experience in care homes surrounding rights to visitation, and workers and residents experiencing the trauma and anxiety of illness and loss.

Balance of rights

The social care regulatory body – the Care Inspectorate – appreciated the challenges and questions which were raised during the period:



One of the big challenges around the pandemic was the extent to which the right to a healthy life...was balanced with other human rights in terms of rights of families to remain connected.

We need reflection on that – whether the right balance was struck.

A core part of the learning, the regulator said, was finding a solution to the right to remain connected and that they as an organisation we are supportive of Anne's Law which would nominate key individuals who could visit care home in emergency situations. The Care Inspectorate representative stated that, 'we're really pleased to see that that is part of the new National Care Service legislation'.

The regulator also accepted that the beginning of the pandemic challenged people's rights, and that there was complexity in weighing up rights when the public health restrictions were necessary to protect life. A theme that emerged throughout the interviews was that, while it was appreciated decisions were being made in an emergency situation, planning must be done so that these decisions are made and agreed before an emergency situation should arise. It was welcomed that this process has been undertaken in the Scottish Parliament since, and that it allows stakeholders to feed in to guidance that may need to be deployed in a structured way.

A theme within both the interviews with the student nurse and the trade union representative is that there needs to be more prominence within the whole discourse around the rights agenda of the rights of workers. The UNISON official stated that 'what is missing is a recognition of the fact that workers' rights are human rights', and indeed that staff working conditions are the conditions in which people receive care.

Also on this theme, the UNISON official noted that the reading of economic, cultural and social rights around work, and the employment practices present in social care in Scotland are 'different worlds'. Concluding on this point by stating 'the inequality is an injustice, It's an abject business failure'. Highlighting that in the sector, human rights — and realisation of them — are not simply a matter for the power dynamics between the State, workforce and those in receipt of care, but also the companies and contractors trusted with the delivery.

Within the discussion on 'balance of rights', there was also a theme that these considerations only actually matter if people are empowered to realise them, and that the first step towards empowerment is awareness. Particularly amongst the most marginalised communities — for whom incorporation could and should make the biggest difference:



A lot more needs to be done to support the community, and work with the community to know about their statutory rights and entitlements, as the first step in realising them.

– MECOPP staff member

During the pandemic, a large part of the issue for marginalised communities in understanding their rights — and responsibilities — was access to ever-changing information. The digital divide (inequalities in access to computers and the internet) was felt acutely as guidance was uploaded online, and nowhere else. There was also an early challenge of ensuring there was information available in Easy Read form, and for different languages. MECOPP took on some of that responsibility over and above their actual work, and absorbed the costs too:



Just the amount of information that was coming out and about what you could and couldn't do and you know, how do you make that accessible to communities with a diverse range of communications support needs. So, we also had to complete, I mean just literally take that on at very short notice and work with the Government around the whole area of public health messaging in community languages and accessible formats. So, it was a huge amount of additional work.

Working during COVID-19

The representative from MECOPP described how very quickly they had to move their organisation online, and that there was an impact on their staff — who were trying to support themselves and their families through a traumatic time — while also supporting those they work with.

Though, the experience was not all negative (in the context of the emergency). They explained there was an extremely good level of collaboration between services and Government, and that quickly relations with Government were streamlined and the views of MECOPP taken on:



[There was] a really high-level group [we sat on] and it was almost like the usual bureaucracy went out of the window. I mean, you know, and that's not that there weren't checks and balances, there were, but we could move much quicker, and things were done that had never been done before because the emergency needed it...And so absolutely a positive experience there – I think – in terms of the public health messaging.

This theme reiterated earlier themes that a large amount of expertise and experience sits within the third sector, and that meaningful collaboration with it, and the ceding of some power from the State to them can ensure better outcomes for those to whom it matters.

The UNISON official described the experience of those working in care at the frontline of the pandemic, and the ongoing effects:



[Shifts were] including bereavements. But also working with loss. We've got testimony from care workers about infections, and the impact within their rounds, or within the residential facility that they worked in...you know experiences like dealing with six infections, of which two people die.

At the core of the impact that remains is the trauma that has been collectively experienced in the sector. Though care workers are trained to deal with loss, and that over time dealing with it becomes part of professional experience, the scale of loss had a cumulative impact — not in the least because staff were simultaneously concerned about their health, the health of their family and keeping those they care for safe as well. Expanding further, the UNISON official stated that ‘eventually, people get to the point where the aggregate effect of it all goes to being separate traumas and gets people to the point where they can't function’. Part of this experience was some staff feeling guilty about the possibility that they were responsible for infections, and that such psychological pressures, as well as the impact of the pressures on services, has increased burnout.

As has been mentioned, there have been huge issues in staffing levels, particularly in the private sector. As desperation for staff continues, more secure and better paid public sector roles are being filled by migration from the private sector.

These conditions were not just experienced in social care settings, but in primary healthcare settings too. Student Nurse A was on a placement within the National Health Service (NHS) during the pandemic. Student Nurse A discussed the working conditions they experienced as part of their degree, a program that required both academic learning and placements in a variety of frontline healthcare settings.

This required a time commitment that by their estimates ‘averaged 60-hour weeks’ over the duration of their course. This included shift patterns of up to 12 hours; common practice within the sector, but a work pattern that was significantly increased depending on where a student was placed. They noted that ‘the uni expects you to travel up to two hours, to placement and home again. So, if you can get there within two hours, you're required to go, and you can't request a change of placement.’

On one placement this required Student Nurse A to take multiple forms of public transport. This placement saw Student A regularly working on wards with patients who had tested positive for COVID-19 and where risk to her health was consistent once in the hospital:



It was a bus, a train, then another bus, it was so stressful and so unreliable that I ended up cycling and getting the train and then cycling from the train station out to the hospital.

This created an environment where Student A was routinely placed in conditions that were dangerous in order to access her placement:



...sometimes I was just so tired. Like, I don't think riding on busy roads was a safe thing to do. But there were times when like, especially from the train station to the hospital in the morning when it was dark. There was a quite a few times when I was riding in pouring rain on a main road and felt quite vulnerable. So, the only other option was to go like the [specific cycle route, redacted for anonymity] which wasn't safe to go in the dark.

Working time directives are a tool used in this sector to ensure that staff are able to safely carry out their tasks, protecting both staff and patients. The experience of Student Nurse A raises questions regarding what a rota shift looks like in comparison to an actual working day as experienced by student nurses. In their account, Student Nurse A also discussed the increased pressure brought by having academic deadlines during placement, a situation which has the potential to further extend working days. This has serious potential implications for the practice and health of student nurses.

Despite requesting a placement closer to their home, this was denied, and Student A continued to travel in this way during her placement. Once arrived at the placement (a hospital) pre-working conditions were found to be poor:



...there was no changing facilities – everyone just got changed in the toilet.... you had to get there pretty early to be able to get changed, it was quite stressful

In this situation, Student A was effectively powerless to alter the conditions under which they were placed by her university. During this placement, they described regularly exceeding her working time directive, and working on wards that were at times operating with reduced staffing levels, that they (Student A) considered to be 'really unsafe'.

The navigation of this course — and the workload she experienced — was cited as having had a significant negative impact on Student A's physical and mental health. They highlighted regular instances of ill health which they felt they were required to work through in order to maintain their place in the course. They provided a raw account of how their mental health had deteriorated to the point that they needed to access counselling support:



My temper has been really bad... I've completely lost my patience with my child and got to a point where life just managing him was just so difficult. So, I actually pay to see a counsellor just to support me through that. And to kind of help me deal with just to have an outlet I think to deal with all the emotions and the overwhelm.

This wider impact on family life was further unpacked in relation to the cost that they felt becoming a nurse had on her family life, before they spoke of their belief that practices and impacts developed relating to eating habits and domestic life, had become habitual:



...they never said at the start, you can't have a family and do this course. Or they never said at the start, you can't be a carer for someone, or you can't have a sick mother. Or if you do get sick, by the way, you can't continue the course because it's so tight, like the culture is work as hard as you can for someone else, for the patients. You do everything for your patients, and you kind of do it at the expense of yourself.

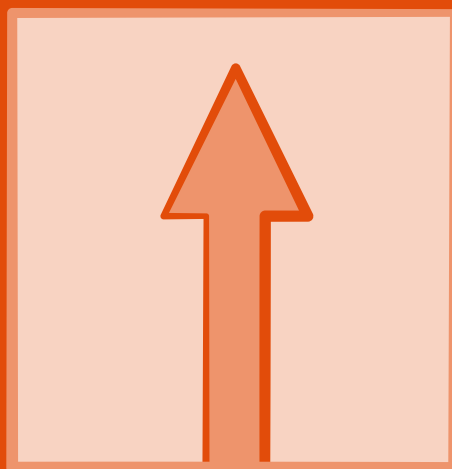
This again highlights the need for a holistic approach to support understanding of student nurses' experience. It also suggests the need for greater understanding of the potential impacts of undergoing this training — particularly in the case of the cohorts that worked in healthcare settings during the pandemic.

Chapter six: human rights in healthcare education

The aim of this case study is to explore emerging best practice at the University of the Highlands and Islands who have incorporated an online resource on 'dignity in care through a human rights based approach' into a nursing degree program. The resource was developed in a cross-institutional research project (funded by the Sir Halley Stewart Trust). The project focused on future nursing practitioners engaging with their practice through the lens of human rights. It also considered the experience of a student nurse who was not at a university who took part in DigniSpace.

Four interviews formed the basis of the analysis of this case study (though one other interview extract was also used):

- Student Nurse A – Nursing student from a University which did not take part in DigniSpace
- Student Nurse B – Nursing student from the University of the Highlands and Islands, who took part in DigniSpace
- Dr Elaine Webster, Senior Lecturer, Law School, University of Strathclyde
- Dr Leah Macaden, Senior Lecturer, Department of Nursing and Midwifery, University of the Highlands and Islands.



The aim of the course



And what we did was, is asked ourselves, is dignity, something teachable?

– Dr Webster

A central aim of this student-centred resource is, according to Dr Webster 'to increase nursing students' confidence, and competence to, to deliver dignity and care within a human rights framework.'. The project aims to contribute to culture change within the sector through empowering student nurses. The embedding of this approach within the education of student nurses aims to ensure this culture change is sustainable. Central to the innovative approach of the resource is the space afforded to students to intellectually engage, from the perspective of human rights law and dignity, and how this applies to their own practice.

To achieve this, an approach was taken where learning would begin from a place of familiarity using the principle of 'dignity', which was in itself a pre-existing embedded principle within nursing as well as being a value underpinning human rights. The approach was pioneering in that the resource was co-produced, primarily with nursing students. It also considered 'dignity' not from the perspective of practitioners or people receiving care, but from the perspective of the future workforce.

Dignity was presented to students as a 'pre-PANEL principle', which was further broken down into 'power, respect, and equal humanity'.

Pre-existing knowledge of human rights prior to students engaging with the course was described as 'pretty minimal' - Dr Macaden, and not related to a person's previous education or age, but by pre-conceptions gleaned from sources such as the media. By beginning with a concept that was already familiar, and whose language regularly appeared in day-to-day life, policy and regulatory contexts, and then moving towards human rights, a connection was maintained between the more familiar, the concept of dignity, and the newer, human rights. This familiarity was utilised as 'a way into talking about a human rights based approach' – Dr Webster. Human rights then served as a lens to explore 'how you can actually uphold someone's dignity' by Dr Macaden. This approach was unique to this specific nursing degree, and in contrast to the (lack of) human rights education that was the experience of Student Nurse A.

Use of PANEL

The PANEL principles were utilised as an overarching framework to inform the design of DigniSpace, and then utilised as learning tool. DigniSpace situated PANEL within the specific context of practice, and then proceeded to 'unpack' them in relation to the concept of dignity. Dignity was presented to students as a 'pre-PANEL principle', which was further broken down into 'power, respect, and equal humanity'.



So, we asked them... How does participation relate to dignity? So, we see, is it really about power? Or is it really about respect? Or is it really about equal humanity, you know, that kind of very kind of, like, deep level sense of equality, kind of substantive sense of equality?

– Dr Webster

The PANEL principles 'guide us as to what a human rights based approach looks like. Dignity tells us why a human rights based approach is important', according to Dr Webster. The use of the concept of dignity was again vital as it further enabled students to apply relevance to their learning. This relevance – a valuable teaching tool – provides a blueprint for staff training in the sector, and more widely.

The 'unpacking' of the PANEL principles produced insights into the use of PANEL itself. Dr Webster underlined the need to engage with all five areas, and the need to engage with the 'L' – legality in PANEL. Legality was highlighted as 'absolutely central', but as something that needed to be broken down. For example, in nursing practice 'legality' is associated with 'accountability'. An explicit clarification was needed, of the distinction between legal accountability that is inherent in health and social care, and human rights accountability. Health and social care providers should be aware that this requires time, knowledge, and commitment to engage with all the principles contained within PANEL. This again underlines the need for organisations that wish to, or become required to, engage with human rights to be able to have access to knowledge and training. For human rights to firmly take root in the health and social care sector, access to these resources is needed. This must apply to all stakeholders in the sector, from major organisations and duty bearers to smaller organisations and crucially those providing unpaid care.

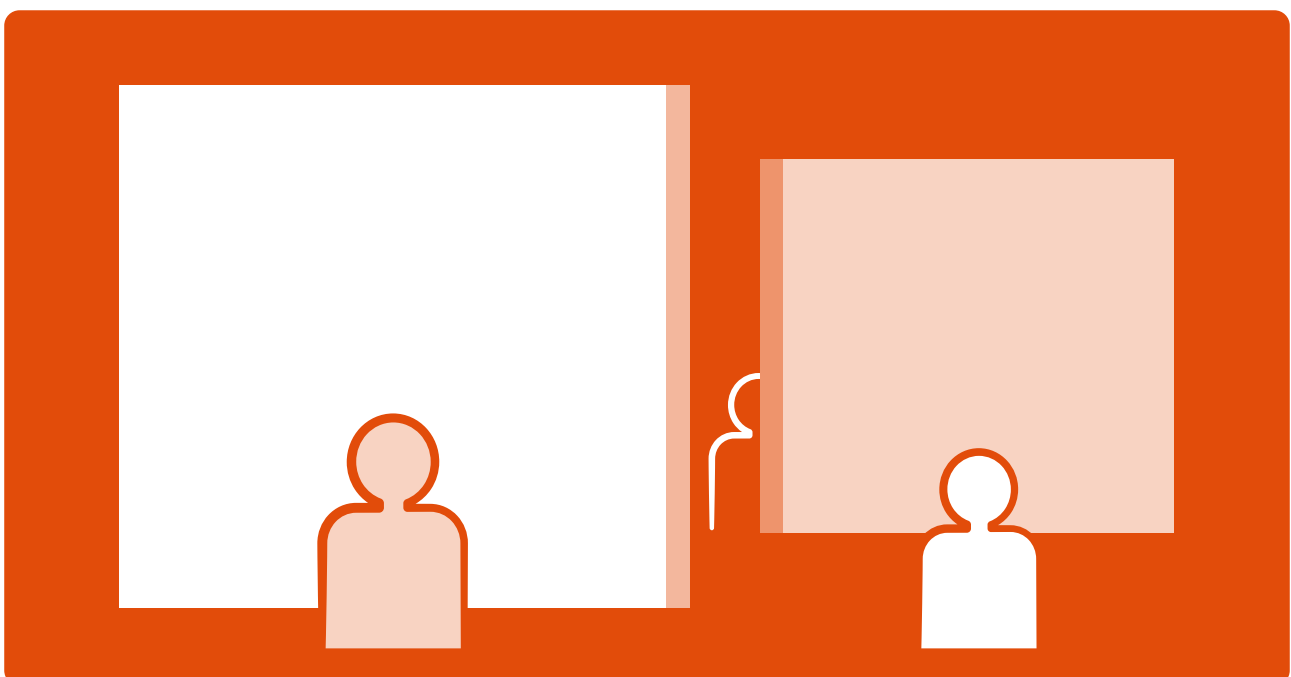
Barriers

There was a strong recognition of the conditions and environment under which student nurses learn and practice. By increasing their own knowledge and confidence in human rights, student nurses would be better equipped to 'recognise when someone's dignity and... human rights are not being upheld in practice.' - Dr Webster – even if they were not necessarily in a position to always challenge it. By unpacking their experience and understanding, barriers to the implementation of their human rights education were revealed:



They [the student nurses] recognise that providing dignity and care was absolutely, you know, paramount. But at the same time, we did talk about the barriers, you know, the time, the confidence to challenge just to work towards the kind of the rate, yeah, that I think those were the main things that the time pressures, the workload pressures... the influence of senior staff as well, especially for students who are in placement... we started to see clearly that there are issues of accountability here as well.

By situating the human rights based approach in context and practice, learning emerged that was particularly relevant to those engaging with DigniSpace. This was highlighted by the particular relevance of 'accountability' — a PANEL principle in itself — given the regulatory and legal implications of accountability in health and social care settings.



Learnings

Whilst DigniSpace was designed primarily for nursing students, the learnings have clear relevance for the health and social care sector as a whole. The need to take time to unpack the terminology was highlighted as required to challenge preconceptions of human rights as being a potential means of scrutiny:



If you're training staff who work in a care home, and you start talking about human rights, I think people do sometimes justifiably have a kind of concern about people being like, well, what's this about?

– Dr Webster

This highlights the complexity of the approach in settings where people are employed in roles on behalf of a duty bearer, and a challenge when engaging in the sector. The need for these approaches to go beyond surface level was highlighted by the researchers:



...for other organisations who want to use a human rights based approach, I would see like to dig into them, you need to dig into them, don't just take it and let it sit there and just talk around it or as if you're doing it, like you have to really grapple with it... in a particular context of practice.

This indicates a need for resources to ensure that people engaging in similar programs have the time and space to understand what a human rights based approach is, and why it is relevant to them and their practice. This relevance must also therefore be recognised by employers and educational institutions who are able to provide the resources — such as the time and training — to achieve this 'realisation'.

Undergraduate students were engaged as it enabled access to large numbers of students at the beginning of their learning journey. By embedding the approach from the outset of the student's degree course, it also allowed for a project that built on learning year-on-year. The researchers reported that this was highlighted by the students who identified the need, in the early stages of co-production, for this training to exist – almost in addition to their qualification. This could be constituted as a form of Continuing Professional Development (CPD). The reality that student nurses will quickly form an essential part of the frontline workforce as part of their training and studies, further underlined the need to engage those working in the sector as early as possible.

An interdisciplinary approach

Both Dr Webster and Dr Macaden discussed the value of having a team drawn from a range of disciplines, each coming at human rights from a different area of expertise:

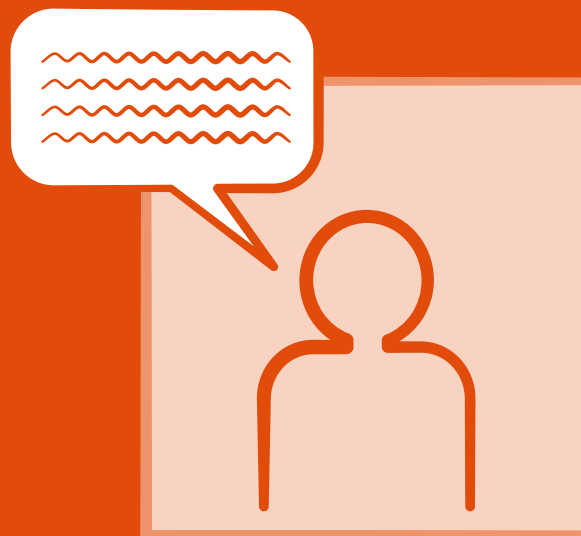


We had a team of colleagues who had this expertise. So, it was almost like, you know, an amalgamation of all these experts and expertise, who are all working towards that same cause, but bringing in their skill set, talent. So, it's quite unique in that sense as well.

– Dr Macaden

This interdisciplinary method to human rights education enabled an approach where expertise in areas such as human rights law, nursing, and education was utilised. It also was able to channel expertise in areas such as co-production (the resource was developed alongside nursing students). This enabled a holistic approach and created an environment where the team involved in delivery of the project grew their own knowledge of human rights and methods.

Student Nurse B spoke of the positive impact of DigniSpace on her practice as a nurse, and how it had raised her own awareness of the role of human rights in nursing; an awareness that they felt they could now communicate to patients. This highlights the potential role for health and social care frontline have to play in the realising of human rights. Nurse B spoke of her previous experience of working in the social care sector and the lack of understanding of human rights in practice:



Student Nurse B spoke of the positive impact of DigniSpace on her practice as a nurse, and how it had raised her own awareness of the role of human rights in nursing; an awareness that they felt they could now communicate to patients. This highlights the potential role for health and social care frontline have to play in the realising of human rights. Nurse B spoke of her previous experience of working in the social care sector and the lack of understanding of human rights in practice:



Everyone knows dignity and privacy, dignity and respect. But like, in terms of how human rights deal with it, is, it's like a question mark.

– Dr Macaden

Student Nurse B went on to call for the widening of access to human rights education to people involved in all areas of healthcare by saying that ‘it needs to inculcate in each student, or anyone working in a healthcare profession, or even this, this consultant or doctors.’ In contrast to the experience of Student Nurse A, they also remarked that the ‘university was really supportive’ during her studies and placements.

Student Nurse B’s call chimed with the work that is currently being carried out to disseminate the learnings from the project more widely. The researchers have shared insights from the resource with organisations outside of higher education, including Scottish Care and the General Medical Council’s Standards and Ethics Team, and plan to explore its application with other bodies, including the Royal College of Nursing and the Nursing and Midwifery Council. There is potential for the value of the approach – and its wider applicability – to be recognised across the sector and beyond.



Chapter seven: reflections and aspirations for Scotland's National Action Plan for Human Rights (SNAP)

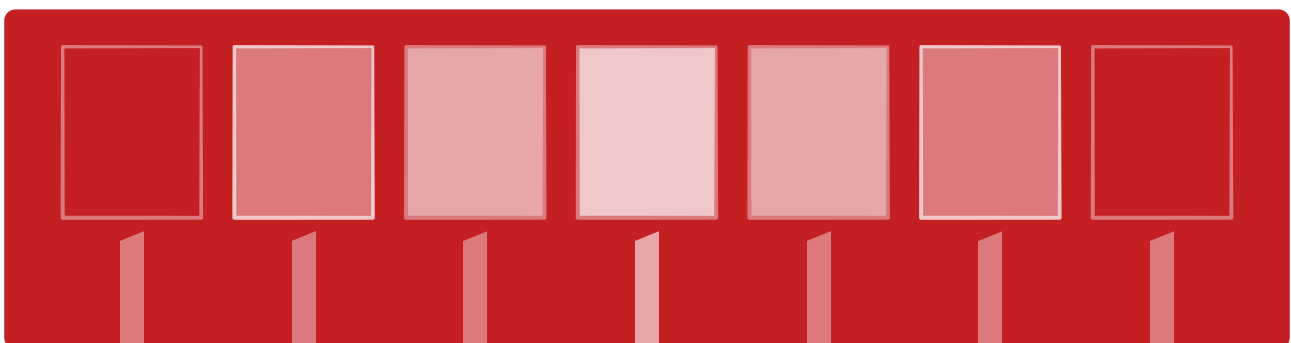
The Scottish National Action Plan on Human Rights (SNAP) was launched in 2013, and its intention was to set out a roadmap towards rights realisation.^{54 55} The first of its kind in the UK, the plan drew together a wide range of stakeholders and developed the route forward together.⁵⁶

The aim of this case study was to reflect on progress made since the launch of SNAP, to gain learning from one of the organisations which was involved in the process, and to look ahead and discuss the aspirations for the second Scotland's National Action Plan for Human Rights (SNAP 2⁵⁷) – which is in progress at the time of writing (August 2022).

Three interviews formed the basis of the analysis of this case study:

- Pam Duncan-Glancy MSP, an opposition MSP, and Scottish Labour's Shadow Cabinet Secretary for Social Justice and Social Security
- A member of mental health charity 'C-Change'
- A senior manager in the third sector, with professional experience in international and domestic human rights campaigning and policy

One of the case studies that was used within the Plan was focused on the work of C-Change — an organisation which works in the area of learning disability, and aims to promote awareness, deliver meaningful support, reduce stigma and work inclusively towards rights realisation.



C-Change: SNAP1

A member of their leadership team set out why they were involved as a case study:



We were asked, because we had used a human rights based approach to our work, we frame what we do, in our work, in terms of human rights, so we think that human rights are incredibly powerful for the people that we work for. And it's the work that we do, in living rooms, and intimate spaces in people's lives, is human rights. It's preserving dignity. It's connected, through intimacy to the national level but also internationally.

Expanding on the universality of human rights language, they said:



Just using the language of human rights gives us a way of connecting to something in your day to day, connecting to something that has such deep roots and international reverberations. It's a unifier. It gives us a system of connection.



Within the case study in SNAP, they reflected that one of the people involved stated that ‘well I knew I had human rights, but I didn’t think they were the same as yours’. One of the key benefits identified about using a human rights based approach was described as giving something to ‘aim for’ — a destination within your work on which every decision can be based on whether you are furthering yourself or the organisation towards that:

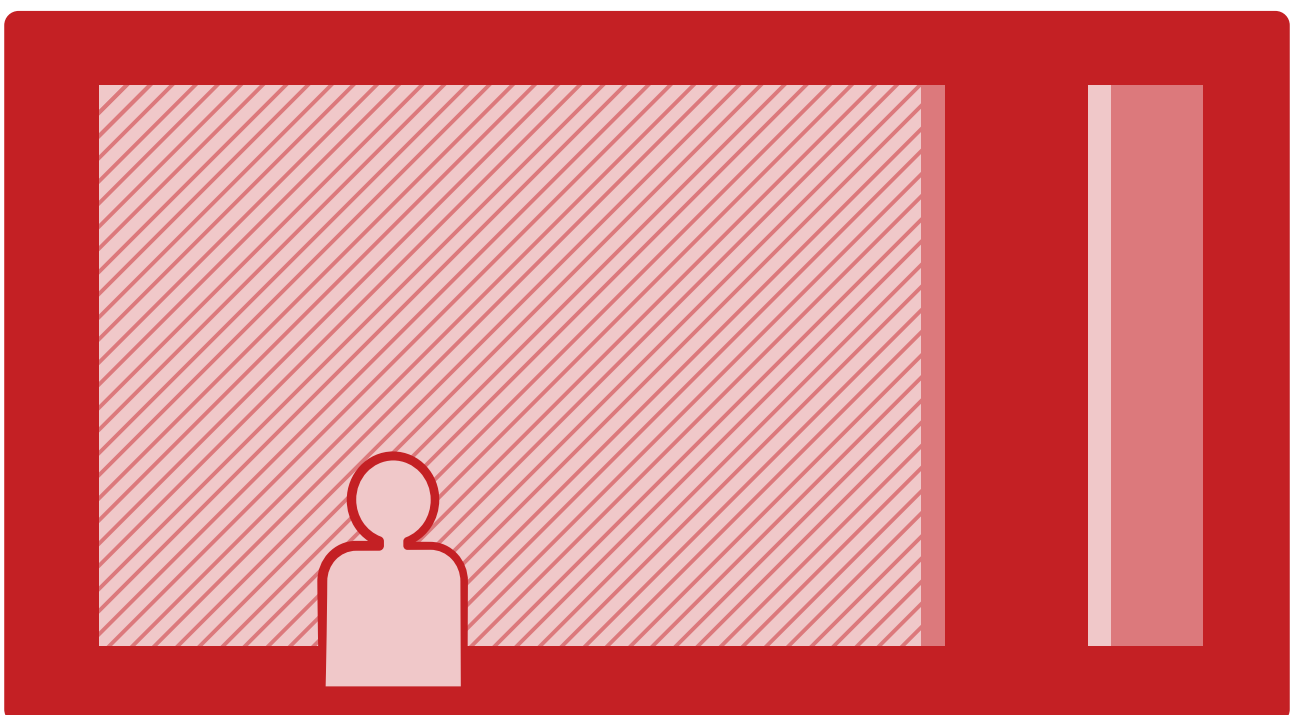


It’s like you have got a north star, you have a direction, something to check. And it just should kind of help you steady yourself. And particularly in the organisation, if we get into a tricky place then we ask, ‘what should we do?’

Reflecting on the journey towards realisation, the C-Change representative noted that barriers exist, particularly in relation to defining ‘minimum core obligations’. Much of these barriers existed within the institutional structures of duty bearers. There is an economic argument that maintains human rights based approaches are too expensive to implement, but the participant set out that the argument does not make sense:



...spend huge amounts of money doing things to people that do not want them done to them. Because the systems say that’s what we should do.



This was illustrated by an example of an experience engaging with a family that the organisation supported:



We were supporting a family, the adult children, the older son ...the family had experienced a lot of trauma, and the older son was removed. The family were trying really hard to hold things together, the son was very distressed, and we were asked to be involved.

He then got excluded from school, the dad asked for some extra funding to support with attending hospital appointments, and help with issues, and the dad asked us for additional support. The additional support they could have, or should have had, would have given him some time to recharge his batteries.

It wasn't a lot to ask for because people don't ask ... what he really needed was more, he needed to have some time to himself. The time that he did ask for, he didn't get. And it fell apart. And I'm not sure that we, as an organisation ... perhaps we lost sight that as an organisation we should be standing alongside him and his son.

It was then decided that [the son] would have to go to a residential school. He was incredibly upset about it and the cost of that was around £200,000. When support would have been a fraction, you know the support needed by him and his dad.

There isn't an economic argument that stands up to that, it makes no sense. And that's without costing the harm that we're doing to the children and families.

The example sets out that in the long run that 'crisis' costs more than 'prevention' and that a restructure in power of public services, from reactive to more preventative, and led by those who need them, is not only a more progressive way of organising public services but makes economic sense as well.

Concluding — and looking to SNAP2 and the imminent legislation — they set out optimism that Scotland was on this journey, and having these discussions:



They have [the Government] got cross-party agreement. So of course, I've got to be optimistic. Because at least, there is an attempt at a direction of travel. There is some resistance [from the UK Government] on Conventions on the Rights of the Child, it's tricky, of course it's tricky, but there is an intent.

Aspirations for SNAP2

Following the success of SNAP, the second Scottish National Action Plan for Human Rights (SNAP2) is currently underway, with the secretariat appointed. The third sector participant highlighted that the new SNAP is being launched on the back of a lot of work, by many, over a sustained period of time:



A huge amount of development work has gone into the next SNAP, you know, four years of development work on top of all the learning that we've got from SNAP1. Including Jo Ferrie's evaluation report,⁵⁸ but also the work of things like the Health and Social Care Action Group and others, and all of which have been very heavily involved for a number of years.

Shape of SNAP2

It is still unclear what 'shape' SNAP2 may take. In terms of the number of 'actions' that may stem from it, their scope and who it will demand action from. This is in part due to the collaborative nature of the project, and that stakeholders — including rights holders — will be empowered to form the shape and intentions of the Plan.

Ownership

What is however an important early consideration in the matrix, however, surrounds where SNAP2 fits in with incorporation legislation. The engagement exercise for the Plan will (likely) run concurrently with the legislation's journey through Parliament. This raises questions in relation to the ownership of SNAP:



Some people are thinking SNAP should be in the legislation. That SNAP should be referred to and made an obligation on the part of government and stuff like that.

There is a danger that — according to the participant — if SNAP2 is within the legislation, the Government become owners of it, and the collaboration that is central to its success is threatened:



We run the risk then of SNAP becoming a Government thing because it will be held accountable for it and it will have to report to Parliament on it, and so on, that threatens it being a collaboration of equals...Duty bearers, civil society and rights holders [should be] working together as part of its governance, in the form of the SNAP Leadership Panel, but also in every single action...

...if it's not [community] owned, [it] becomes something that the Government is held accountable to, it will want to be in charge of how it's done, and therefore it won't be a collaboration anymore. It will be asking civil society and others to just advise it on stuff. And that's not the same as sharing power. It's not collaborative leadership, and it's certainly not consensus decision making.

Cultural Change

A potential aspiration for SNAP2 is to work with the broader legislation to instigate cultural changes in the understanding and appreciation of rights which people — as Pam Duncan-Glancy MSP reflected on — do not always feel are relevant to them:



[Rights realisation is] difficult because 'human rights' initially probably come to people's consciousness as something that happens elsewhere in the world, so they just assume human rights are not a problem here.

The potential for SNAP2 to be the vehicle for cultural shifts, alongside the legislation which will extend rights, was reflected upon:



If you think of incorporation as being the kind of the legal and the policy level of stuff, is that SNAP will be one of the mechanisms by which that will actually translate into palpable action that will lead to palpable change in people's lives...SNAP2 could be doing a lot of heavy lifting...like the wider sort of human rights education and awareness piece in order that the incorporation will actually work overtime and so on and be more focused on getting Scotland to have more human rights culture broadly across the whole of society and stuff like that.

– Third sector participant

Indeed, a strong theme throughout the interviews of all case studies was about the need for greater education and awareness of rights — both generally, and particularly for minority groups who face barriers in accessing and realising their rights:



...that education and awareness raising is going to actually happen now. There might be something in the Incorporation Bill or secondary legislation about that, but SNAP2 might actually be the place where there's an action that local authorities, Scottish Government health boards, partnerships, civil society and rights holders will work together to develop a human rights education and awareness raising program for commissioners and service providers in health and social care.

This highlights that SNAP2 has potential to further be of value as a means of forcing collaboration in empowerment and raising awareness. This further underlines its central importance to the realisation of rights in Scotland.



Conclusion

The Scottish Government's policy intentions for the incorporation of human rights are to be welcomed. There is anticipation and expectation within the sector that the National Care Service reforms – as well as the incorporation legislation – will begin to improve standards, conditions, and care within the health and social care sector. Described as creating a 'unique human rights landscape', the current signal of trajectory is a positive one. Though – at the time of writing (August 2022) – the draft incorporation legislation is still to be published, there is some evidence of planning in the sector already being underway.

Serious questions remain, however, surrounding how well rhetoric meets reality in Scotland with regards to human rights realisation. The 'pandemic experience' – which was pointed out is not yet over – has 'supercharged' inequalities and exacerbated the existing issues within the sector. Low pay, precarity, irregular working patterns still dominate the sector, with high staff turnover increasingly putting pressure on the sustainability of services. Some participants within the research emphasised that 'workers' rights are human rights' and that staff working conditions are the conditions in which people are cared for. Workers must also be viewed as rights holders themselves. Current descriptions of pressures facing staff in health and social care settings – as well as unpaid carers – and their morale, is not a position of strength on which to launch serious structural reform.

There are also positive innovations emerging of how a human rights based approach can improve practice and positively impact care within the sector. This was evidenced through DigniSpace at the University of the Highlands and Islands, which was aiming to grow the understanding and practice of human rights in pre-registration education and in frontline healthcare settings. A key part of DigniSpace's success was the situating of human rights within a context that was familiar with those taking the course – nursing – and using a concept that also had familiarity: dignity. This approach is clearly scalable and applicable across sectors.

The policy making process was also highlighted as a barrier, with calls for a need of greater collaboration, and of assessing policy more holistically. So too, is a need for a 'maximalist' approach to human rights incorporation, which empowers rights holders to access their rights through primary legislation. Human rights based approaches require analysis of the inequalities that exist between duty bearers and rights holders. This highlights the need for a transparent recognition of existing power imbalances, and processes to re-distribute power.

Also identified was a need for a cultural shift as to how Scottish society more generally understands rights and their relevance to life here. The second Scottish National Action Plan for Human Rights (SNAP2) has clear potential to be a vehicle for instigating such change, while the Incorporation Bill is the vehicle for legal change – and may begin the vital process of rebalancing resources and power. Human rights legislation was understood as having the potential to deliver a significant shift in who will hold the power to realise human rights, and how easily duty bearers will be held to account for delivering against their obligations.

This report has highlighted the potential of human rights based approaches to re-distribute power within the health and social care sector. What is clear is that for human rights based approaches to take root and enact change within the sector, those with power currently, must operate with less of it.

Recommendations

We make the following recommendations:

- Incorporation of human rights should take a 'maximalist' approach, which sets out rights and access to rights in primary legislation.
- Organisations in health and social care should take a human rights based approach to evaluating their own current practices and staff terms and conditions, analysis of the inequalities that exist between duty bearers and rights holders.
- Staff working in health and social care must have their human rights upheld and be empowered to name and claim them.
- Human rights based approaches should carry greater weight in commission and tendering processes in health and social care.
- Wider roll out of human rights education in practice should be considered by Government, national bodies, and institutions.
- Organisations which claim to use a human rights based approach should clearly evidence how rights holders are involved at each stage of their process.
- Increased and robust data collection is needed to understand intersectional inequalities in health and social care.
- Though there has been good progress and initiatives, wider awareness raising, and cultural understanding of human rights is needed across society – particularly amongst those communities who are the furthest from the realisation of rights.

References

The Health and Social Care Alliance Scotland (the ALLIANCE) (2022) *Ensuring a person-centred approach to re-mobilisation across health and social care services in Scotland*. ALLIANCE. Available from: <https://www.alliance-scotland.org.uk/people-and-networks/people-at-the-centre-engagement-programme/>

Animate Consulting Ltd (2017) *Does it matter? Decision-making by people with learning disabilities*. People First (Scotland). Available from: <https://www.drilluk.org.uk/wp-content/uploads/2017/08/People-First-Scotland-Animate-Full-research-report.pdf>

Audit Scotland (2022) *Social case briefing*. Audit Scotland. Available from: https://www.audit-scotland.gov.uk/uploads/docs/report/2022/briefing_220127_social_care.pdf

Blasey, Laura and Hubbard, A. (2022) *Today's Headlines: Long COVID, the 'mass disabling event'*. Los Angeles Times.

Care Inspectorate (2022) *Covid-19 adult care home statistics*. Care Inspectorate. Available from: <https://www.careinspectorate.com/index.php/site-search>

Carers Scotland (2014) *Facts & Figures*. Carers Scotland. Available from: <https://www.carersuk.org/scotland/news/facts-and-figures>

Carers Trust (2022) *Our work in Scotland*. Carers Trust. Available from: <https://carers.org/our-work-in-scotland/our-work-in-scotland>

CarersUK (2020) *Caring behind closed doors: Forgotten families in the coronavirus outbreak*. CarersUK. Available from: https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf

Christie, B. (2020) Covid-19: 338 patients with the virus were discharged from Scottish hospitals to care homes. *BMJ*, 371: m4225 <https://doi.org/10.1136/bmj.m4225>

COSLA (no date) *National Care Service plans could threaten delivery of vital services, COSLA warns*. COSLA. Available from: <https://www.cosla.gov.uk/news/2022/national-care-service-plans-could-threaten-delivery-of-vital-services,-cosla-warns>

COVID-19 Longitudinal Health and Wellbeing National Core Study (2021) *Short Report on Long COVID*. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1007511/S1327_Short_Long_COVID_report.pdf

DigniSpace (2022) *Online Dignity Engagement Space For Nurse Education*. DigniSpace. Available from: <https://dignityandhumanrights.uhi.ac.uk/site/>

Feeley, D. (2021) *Independent Review of Adult Social Care (IRASC)*. Scottish Government. Available from: <https://www.gov.scot/publications/independent-review-adult-social-care-scotland/documents/>

- Ferrie, J. (2019) *Evaluation of Scotland's National Action Plan for Human Rights (SNAP) 2013-2017*. SNAP Rights. Available from: <https://www.snaprights.info/wp-content/uploads/2019/07/SNAP-Evaluation-vFinal-16-July-2019.docx>
- Hochschild, J.L. (2009) *Conducting Intensive Interviews and Elite Interviews*. Workshop on Interdisciplinary Standards for Systematic Qualitative Research. Available from: <https://scholar.harvard.edu/jlhochschild/publications/conducting-intensive-interviews-and-elite-interviews>
- Home Office and UK Visas and Immigration (2020) *New immigration system: what you need to know*. Gov.uk. Available from: <https://www.gov.uk/guidance/new-immigration-system-what-you-need-to-know>
- Human Rights Consortium Scotland (HRCS) and Amnesty International Scotland (AI Scotland) (2020) *Delivering Human Rights In Scotland During COVID-19: A 2020 Survey of Public Authorities*. Human Rights Consortium Scotland. Available from: <https://hrcscotland.org/wp-content/uploads/2021/05/Final-Delivering-Human-Rights-During-COVID19-survey-report-May-2021.pdf>
- Inspiring Scotland (2021) *Equality and Human Rights*. Inspiring Scotland. Available from: <https://www.inspiringscotland.org.uk/equality-and-human-rights-fund/>
- International Justice Resource Centre (no date) *Economic, social and cultural rights*. International Justice Resource Centre. Available from: <https://ijrcenter.org/thematic-research-guides/economic-social-and-cultural-rights-2/>
- Jones, G. (2020) *Social care "postcode lottery"*. Third Force News (TFN). Available from: <https://tfn.scot/news/social-care-postcode-lottery>
- Justfair (no date) *About economic, social and cultural rights*. Justfair. Available from: <https://justfair.org.uk/about-us/economic-and-social-rights/>
- Long Covid Scotland (2021) *Long Covid Scotland are collaborating with partners to find solutions for people living with Long Covid*. Long Covid Scotland. Available from: <https://www.longcovid.scot/manifesto>
- Macaden, L., Kyle, R., Medford, W., Blundell, J, Munoz, A., and Webster, E. (2017) 'Student nurses' perceptions of dignity in the care of older people', *British Journal of Nursing*, 26(5), pp. 274–280. Available from: <https://doi.org/10.12968/bjon.2017.26.5.274>.
- Marmot, M., Atkinson, T., Bell, C. Broadfoot, P., Cumberlege, J., Diamond, I, Gilmore, I., Ham, C., Meacher, M., and Mulgan, G. (2010) *Fair Society, Healthy Lives: The Marmot Review*. Available from: <https://www.parliament.uk/globalassets/documents/fair-society-healthy-lives-full-report.pdf>
- McGregor, R. (2020) *Services for Who? The experiences of disabled people with other characteristics when accessing services*. Inclusion Scotland. Available from: <https://www.drilluk.org.uk/wp-content/uploads/2020/06/Services-for-who-final-report-1.pdf>

Mental Welfare Commission for Scotland (2021) *New consultation – investigating deaths during compulsory care and treatment under mental health laws in Scotland*. Mental Welfare Commission for Scotland. Available from: <https://www.mwscot.org.uk/news/new-consultation-investigating-deaths-during-compulsory-care-and-treatment-under-mental-health>

Miller, A. (2022) *The Supreme Court's judgment on the UNCRC (Incorporation) (Scotland) Bill – what will be the impact on Scotland's human rights journey?* University of Strathclyde. Available from: <https://www.strath.ac.uk/humanities/lawschool/blog/thesupremecourtsjudgmentontheuncrcincorporationscotlandbill/>

Miller, C. (2019) *A human rights based approach to self-directed support for older people*. Scottish Care. Available from: <https://scottishcare.org/wp-content/uploads/2019/11/A-Human-Rights-Based-Approach-to-SDS-for-Older-People.pdf>

Moyser, G. (2006). Elite interviewing. In V. Jupp (Ed.), *The SAGE dictionary of social research methods* (pp. 85-86). SAGE Publications, Ltd. Available from: <https://dx.doi.org/10.4135/9780857020116.n60>

NHS inform (2022) *What is long COVID?* NHS inform. Available from: <https://www.nhsinform.scot/long-term-effects-of-covid-19-long-covid/about-long-covid/what-is-long-covid>

Pearson, P., Robertson, L., McHardy, F. (2022) *Marginalised Communities and Economic, Social and Cultural Rights in Scotland: A literature review*. The Poverty Alliance. Available from: <https://www.povertyalliance.org/wp-content/uploads/2022/05/RIA-Review-April-2022-Final-PDF.pdf>

Public Health Scotland (2021) *What are health inequalities?* Public Health Scotland. Available from: <http://www.healthscotland.scot/health-inequalities/what-are-health-inequalities>

Public Health Scotland (2022) *Insights in social care: statistics for Scotland*

Scotland in Lockdown (no date) *Home*. Scotland in Lockdown. Available from: <https://scotlandinlockdown.co.uk>

Scotland's National Action Plan for Human Rights (no date) SNAP 1 Evaluation. SNAP Rights. Available from: <https://www.snaprights.info/evaluation>

Scottish Government (2018) *EU workers in Scotland's social care workforce: contribution assessment*. Scottish Government. Available from: <https://www.gov.scot/publications/contribution-non-uk-eu-workers-social-care-workforce-scotland/>

Scottish Government (2022) *COVID-19 Inquiry*. Scottish Government. Available from: <https://www.gov.scot/publications/covid-19-inquiry/>

Scottish Government (2022) *National Care Service Bill Published*. Scottish Government. Available from: <https://www.gov.scot/news/national-care-service-bill-published/>

Scottish Government (no date) *National Care Service*. Scottish Government. Available from: <https://www.gov.scot/policies/social-care/national-care-service/>

Scottish Government (no date) *Social care*. Scottish Government. Available from: <https://www.gov.scot/policies/social-care/>

Scottish Human Rights Commission (2010) *A human rights based approach: an introduction*. Available from: https://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf

Scottish Human Rights Commission (2020) *COVID19: Care homes and human rights*. https://www.scottishhumanrights.com/media/2054/coronavirus-care-homes-briefing-140720_vfinaldocx.pdf

Scottish Human Rights Commission (2022) *Scotland's National Action Plan for Human Rights (SNAP)*. Scottish Human Rights Commission. Available from: <https://www.scottishhumanrights.com/projects-and-programmes/scotlands-national-action-plan/>

Scottish Human Rights Commission (2022) *Social Care*. Scottish Human Rights Commission. Available from: <https://www.scottishhumanrights.com/our-law-and-policy-work/social-care/>.

Scottish Human Rights Commission (2022) *Scotland's National Action Plan for Human Rights*. Available from: <https://www.snaprights.info/#:~:text=Since%20late%202017%2C%20work%20has,2017%20involving%20over%201%2C000%20people>

Skillsforcare (2021) *The state of the adult social care sector and workforce in England*. Skillsforcare. Available from: <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/national-information/The-state-of-the-adult-social-care-sector-and-workforce-in-England.aspx>

SNAP (2013) *Scotland's National Action Plan for Human Rights 2013 – 2017*. SNAP Rights. Available from: <https://www.snaprights.info/wp-content/uploads/2016/01/SNAPpdfWeb.pdf>

Support provided or funded by health and social care partnerships in Scotland 2019/20 - 2020/21. Public Health Scotland. Available from: <https://publichealthscotland.scot/publications/insights-in-social-care-statistics-for-scotland/insights-in-social-care-statistics-for-scotland-support-provided-or-funded-by-health-and-social-care-partnerships-in-scotland-201920-202021/>

The Fawcett Society (2022). *Disabled women and COVID-19*. The Fawcett Society. Available from: <https://www.fawcettsociety.org.uk/disabled-women-and-covid-19>

The Health Foundation (2022) *Health inequalities in Scotland: An independent review*. The Health Foundation. Available from: <https://www.health.org.uk/what-we-do/a-healthier-uk-population/mobilising-action-for-healthy-lives/health-inequalities-in-scotland-an-independent-review>

The Supreme Court (2021) *REFERENCE by the Attorney General and the Advocate General for Scotland – United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill*. The Supreme Court. Available from: <https://www.supremecourt.uk/cases/uksc-2021-0079.html>

UNISON Scotland (2020) *UNISON Scotland – written evidence to Scottish Parliament’s Health & Sport Committee Inquiry: The Future of Social Care*. Unison Scotland. Available from: <https://www.unison-scotland.org/wp-content/uploads/UNISON-Scotland-Evidence-HandS-cttee-future-of-Social-care-Feb-2020.pdf>

Unison Scotland (2021) *The Impact of the COVID-19 pandemic on Equalities and Human Rights*. Unison Scotland. Available from: <https://www.unison-scotland.org/wp-content/uploads/Submission-Human-rights-cttee-Covid19-Dec-20-1.pdf>

United Nations Population Fund (2014) *The Human Rights-Based Approach*. United Nations Population Fund. Available from: <https://www.unfpa.org/human-rights-based-approach>

University of Leeds (2022) *A society fit for autistics*. University of Leeds. Available from: <https://flag.leeds.ac.uk/research/autism-across-the-life-course/>

Wilkinson, R. and Pickett, K. (2010) *The Spirit Level: Why Equality is Better for Everyone*. London: Penguin Books.

Wiseman, P. and Ferrie, J. (2020) Reproductive Justice and Inequality in the lives of Women with Intellectual Disabilities in Scotland. *Scandinavian Journal of Disability Research*, 22(1), pp. 318-329 DOI: <http://doi.org/10-16993/sjdr.677>

Appendix One – Scottish Government Written Answers

The ALLIANCE Health and Social Care Research Responses

Q.1. What importance does the Scottish Government place on the role of human rights in health and social care, and in what ways is this demonstrated?

The NCS is to fundamentally reimagine social care in Scotland and presents an opportunity to change the way support services are designed and delivered, placing human rights at the centre of our decision making. We are committed to putting the person at the centre of care, and recognise the importance of the human rights framework to making that not just an aspiration, but a reality.

The NCS Bill enshrines our commitment to embedding equality and human rights in the NCS through the NCS Principles. The NCS Principles recognise care and community health services as essential to the realisation of fundamental human rights, and that these services will have equality, non-discrimination, and the dignity of the individual at their heart.

We have listened to those that responded to the NCS consultation and equality and human rights experts who told us that we should apply the PANEL principles to the development of the NCS to implement a human rights-based approach. As part of taking a human rights-based approach we are working to deliver a range of policies to further realise human rights in the NCS including:

- Undertaking an extensive programme of co-design to ensure that the development of the NCS is participatory and delivers for people accessing care support.
- Enshrining in law our commitment to equality and human rights in the NCS Principles set out in the NCS Bill.
- Developing a NCS Charter of Rights and Responsibilities to empower people to claim their care specific rights.
- Establishing a complaints and redress process for the NCS that delivers accessible, effectively and timely recourse when people's care specific rights are not met.
- Creating a comprehensive approach to independent advocacy support for the NCS.

Our co-design process aims to ensure that the NCS is built with the people that it serves and those that deliver that care support. We will work closely with people who rely on services and unpaid carers to ensure the NCS meets their needs. We have launched the Lived Experience Experts Panel as an opportunity for adults in Scotland to take part in the co- design and there will be more opportunities in the future for other people including children, young people and families to get involved.

We began co-design on a Charter of Rights and Responsibilities (the Charter) in May that will set out what people can expect from the NCS and what their rights and responsibilities are when accessing care support. The Charter will provide a clear link between the rights in the Charter and how to make a complaint which aims to empower people to claim their care-specific rights. We acknowledge that things sometimes go wrong, and are committed to co-designing a complaints and redress service for the NCS that provides simple, accessible, timely and effective recourse to people wishing to make a complaint about a NCS service. Taken together with the Charter, the complaints service will support people accessing care support to hold the system accountable and ensure that they receive the support they need to thrive.

The Independent Review of Adult Social Care (February 2021) recommended that “more independent advocacy and brokerage services, including peer services, must be made available to people to ensure that their voices are heard, and to help prepare for participation in planning and organising their support.” In response, we are developing a coherent, consolidated and consistent approach to independent advocacy services across the NCS, and will continue to fund a wide range of signposting, brokerage and advice services through a range of third sector organisations.

This work represents the start of a wider programme to apply the PANEL Principles as part of our human rights-based approach. I look forward to working with equality and human rights organisations, such as ALLIANCE, to build on our initial plans to achieve our aim of embedding equality and human rights throughout the NCS.

Following the recommendations of the National Taskforce for Human Rights, the Scottish Government has committed to introducing a new Human Rights Bill that will incorporate four United Nations Human Rights treaties into Scots Law, as far as possible within devolved competence. This will include legislation that enhances human rights for women, disabled people and minority ethnic communities. The Human Rights Bill will also seek to incorporate economic and social rights including the right to the highest attainable standard of physical and mental health. We are working closely with colleagues developing the Bill to ensure that the NCS aligns with their work and will respect, protect and realise the rights of people accessing care support, their families and carers.

Q.2. Participants in the research have discussed the need to have a 'maximalist' approach to Incorporation Legislation (i.e. that as much as possible should be in primary legislation and not in guidance) to allow people to best 'realise' their human rights. Would you agree, or do you feel a different approach is required, and, if so, why?

My colleague, the Cabinet Secretary for Social Justice, Housing and Local Government leads on the Human Rights Bill and is currently working through these issues which have a number of complex dimensions to them, including what the optimal model of incorporation is. The Scottish Government plans to consult on proposals in the first half of 2023.

Q.3. When do you expect to see Incorporation of human rights be implemented into Scots Law?

The Scottish Government is committed to introducing the Human Rights Bill within the Parliamentary session (2021-26). We recognise the importance of effective implementation and are working closely with public bodies and key stakeholders to prepare for this.

Q.4. What key issues do you think the pandemic has caused in health and social care?

Q.5. What impact do you feel the pandemic has had upon staff in health and social care?

Q.6. What is your assessment of the working conditions during the pandemic of social care staff?

There are some key issues that have been impacted by the pandemic which have helped to inform our strategic approach to social care workforce policy for now and in the future. The Scottish Government is aware that the pandemic has had a negative impact on the social care workforce and we are fully committed to improving the experience of the social care workforce as we recognise and value the work they do.

Among our top priorities for rebuilding health and care is the creation of the National Care Service, which will support enhanced pay and conditions for workers and provide better support for unpaid carers. Moving forward it will be critical to have lived experience and co-design at the heart to ensure that we deliver for the needs of people. In the interim, the Scottish Government have continued to progress a number of key projects to champion Fair Work principles that will lead to better terms and conditions and more rewarding roles for the adult social care workforce. This includes people working in social care, care homes, care at home, day care, Personal Assistants, housing and other support services.

The pandemic has placed significant and sustained pressure on the social care workforce both in increasing the need for social care workers and decreasing their supply. This, along with existing and additional pressures such as an ageing population means further recruitment into the social care sector is required to meet both short and long-term increased demand for services. We jointly published the National Workforce Strategy for Health and Social Care with COSLA on 11 March this year, which looks at the whole workforce journey and how we can plan for, attract, train, employ and nurture our Health and Social Care Workforce. We have also taken forward a number of actions in collaboration with key stakeholders, such as hosting job fairs, developing local employability pipelines and running recruitment campaigns to attract the right people into the sector.

Q.7. What is your assessment of the learning conditions during the pandemic of student nurses - particularly in relation to their placements?

Students have shown incredible resilience studying and working throughout the pandemic and we cannot thank them enough.

During the pandemic student learning and assessment, both in university and in practice, continued to be regulated by the Nursing and Midwifery Council (NMC) and quality assured by Higher Education Institutions (HEIs). The NMC introduced Emergency Standards (NMC 2020) to enable programmes to adjust their delivery to protect student learning during this challenging period; these standards have since been replaced by the Recovery Standards for Education (NMC 2021) which remained in force until 30th September 2022, when they – with the exception of 3 standards from that document – were withdrawn.

As you know, programmes across the country were temporarily redesigned in order to accommodate and adjust to the demands in relation to working around the COVID-19 restrictions which impacted on the availability of practice learning experiences, and resulted in paid placements for students in years 2 and 3. The restrictions meant that academic learning moved entirely to online delivery. Sadly, our first year students could not attend their placements.

The restrictions meant that placement capacity within the care home sector was also significantly compromised and some health boards saw the loss of all placement capacity within their geographical boundaries for student nurses to this sector, while the rest had significant reductions. I am pleased that we are now seeing the recovery of that capacity to pre-COVID levels through a variety of cross sector initiatives including the establishment of a Placement Capacity and Capability Group.

This transitional adjustment of education delivery helped to protect student learning and the student experience, however we recognise that students, HEIs and practice partners had to work hard to adjust to challenging learning situations and we are very aware that this required extra effort and resilience.

We worked closely with all parties, including NHS Education for Scotland, to ensure safe and effective delivery of learning and important skills development for students by providing extra funding for HEIs to support the additional development of simulation based education during the COVID-19 pandemic.

Q.8. How do you think Long COVID will impact the health and social care sector in the mid- to long-term?

Globally, science has begun the work of trying to find an explanation – and treatments for long COVID. However the science is still in its early stages and proven, safe, evidence- based treatments are still in their infancy. Our Chief Scientist Office is funding 9 Scottish-led studies which aim to improve the understanding of the long-term effects of COVID-19 on physical and mental health and wellbeing in Scotland, and inform clinical interventions to support recovery and rehabilitation. In the meantime, support is already being delivered and Scottish Government is providing additional resource to NHS Boards to help people affected by long COVID manage the symptoms they are experiencing. This covers a range of different approaches including care co-ordinator roles to provide a single point of contact for people with long COVID as well as bolstering community rehabilitation such as Occupational Therapy and Physiotherapy, to support people with issues affecting their day to day life. This work is currently underway. Once this work has been evaluated, we will be in a position to say more about the medium to long term impacts for health and social care.

Q.9. How can Scotland better integrate human rights into pre-registration training for healthcare and social care professionals, and in ongoing professional development?

We are working to ensure that Equality, Diversity and Inclusion training for Health and Social Care staff incorporates up to date messaging and relevant information on equality including anti-racism, sexual harassment, ageism, LGBTI+ equality, and identifying/reporting incidences of equality based harassment. We are working with NHS Education for Scotland to scope out how we can improve this training, ensure that it is up to date, relevant and not seen as a tick box exercise.

It is important for equality training to clearly outline the devastating impact that discrimination of any kind can have on staff's mental health. We also believe that improved training around equalities will help staff better meet the needs of our diverse work force and the diverse communities they work with.

Q.10. What were the successes of the first Scottish National Action Plan for Human Rights (SNAP), and what role do you think the second SNAP should have, considering it will be running concurrently with the Incorporation legislation's journey through Parliament?

SNAP is Scotland's National Action Plan for Human Rights. Its vision is a Scotland where all can live with human dignity. SNAP fulfils key recommendations from the United Nations and the Council of Europe and has been praised internationally for its collaborative, multi-stakeholder approach. It is regularly cited in reports to the United Nations about Scotland's implementation of its international human rights obligations.

The first Scottish National Action Plan for Human Rights ran from 2013-2017. From 2013 to 2017, SNAP 1 delivered over 50 actions in areas as diverse as criminal justice, housing, health and social care. Actions included pilot projects to test human rights based approaches in practice; national innovation forums to spark creative action on complex human rights issues; and action research projects on specific rights concerns.

During these four years, many SNAP actions seeded longer term programmes of work that continue to drive improvements in Scotland's human rights laws, policies and practices today. For example, the work of the National Taskforce on Human Rights Leadership can be traced back directly to SNAP action in this area. Making Rights Real, Scotland's grassroots human rights organisation, is firmly rooted in the Housing Rights in Practice pilot project pioneered through SNAP.

We are currently exploring the role of the second SNAP, given the upcoming Incorporation legislation.



Q.11. Are there any questions which you expected that we may ask, which were not?

Q.12. Is there anything else you wish to add?

As mentioned in response to the first question, the Scottish Government has committed to introducing a new Human Rights Bill that will incorporate four United Nations Human Rights treaties into Scots Law, as far as possible within devolved competence. The NCS will be a vehicle to realise the aims of the Human Rights Bill – the respect, protection, and full realisation of the rights of everyone – in the care-specific context.

We do not underestimate the challenges we face as we embark on what is the most ambitious reform of public services since the creation of the NHS. In order to allow people engaging with social care support the opportunity to not only to survive, but instead, thrive, it will be vital that we design the NCS with them, their carers, and the workforce. That is why we are co-designing the NCS both with people accessing social care support and their carers, as well as the workforce which will be delivering it.

We welcome the continued engagement with the ALLIANCE, as well as the wide range of equality and human rights stakeholders without whose contributions the NCS project would not be a success. We do not intend stop this engagement once the NCS has been established. We will continue to seek the views of lived experience and organisations such as the ALLIANCE to ensure that the NCS continuously improves and reflects the aspirations of the people of Scotland.



Endnotes

- ¹ <https://www.povertyalliance.org/wp-content/uploads/2022/05/RIA-Review-April-2022-Final-PDF.pdf>
- ² <https://www.inspiringscotland.org.uk/equality-and-human-rights-fund/>
- ³ <https://ijrcenter.org/thematic-research-guides/economic-social-and-cultural-rights-2/>
- ⁴ <https://justfair.org.uk/about-us/economic-and-social-rights/>
- ⁵ <https://www.unfpa.org/human-rights-based-approach>
- ⁶ https://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf
- ⁷ <https://www.supremecourt.uk/cases/uksc-2021-0079.html> <https://www.strath.ac.uk/humanities/lawschool/blog/thesupremecourtsjudgmentontheuncrcincorporationscotlandbill/>
- ⁸ <https://www.unison-scotland.org/wp-content/uploads/UNISON-Scotland-Evidence-HandS-cttee-future-of-Social-care-Feb-2020.pdf>
- ⁹ <https://www.parliament.uk/globalassets/documents/fair-society-healthy-lives-full-report.pdf>
- ¹⁰ The Spirit Level, Wilkinson and Pickett, Penguin Books (2010).
- ¹¹ <http://www.healthscotland.scot/health-inequalities/what-are-health-inequalities>
- ¹² <https://www.health.org.uk/what-we-do/a-healthier-uk-population/mobilising-action-for-healthy-lives/health-inequalities-in-scotland-an-independent-review>
- ¹³ Wiseman, P. & Ferrie, J. (2020) Reproductive Justice and Inequality in the lives of Women with Intellectual Disabilities in Scotland. Scandinavian Journal of Disability Research 22 (1) pp.318-329 DOI: <http://doi.org/10-16993/sjdr.677>
- ¹⁴ <https://www.gov.scot/policies/social-care/>
- ¹⁵ <https://publichealthscotland.scot/publications/insights-in-social-care-statistics-for-scotland/insights-in-social-care-statistics-for-scotland-support-provided-or-funded-by-health-and-social-care-partnerships-in-scotland-201920-202021/>
- ¹⁶ https://www.audit-scotland.gov.uk/uploads/docs/report/2022/briefing_220127_social_care.pdf
- ¹⁷ Independent Review into Adult Social Care (IRASC)
- ¹⁸ <https://www.gov.scot/policies/social-care/national-care-service/>
- ¹⁹ <https://www.gov.scot/news/national-care-service-bill-published/>
- ²⁰ <https://www.cosla.gov.uk/news/2022/national-care-service-plans-could-threaten-delivery-of-vital-services,-cosla-warns>

- 21 https://www.audit-scotland.gov.uk/uploads/docs/report/2022/briefing_220127_social_care.pdf
- 22 <https://www.gov.scot/publications/contribution-non-uk-eu-workers-social-care-workforce-scotland/>
- 23 <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/national-information/The-state-of-the-adult-social-care-sector-and-workforce-in-England.aspx>
- 24 <https://www.gov.uk/guidance/new-immigration-system-what-you-need-to-know>
- 25 <https://carers.org/our-work-in-scotland/our-work-in-scotland>
- 26 <https://www.carersuk.org/scotland/news/facts-and-figures>
- 27 https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf
- 28 <https://www.fawcettsociety.org.uk/disabled-women-and-covid-19>
- 29 <https://www.drilluk.org.uk/wp-content/uploads/2020/06/Services-for-who-final-report-1.pdf>
- 30 <https://flag.leeds.ac.uk/research/autism-across-the-life-course/>
- 31 <https://www.mwscot.org.uk/news/new-consultation-investigating-deaths-during-compulsory-care-and-treatment-under-mental-health>
- 32 <https://www.drilluk.org.uk/wp-content/uploads/2017/08/People-First-Scotland-Animate-Full-research-report.pdf>
- 33 <https://hrcscotland.org/wp-content/uploads/2021/05/Final-Delivering-Human-Rights-During-COVID19-survey-report-May-2021.pdf>
- 34 Covid-19 adult care home statistics - the Care Inspectorate <https://www.careinspectorate.com> › documents
- 35 <https://www.bmj.com/content/371/bmj.m4225>
- 36 https://www.scottishhumanrights.com/media/2054/coronavirus-care-homes-briefing-140720_vfinaldocx.pdf
- 37 <https://www.gov.scot/publications/covid-19-inquiry/>
- 38 <https://www.unison-scotland.org/wp-content/uploads/Submission-Human-rights-cttee-Covid19-Dec-20-1.pdf>
- 39 <https://www.alliance-scotland.org.uk/people-and-networks/people-at-the-centre-engagement-programme/>
- 40 <https://scotlandinlockdown.co.uk>
- 41 <https://www.nhsinform.scot/long-term-effects-of-covid-19-long-covid/about-long-covid/what-is-long-covid>
- 42 <https://www.latimes.com/world-nation/newsletter/2022-07-26/todays-headlines-long-covid-todays-headlines>
- 43 <https://www.longcovid.scot/manifesto>

- 44 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1007511/S1327_Short_Long_COVID_report.pdf (page 16)
- 45 <https://www.scottishhumanrights.com/our-law-and-policy-work/social-care/>
- 46 <https://www.alliance-scotland.org.uk/wp-content/uploads/2020/10/ALLIANCE-SDSS-MSMC-National-Report-Oct-2020.pdf>
- 47 <https://scottishcare.org/wp-content/uploads/2019/11/A-Human-Rights-Based-Approach-to-SDS-for-Older-People.pdf>
- 48 <https://tfn.scot/news/social-care-postcode-lottery>
- 49 <https://pubmed.ncbi.nlm.nih.gov/28328265/>
- 50 <https://pubmed.ncbi.nlm.nih.gov/28328265/>
- 51 <https://dignityandhumanrights.uhi.ac.uk/site/>
- 52 <https://methods.sagepub.com/reference/the-sage-dictionary-of-social-research-methods/n60.xml>
- 53 <https://scholar.harvard.edu/jlhochschild/publications/conducting-intensive-interviews-and-elite-interviews>
- 54 <https://www.scottishhumanrights.com/projects-and-programmes/scotlands-national-action-plan/>
- 55 SNAP-Evaluation-vFinal-16-July-2019.docx (live.com)
- 56 <https://www.snaprights.info/wp-content/uploads/2016/01/SNAPpdfWeb.pdf>
- 57 <https://www.snaprights.info/#:~:text=Since%20late%202017%2C%20work%20has,2017%20involving%20over%201%2C000%20people>
- 58 <https://www.snaprights.info/evaluation>

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.

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.

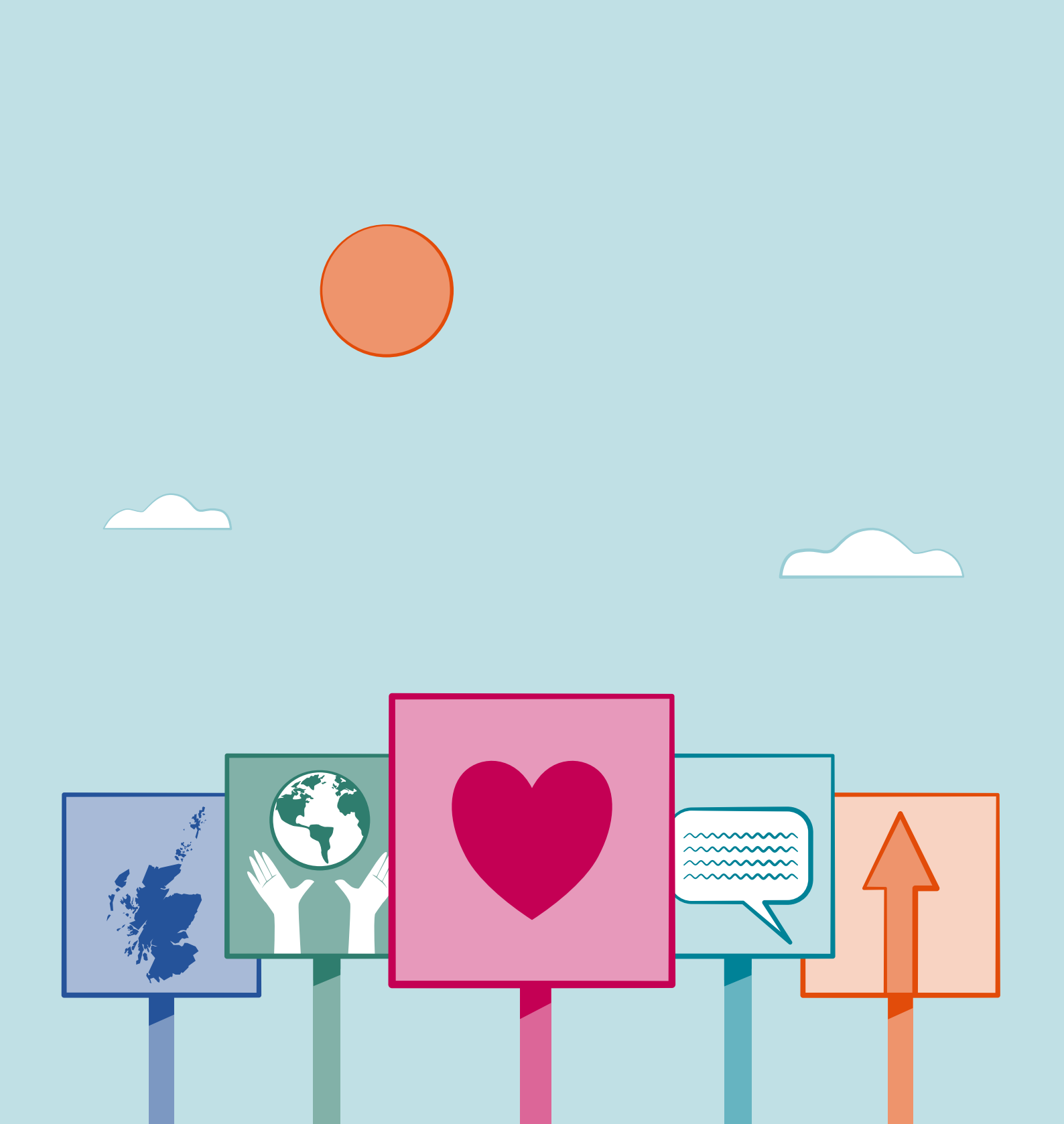
Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

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.



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre



☎ 0141 404 0231 ✉ info@alliance-scotland.org.uk 🐦 @ALLIANCEscot 📘 ALLIANCEscot
📷 [alliance.scot](https://www.instagram.com/alliance.scot) 🌐 [alliancescotland](https://www.linkedin.com/company/alliancescotland) 📺 [alliancescotland](https://www.youtube.com/channel/UCqT31T1D831T1D831T1D831) 🎧 ALLIANCE Live

www.alliance-scotland.org.uk

Health and Social Care Alliance Scotland (the ALLIANCE)
Venlaw Building, 349 Bath Street, Glasgow, G2 4AA



The ALLIANCE is supported by a grant from the Scottish Government. The ALLIANCE is a company registered by guarantee. Registered in Scotland No.307731. Charity number SC037475. VAT No. 397 6230 60.