SHRC
Scottish
Human Rights
Commission

COVID-19, Social Care and Human Rights: Impact Monitoring Report

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"…individualized support services must be considered a right… access to a range of individualized support services is a precondition for independent living within the community"

(United Nations Committee on the Rights of Persons With Disabilities)

"All the flaws in the system are being horribly exposed in a way that no-one ever thought they would be."

(Interviewee)

Contents

Executive Summary

In summer 2020, the Scottish Human Rights Commission carried out monitoring research into the impact of the COVID-19 pandemic, and how it has been managed, on people's rights in the context of care at home and support in the community.

This report shares the findings of that research. It details how legislative, policy and practice decisions taken by public authorities have affected the rights of people who access, or wish to access social care, unpaid carers, and people who work in social care. The report makes 24 recommendations, some of which call for urgent action to resolve immediate human rights concerns.

Human rights and social care

The provision of accessible, appropriate and quality social care is an essential investment in the rights of disabled and older people, unpaid carers, and children and young people. Social care, delivered to support people in the way that they need, enables people to access many of their other rights, including family life, health, education, employment and independent living in the community.

The importance of social care to people's rights is emphasised by the United Nations Committee on the Rights of Persons with Disabilities:

> …individualized support services must be considered a right… For many persons with disabilities, access to a range of individualized support services is a precondition for independent living within the community.[1]

Impact monitoring research

The Scottish Human Rights Commission is Scotland's National Human Rights Institution. The Commission has a statutory duty to promote and protect human rights for everyone in Scotland, and specific powers to carry out research, monitor and report on how human rights are being respected, protected and realised in practice.

As part of our response to the COVID-19 pandemic, the Commission carried out this impact monitoring research. The research process involved a series of in-depth interviews with a range of different stakeholders in social care, including social care providers and provider organisations, disabled people's organisations, carers' organisations, mental health professionals, specialist legal professionals and advocacy organisations. We also reviewed other sources of evidence such as Freedom of Information requests, surveys and reports from other organisations.

Conclusions

Evidence from this research, assessed against the relevant human rights standards, shows the following:

1. COVID–19 has had a profound impact on the way in which social care support has been delivered in Scotland, leading to significant gaps in the realisation of rights for people who rely on such support, including unpaid carers.

2. A considerable proportion of people who use social care support at home have experienced either a reduction or complete withdrawal of support. In many cases, the withdrawals and reductions seen in the early months of the pandemic happened rapidly, without either adequate communication or assessment of the proportionality of such decisions.

3. The impact of this policy and practice has had a direct and detrimental effect on people's rights, including those protected by the European Convention on Human Rights and by international instruments such as the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of Persons with Disabilities. This includes potential non-compliance with people's rights to physical and psychological integrity, and negative impacts on people's rights to a private and family life without recourse to the normal assessment and review procedures.

4. The Commission is deeply concerned about the future social care support available to people whose packages were reduced or withdrawn over the period, and the potential impact that this could have on how their rights are realised, both now and in future.

5. The COVID-19 pandemic has also exacerbated pre-existing inadequacies in the models of social care access, funding, procurement and commissioning, which are unable to provide people with the support which best and most appropriately fits their life.

6. Legislative changes as a result of the pandemic have been poorly explained, and implementation of the legislation lacks transparency. This is confusing for people accessing the system for the first time and detrimental to proper scrutiny and use of public funds. Without further information as to the factors influencing the decision to adopt the provisions of the Coronavirus Act 2020, there is very little opportunity for scrutiny by relevant parties, including the Scottish Parliament.

7. It is clear that there is a need to strengthen the framework of decision making in social care, through applying a rights based approach. This would ensure stronger protection and respect for people's rights as we continue to deal with COVID-19, including any potential second wave of infections.

8. There is an opportunity to invest in a social care system, based on human rights, capable of delivering the outcomes which are enshrined in the Convention on the Rights of Persons with Disabilities.

10. The international human rights legal framework should inform the provision of social care much more strongly, including through the integration of health and social care. This has the potential to inform the development of more robust accountability processes, both in relation to individual complaints and accountability mechanisms, but also in connection with budget scrutiny and transparency, through human rights budgeting.

Recommendations

To address the concerns and issues highlighted in our conclusions, the Commission makes the following recommendations.

Resumption of care and support

1. The Scottish Government and COSLA should jointly commit to re-commencing care and support at pre-pandemic levels, as a minimum. Where people indicate that they have increased support needs due to the effects of COVID-19 or of lockdown, they should receive a full assessment. The new powers brought in under s16 and 17 of the Coronavirus Act should not be used to alter support packages for people with pre-existing social care arrangements (those in place before January 31st).

2. In planning for the resumption of pre-pandemic services, local authorities and Health and Social Care Partnerships (HSCPs) must either recommence the pre-COVID care package, or if the person's circumstances have substantively changed, they must fairly and systematically assess need.

3. It should not be assumed that family supports which have been in place during the crisis are sustainable over the long term. Disabled people, family carers, older people and children and young people must be informed in an accessible and timely manner of the next steps in relation to the resumption of their pre-pandemic care package.

4. In line with the recommendation set out in Scottish Government guidance, people who have had no, or partial social care assessments should have a review within six weeks. Where it is not possible for this to be delivered, local authorities should communicate clearly and proactively with people and their families as to the expected timescale for a full assessment, and any implications this will have for care-charging.

Involvement in decision making

5. The Scottish Government and COSLA should develop an emergency decision making framework for social care which is grounded in rights-based principles of inclusion and participation in decision making, and transparency. This should also meet critical human rights standards:

    - ensure non-regression
    - be temporary and time-limited
    - be necessary and proportionate
    - be non-discriminatory and mitigate inequalities
    - ensure the protection of a minimum core content of rights
    - consider all other options, including financial alternatives.

6. In future situations of emergency where resources are stretched, disabled people, family carers, older people and children and young people must be involved in a meaningful conversation about prospective decisions to cut their care packages. This is especially the case where people need support to make decisions or another person has power of attorney or is a welfare guardian.

Ensuring lessons are learned

7. In order to understand the impact of the pandemic on care and support at home, the Scottish Government should immediately establish data collection mechanisms to monitor the nature and extent of reductions and withdrawals of care and support. This will help support the social care sector to respond effectively in the event of a resurgence in the virus or further complications related to a combination of winter flu and COVID-19. It will also help to ensure the availability and adequacy of social care support during periods of crisis.

8. The impact of COVID-19 on the human rights of older and disabled people who get care and support at home and in the community should be included in any future inquiry into the pandemic. Our separate briefing on the impact of COVID-19 in residential and nursing homes sets out the relevant rights based standards.[2]

9. The Scottish Government should publish a more detailed and transparent account of which Health and Social Care Partnerships and local authorities have made use of powers in relation to assessments under s16 and 17 of the Coronavirus Act, which are intending to use the powers, and the decision-making framework they have used in choosing whether or not to implement the powers. This will assist the required scrutiny of the necessity and proportionality of the use of powers into the future.

A rights based social care system

10. The Scottish Government should rethink and refocus social care as a delivery mechanism for realising people's human rights. To address the longstanding inadequacies in the social care system, an integrated programme of reform must take place, explicitly grounded in human rights standards, which makes changes at legislative, budgetary, policy and implementation levels.

Human rights based budgeting

11. The Scottish Government should take a human rights based approach to future public finances, which considers the impact of financial decisions on the rights of older and disabled people and closely interrogates claims in relation to limited resources. This could make a significant shift in the way that budgets are generated, allocated and spent, with a corresponding significant impact on how people's rights are realised.

Legislative powers

12. The Commission recommends that the Scottish Government works in partnership with local authorities who are using, or have used, the powers to gather data on the number and identity of individuals affected by the provisions under s16 and s17 of the Coronavirus Act 2020. The Commission recommends that the Scottish Government collates, analyses and publishes this information to enable additional scrutiny of the use of these provisions by relevant parties.

13. The Commission recommends that the Scottish Government undertakes research with people affected by these powers, and where appropriate, their families and unpaid carers, to understand more about their experiences and identify if there have been any concerns in relation to their care and support.

14. The Commission agrees with the Scottish Government guidance on social care assessments under the powers that 'arrangements should be made to conduct assessments for people who did not receive a full assessment while section 16 was switched on. For adults with incapacity, a review of those adults subsequently identified as lacking capacity should follow the principles of the AWI Act and the recommendations of the United Nations Convention on the Rights of Persons with Disability.' The Commission recommends that local authorities and HSCPs clearly and proactively communicate with people and their families as to when this assessment should take place.

15. We also recommend that the powers under the Coronavirus Act should not be used in relation to people who had already had an assessment and were in receipt of a care and support package prior to 31st January 2020. People with existing packages should not have these altered without recourse to a full assessment.

16. The Commission recommends that the effect of Schedule 3, s11 (3) (b) of the Coronavirus (Scotland) Act 2020 should only be revived where it is absolutely necessary and proportionate to do so and that it apply for the shortest time possible, given the impact that these provisions have on the length of guardianship orders and the opportunities to review or appeal these.

17. Where someone has a welfare power of attorney or a welfare guardian, local authorities should ensure that individual is contacted to discuss potential changes in a care package, even in times of crisis and extreme pressure. This can avoid both failures of procedural safeguards and detrimental impacts on rights.

Guidance

18. Social care experts, including disabled people and unpaid carers, should be involved in the development of guidance going forward, and in particular in planning for future crises, including a resurgence of the virus.

19. The Scottish Government should undertake a review of how a social model and human rights approach to decisions taking under the pandemic could have improved practice, particularly in terms of ensuring that disabled and older people faced fewer barriers to living their everyday lives.

Personal Protective Equipment and Testing

20. The Scottish Government should take steps to ensure that in the event of future resurgence of the virus, personal protective equipment and testing is available to everyone who requires or provides personal care in a social care environment.

Workforce

21. The Commission recommends that all social care staff should have access to adequate and appropriate mental health and trauma support, in light of the nature of the experiences they have been exposed to during the COVID-19 pandemic.

Convention on Rights of Persons with Disabilities

22. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) should be incorporated into Scots law and therefore into policy design and delivery. This would be an important step in ensuring that the negative impacts on people's rights that have happened during the pandemic do not happen again.

23. Incorporation of the CRPD should include duties on public authorities to embed Convention rights into decision making, as well as a duty to comply with the Convention. This could help to resolve some of the differences in approach between local and central government, as well as providing a more robust mechanism for people to hold public authorities to account for decisions in relation to their social care. It would also provide the domestic courts with clearly articulated rights-based norms and standards when considering complex cases in the context of finite resources.

24. The National Taskforce on Human Rights Leadership, established to take forward recommendations for new human rights laws in Scotland, should take the opportunity to advance the incorporation of the Convention into Scots law.[3]

Closing remarks

The COVID-19 pandemic has exposed and exacerbated the inadequacies of the ways in which social care is accessed, funded, procured and commissioned in Scotland. The current social care system is unable to provide people with the support that fits their life best and most appropriately, and to ensure their rights are respected, protected and realised.

Short and longer term change is needed to address the significant human rights concerns we have identified, and to ensure the level of decline in the realisation of people's rights that has taken place never happens again. The Commission hopes that this impact monitoring research will now be acted upon by the Scottish Government, COSLA and other relevant public authorities.

1. Introduction

The Scottish Human Rights Commission has been monitoring the impact of COVID-19 across a whole range of legislative and policy environments and rights concerns.[4] In June 2020, the Commission set out to document the impact of COVID-19, and the management of it, on people who require social care support, unpaid carers, families and people who work in the sector. This is an area which engages a significant number of human rights issues.

This report provides an overview of the impact of the pandemic, and its management, on the provision of care at home and support in the community. It sets out the human rights impacts of legislative, policy and practice decisions on people who access, or wish to access social care, on unpaid family carers and on the people who work in social care.

The report is based on both desk-based research and a set of qualitative interviews carried out with a number of individuals who work in the field of social care. The Commission would like to thank all of the people who took part in this research for giving their time and expertise so generously. We have quoted participants verbatim throughout the report as indicated by indented text and the use of quotation marks.

The report shares some distressing testimony about people's experiences: we would like to both acknowledge that, and provide advance warning for readers who may find this upsetting.

Recommendations for change are identified in each section, and collated in the final section.

Please note the Commission has also published a separate briefing on residential and nursing care homes[5] and the standards that any future public inquiry into the effect/handling of COVID-19 on people who live and work in these settings should meet.

2. Methodology

To carry out this research, we used two different and complementary methods of data collection:

1. Desk based research and analysis of a range of information sources including surveys, Freedom of Information requests and reports from other organisations. These have been referenced throughout this report where appropriate.

2. Semi-structured interviews, based around a questionnaire about specific rights issues in social care, with a range of different actors and organisations. These included social care providers and provider organisations, disabled people's organisations, carers' organisations, mental health professionals, specialist legal professionals and advocacy organisations. The organisations we contacted were both local and national in scope; while some focused on provision in a specific health and social care partnership area, others worked across a range of areas, and others across the whole of Scotland.

We did not speak directly with people who use social care and their families as part of this research. We would have preferred to work in this way; however, on this occasion, we did not have the capacity to support and facilitate this kind of participation in an appropriate and meaningful way. We did hear from disabled people's organisations and user led organisations representing a large number of individuals, as well as receiving some information through individual enquiries received.

3. Human Rights and Social Care

This chapter provides a detailed overview of the human rights laws, standards and norms that are of particular relevance to social care.

Introduction

Social care in Scotland is defined by the Scottish Government as 'all forms of personal and practical support for children, young people and adults who need extra support. It describes services and other types of help, including care homes and supporting unpaid carers to help them continue in their caring role.'[6] The Scottish Government also notes that social care support is intended to enable people to:

- live independently
- be active citizens
- participate and contribute to our society
- maintain their dignity and human rights.[7]

Human rights laws and standards set out the duties on governments and public authorities as to how they must treat the people under their jurisdictions at all times. In Scotland, human rights are directly protected through the Human Rights Act 1998, which incorporates the European Convention on Human Rights (ECHR) into Scots law, and prohibits public authorities from acting incompatibly with ECHR rights. The Act also enables individuals to raise complaints about interferences with their ECHR rights in the domestic courts. The Scotland Act 1998 prohibits the Scottish Parliament from legislating in a way that is incompatible with ECHR rights and prohibits Scottish Ministers from acting incompatibly with ECHR Rights.

Social care engages a whole range of human rights issues under the ECHR, as well as under international protections set out in the International Covenants on Civil and Political Rights (ICCPR) and on Economic, Social and Cultural Rights (ICESCR) and the Convention on the Rights of Persons with Disabilities

(CRPD). The UK has signed and ratified these treaties, creating legal obligations to respect, protect and fulfil the rights set out within them. Progress towards the implementation of the rights within these treaties is monitored by separate expert Committees at the United Nations. Unlike the ECHR, it is not currently possible for an individual to bring a case to a domestic court in Scotland if they believe their rights under these treaties have been breached.

Some human rights in relation to social care are concerned with good quality outcomes for people, for example the right to live independently in the community (Article 19 of the CRPD) and others are concerned with procedural safeguards and fairness, for example ensuring that there is impartial judicial oversight of guardianship orders to safeguard the liberty and autonomy of people who may lack capacity to make some decisions about their lives (Articles 5 and 8 ECHR).

Additionally, it should be noted that there are significant rights issues in play for people who work in social care, in terms of just and favourable conditions of work (Articles 6 and 7, ICESCR), and in the context of the COVID-19 pandemic, the rights to life (Article 2 ECHR) and to health (Article 12, ICESCR).

European Convention on Human Rights

ECHR rights in relation to social care include, but are not limited to, the right to life (Article 2), the prohibition on torture, cruel, inhuman and degrading treatment (Article 3), the right to liberty (Article 5), access to justice (Articles 5 and 6), the right to private and family life (Article 8), and the prohibition on discrimination (Article 14).

Jurisprudence under the ECHR in relation to social care has tended to focus heavily on the important relationship between capacity and liberty under Article 5 ECHR.[8] This jurisprudence has led to a renewed focus on the issue of deprivation of liberty where an adult may lack capacity to consent to their living arrangements, and also of the compatibility of Scots law with the standards set out within Article 12 of the Convention on the Rights of Persons with Disabilities, particularly in relation to the issue of substituted decision-making versus supported decision-making.

There has been limited jurisprudence at the European Court of Human Rights (the Court) on decisions relating to the nature and quality of social care

provision, with the notable exception of *McDonald v UK*.[9] This case confirmed that the provision of social care engages human rights obligations, including those under Article 8 ECHR, the right to private and family life, home and correspondence, which covers issues of physical and psychological integrity, personal development and autonomy.[10]

Article 8 is a qualified right, which means interferences with the right can be justified as long as they are: in accordance with the law; in pursuit of a legitimate aim; and necessary in a democratic society. Generally, interferences will be considered necessary in a democratic society for a legitimate aim if they answer a "pressing social need" (such as public health reasons), if they are proportionate to the legitimate aim pursued and if the reasons given by national authorities to justify the interference are relevant and sufficient. It is important to note that a measure that was once accepted as proportionate may cease to be, both having regard to the evolving nature of the pandemic and the changing health and wellbeing of individuals.

In *McDonald v UK*, the local authority based its decision to provide incontinence pads to Ms McDonald, rather than support to use a toilet, without conducting an adequate assessment of need. The Court found that this was a violation of her Article 8 rights, at least insofar as the decision to change the care plan without an appropriate assessment had not been 'in accordance with the law.' This is of relevance to the experience of people whose care packages were reduced or withdrawn during the COVID-19 pandemic, described later in this report, since evidence suggests this often took place without an assessment of their ability to manage without the relevant care.

The McDonald case is also relevant since it speaks to a key pre-COVID challenge identified by many participants in this research – that of accessing adequate and appropriate social care support in a system subject to significant financial constraints and seeking accountability when this is not provided. Once Ms McDonald had received a proper assessment, the Court held that the decision to supply incontinence pads rather than support from personal assistants, was one which balanced the rights of Ms McDonald with those of the wider community in a context of scarce resources. The Court set out that 'States are afforded a wide margin of appreciation in issues of general policy, and that margin is particularly wide when the issues involve an assessment of the priorities in the context of the allocation of limited State resources.'[11]

This approach has also been taken by the Scottish Courts, where it has been found that it is not for the courts to take decisions which Parliament has empowered to a local authority and that 'local authorities have finite resources and the court has to recognise that it is for the local authority to determine where resources should be spent and in what manner.'[12] It has also been highlighted however, that transparency as to the manner in which the estimate of the cost of a care package was reached is vital since it enables individuals to bring a challenge where they felt the amount allocated to a care package was unreasonable:

> There is an onus on the respondent to the extent of providing, in a reasonably comprehensible way, an explanation of how it has calculated what it would claim is a reasonable estimate of the cost of securing the provision of such community care services as it considers are called for. Such an explanation may then be challenged, either on the ground that its reasoning is insufficient or that the amount calculated on the basis of that reasoning is not in fact a reasonable estimate. In the latter case we would see the onus as being on the supported person to establish that the estimate is not reasonable.[13]

It is clear therefore that under the current framework courts have not interfered with financial decisions taken by local authorities in the provision of social care in a context of scarce resources, where proper procedures have been followed, even if rights are affected. However, courts will adjudicate where there are procedural failures, such as a failure to undertake a proper assessment or to provide a proper rationale for decisions.

United Nations International Human Rights Treaties

Social care engages a range of rights set out in other international human rights treaties, including the Convention on the Rights of Persons with Disabilities and the International Covenants on Civil and Political and on Economic, Social and Cultural Rights. These include the right to an adequate standard of living, food and housing (Article 11 of ICESCR), the highest attainable standard of physical and mental health (Article 12 of ICESCR) and the right to live independently and be included in the community (Article 19 of the CRPD). While these rights place binding legal obligations on States who have signed and ratified these treaties, they are not currently directly protected in domestic law, and cannot be relied on by an individual to bring a case in the domestic courts.

To be considered as fulfilled or 'realised', economic, social and cultural rights, such as the rights to an adequate standard of living, health, housing or social security are partly measured through consideration of the following standards in relation to the provision of good and services:

- Available – are the resources needed to realise a right available in sufficient quantities?
- Accessible – can people access these resources?
- Acceptable and adaptable – are the resources available in a way that is culturally and socially acceptable?
- Quality – are the available resources of an adequate and safe standard?

Under the international rights framework, States have three different types of obligations in relation to the realisation of human rights. States must act, or refrain from acting, to 'respect, protect and fulfil' human rights. Obligations of 'respect' require States to refrain from interfering with a person's human rights. Obligations to 'protect' require States to protect individuals from interferences from other actors, including private actors. Obligations to 'fulfil' refer to the provision of a right where a person may be unable to ensure this for themselves. Many rights in the international framework, such as the right to health and the right to independent living in the community are subject to important norms and standards which set out the duties of the State in more detail. These are as follows:

- the realisation of these rights should continuously improve. While it is recognised that full realisation of all economic, social and cultural rights will generally not be able to be achieved in a short period of time, the rights framework imposes an obligation to move 'as expeditiously and effectively as possible' towards that goal (progressive realisation);[14]
- these rights depend on governments using the 'maximum of available resources' for their realisation;[15]
- the realisation of these rights should not get worse (non-retrogression);[16]
- discrimination in the realisation of these rights is prohibited and represents an immediate, rather than a progressive, obligation on States.[17]

The Right to Live Independently and Be Included in the Community and Social Care (Article 19 CRPD)

The Convention on the Rights of Persons with Disabilities interprets already existing human rights standards in the context of the lives of disabled people. The Convention takes a social model approach. Disability rights advocates have long promoted the social model of disability, which locates disability not in a person's impairment, but rather recognises that disability arises where societal structures, whether environmental, attitudinal, informational or other, fail to accommodate a person with impairment, creating barriers to the inclusion and participation of people in society. The implication of the social model is that policy and legislation must focus on how exclusionary structures can be addressed, whether through design, support, accessible information or other means.

Article 19 develops the principle of the social model into a right, enshrining in rights language the requirement to ensure that disabled people have the support they need to live in the community on an equal basis with others. The Article represents a stark contrast to the historical context and lived experience of many disabled people, including in Scotland, who until relatively recently were often held in institutional settings, unable to access community services, purely on the basis of disability.[18] Article 19 sets out that:

> States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:
>
> (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
>
> (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

> (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

In its General Comment[19] on Article 19,[20] which aims to assist States in the implementation of Article 19 and to fulfil their obligations under the Convention, the UN Committee on the Rights of Persons with Disabilities has confirmed that

> individualized support services must be considered a right… For many persons with disabilities, access to a range of individualized support services is a precondition for independent living within the community.[21]

Without appropriate social care support therefore, the realisation of the rights enshrined in Article 19 will not be possible. In this way social care support should be understood as a key mechanism through which to ensure that the human rights of older and disabled people are respected, protected and fulfilled.

In addition, the Committee has confirmed that Article 19(b) of the CRPD, 'the right to access individualized, assessed support services' is an economic, social and cultural right.'[22] This is significant since it means that the provision of social care for disabled people in Scotland is subject to, and can be assessed against, the standards of availability, accessibility, acceptability, and quality discussed above; the General Comment also stresses the importance of the affordability of disability support services. Moreover, public authorities, including the Scottish Government, local authorities and Health and Social Care Partnerships are under the legal obligations of progressive realisation, use of the maximum available resources, non-retrogression and non-discrimination within the respect, protect and fulfil framework set out above.

The nature of the obligations to respect and protect rights to independent living include, but are not limited to:

- the duty to refrain from directly or indirectly interfering with or in any way limiting the individual exercise of the right to live independently and be included in the community (respect);

- to phase out institutionalisation (respect); and
- to prevent third parties from directly or indirectly interfering with the enjoyment of the right to live independently within the community (protect).

The obligation to fulfil is well developed within the General Comment and includes a range of obligations on States Parties. The obligations of most relevance to the social care context are as follows:

- to promote, facilitate and provide measures to ensure the full realization of the right to live independently and be included in the community; to take measures to eradicate practical barriers to the full realization of the right to live independently;
- to closely consult and actively involve a diverse range of persons with disabilities;
- to ensure that disability support services are available, accessible, affordable, acceptable and adaptable to all persons with disabilities;
- to empower family members to support the person they care for to live independently in the community;
- eligibility criteria for access to assistance should feature an assessment based on a human rights approach to disability, focusing on the requirements of the person that exist because of barriers within society rather than the impairment; the assessment must take into account, and follow, a person's will and preferences and ensure the full involvement of persons with disabilities in the decision-making process; and
- to adopt a strategy and a concrete plan of action for deinstitutionalization.[23]

The norms, standards and obligations set out in relation to the right to independent living by the Committee are an important benchmark for the consideration of the impact of COVID-19 on the provision of social care, and in consideration of the future provision of social care in Scotland.

Human Rights Standards in a Time of Pandemic

When there is a crisis, such as the COVID-19 pandemic, some lessening of the protection of rights may occur. However, it should be noted that any limitation of rights is also subject to important human rights standards and principles. Limitation of rights must:

- be temporary and time-limited;
- be necessary and proportionate;
- be non-discriminatory and mitigate inequalities;
- ensure the protection of a minimum core content of rights; and
- consider all other options, including financial alternatives.

Several of these principles, and especially the principle of non-discrimination are reflected in Article 11 of the CRPD which sets out that States parties shall:

> take all possible measures to ensure the protection and safety of persons with disabilities in the national response to situations of risk and humanitarian emergencies. This comprises measures in all areas of life of persons with disabilities, including the protection of their access to the highest attainable standard of health without discrimination, general wellbeing and prevention of infectious diseases, and measures to ensure protection against negative attitudes, isolation, and stigmatization that may arise in the midst of the crisis.

The United Nations Treaty Body Committees have set out guidance for the way in which public authorities should continue to respect, protect and fulfil their human rights obligations throughout the pandemic. Notably, the Chair of the UN Committee on the Rights of Persons with Disabilities, Danlami Bashuru articulated that during the COVID-19 pandemic:

> the range of support in the community, including home-care and personal assistance support, and rehabilitation services, when necessary, must be ensured and not discontinued as they are essential for the exercise of the rights of persons with disabilities.[24]

The Scottish Human Rights Commission wrote to the Equalities and Human Rights Committee of the Scottish Parliament in April 2020 to note our concerns about reports of reductions in care packages. We noted that:

> while adjustments may be necessary to protect the individual or staff from the virus, it is essential that the care required by disabled people in their daily lives is maintained and that reductions in care do not result in risks to life or create the potential for inhuman and degrading treatment.[25]

It should be noted that in relation to the European Convention on Human Rights, while some rights such as the rights to privacy, free expression and assembly are qualified and can be interfered with under certain circumstances and if a number of specific tests are met, others can never be interfered with under any circumstance, including the right to life and the prohibition on torture, cruel, inhuman and degrading treatment.

4. COVID-19 Legislation

Introduction

During February and March 2020, the UK and Scottish Parliaments introduced temporary legislation to manage the response to the COVID-19 pandemic. Both the UK and Scottish Coronavirus Acts had an impact on social care provision in ways that had the potential to interfere with how people's rights are realised. This chapter discusses and assesses this impact and makes recommendations for appropriate action.

Coronavirus Act 2020 – Effect on Duty to Assess

The Coronavirus Act 2020 contains several provisions in relation to social care. The relevant sections are s16 and s17 of the Act, which amend, among others, the Social Work Scotland Act 1968, the Social Care (Self-directed Support) Scotland Act 2013 and the Carers (Scotland) Act 2016. In the case of the Social Work Scotland Act 1968, the provisions set out that a local authority need not comply with the duty to assess a person for support, if to do so would be 'impractical' or would cause 'unnecessary delay' in providing community care services or support. In addition, if an authority does not do, or only undertakes to do a partial assessment, the local authority would not need to adhere to the general principles of the Social Care (Self-directed Support) (Scotland) Act (2013) (SDS Act), including involvement and collaboration of the person in assessment and provision of support or assistance to express their views and make an informed choice on the options. Where a full assessment is undertaken, the local authority must enable these principles as usual. The Coronavirus Act also sets out that where a partial assessment is undertaken, the local authority may not recover charges for the support. Other provisions convert the duty to create a support plan for adult carers or young carers under the 2016 Act into a power to do so. These sections were brought into force by a Scottish Statutory Instrument on 5th April 2020.[26]

It should be noted that the local authority continues to have a duty to provide support under the 1968 Act, the changes only relate to the level of assessment it needs to make.

The Scottish Government developed guidance for local authorities in relation to the new powers.[27] This guidance relies upon the UK Government ethical framework on social care.[28] The Commission has previously commented on this guidance in a letter to the Scottish Parliament's Equality and Human Rights Committee,[29] noting that the latter is not sufficiently robust in places and does not set out with sufficient clarity the legal duties which continue to apply to the actions or omissions of public authorities, in particular under the Human Rights Act 1998. Additionally, there is limited reference to human rights within the ethical framework and no reference to the principles of the UN Convention on the Rights of Persons with Disabilities, to which the UK has been a State Party since 2009. This is of concern given the very different approach which has been taken in Scotland in relation to the CRPD, and which would have provided a rights based framework for the development of guidance and policy. These standards are especially important in responding to need during the pandemic period. While the UK guidance therefore provides a strong starting point, it would seem appropriate to have developed Scottish specific guidance which takes account of the devolved nature of social care and the existing use of CRPD as a basis for policy-making.

At the time of the introduction of the Coronavirus Act 2020, the Commission had several concerns about the potential impact of the powers. In particular, the Commission was concerned that the removal of requirements to apply the principles of the SDS Act where no or only a partial assessment takes place would mean that people would not be supported to participate in the process and to have choice and control. This is in contradiction to the right to independent living, which requires that individuals with disabilities are 'provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives.'[30] The provisions of the Coronavirus Act and its implementation could also be read as a direct interference with the individual exercise of the right, thus engaging 'obligations of respect' articulated in the General Comment.[31]

Other concerns included that older and disabled people may end up with an inappropriate or inadequate care or support package due to lack of proper assessment, or in the case of adults with incapacity, the lack of a full assessment may have further repercussions with respect to procedural safeguards. Additionally, the conditions of lockdown under the Health Protection (Coronavirus) (Restrictions) (Scotland) Regulations 2020, were likely to mean that carers would have to take on a far greater responsibility for care and support at home, but without the guarantee of an assessment or the potential for support to undertake this role.

Monitoring of the Powers under the Coronavirus Act 2020

The Commission has previously set out that human rights principles of time-limitedness, necessity, legitimate aim and proportionality must apply to all emergency legislation and that should these tests no longer be met, then Scottish Ministers should repeal the relevant statutory instruments so that the usual system of assessment can recommence. At the introduction of the Coronavirus Act 2020, the Commission noted the importance of proper recording of the reasons why a local authority might choose to use these provisions and also the impact of this on people's experiences, to ensure that decisions being made were proportionate and that there was a robust accountability framework in place.[32]

In the Scottish Government's June 2020 report to the Scottish Parliament on the use of the provisions of the Coronavirus Acts it is recorded that the Government had undertaken a survey of HSCPs to establish whether they were using the powers and the extent to which they were using them. The report noted that:

> Responses were received from 26 Local Authorities/Health and Social Care Partnership areas. Of these, five partnership areas comprising six Local Authorities said they were using the powers. Some are using the powers across the whole authority area and all services, while others are using the powers in a more targeted way, for example, on particular services only. Some of the reasons for the use of the powers included: to support quick access to services where face to face assessment cannot take place, to allow staff to support frontline duties and reduce bureaucracy, and to avoid delays in the provision of care.[33]

The Commission notes that some additional further information from the Scottish Government as to which local authorities were making use of the provisions brought in by the Coronavirus Act has been made available by the second report to Parliament.[34] This followed a second survey between 17 May and 3 July 2020, to which all 31 HSCPs responded and which confirmed that Dundee, East Renfrewshire, Highland and South Lanarkshire were using the powers during this period. However, the identity of the initial six authorities to use the powers remains unconfirmed. Reasons given for use of the powers during this second period included:

> to allow staff to support front line duties, to provide flexibility to enable targeting of resources on those with most needs, and to ensure people receive appropriate care promptly.[35]

The Scottish Government also indicated that its survey requested further information as to:

> what arrangements were in place to ensure that these powers are being used in a way that protects human rights, including the rights of children. Responses included the continued focus on Health and Social Care Standards and Social Work protocols that emphasize human rights principles.[36]

While this additional information is welcome and helpful, it provides little information as to the numbers of people in receipt of support without full assessment, or the identity of these individuals and whether any specific groups are more affected than others. More detailed monitoring and reporting would enable a more robust assessment of the necessity of the legislation continuing to be in place and whether the decisions by individual HSCPs are proportionate. Additionally, while the Commission welcomes the requirement to report on rights protections, it is not clear that regard to Health and Social Care standards or social work protocols alone is sufficient to ensure that specific rights standards and obligations are being met, particularly when important procedural safeguards designed to protect autonomy, liberty and private and family life are engaged, or absolute rights such as the prohibition on cruel, inhuman or degrading treatment are at stake.

Views and Experiences of Interviewees in relation to the Coronavirus Act 2020

In our research, the Commission was interested in finding out more about whether the new powers were being implemented in local authority areas and how this was affecting delivery of social care for the people concerned. We asked interviewees if they had had information from the local authority areas where they worked and, if the powers had been adopted, how this was working.

Only one interviewee had had information about the actual or intended implementation of the new powers. Most people (10 of 15) said that they had had no information about where and whether the powers were being adopted and for what reason, and commented on the lack of transparency as to whether the powers were being used and on what basis:

> "I don't think we have received any formal communication from any local authority about that. We have been told when some of the weekly meetings have met, about the fact that full assessments may not be undertaken, I don't think that's been followed up by any written information". (Provider)

> "I think our members have never been informed by the local authority area of whether they are implementing the emergency legislation or not. No, no, no, not at all and there is very little public information available and certainly our members have not been informed. People understand there is a bit of legislation that has passed, but don't really know whether that means it has been enacted or it's not." (Umbrella organisation)

Some interviewees expressed concern about the lack of transparency in the use of the powers and the fact that this did not enable appropriate scrutiny of whether the powers continued to be required.

> "One of the things we have asked the Government to clarify is what are the decision making criteria that authorities have used to make these decisions, can we see them? We don't know, the problem is that we just don't know, even which HSCPs have not reported to the Scottish Government." (Third sector organisation)

Other interviewees also noted how this lack of transparency filtered down to individual level:

> "I think there is something about having an understanding that perhaps having to do a truncated one, in some ways it makes sense, but what are the safeguards in that to make sure that the next step is done quickly and it's not left to drift? You might understand why this might be happening, but actually people need clear information that needs to be publicly available, again it's about transparency." (Carers' organisation)

Coronavirus (Scotland) Act 2020

The Scottish Parliament passed legislation making provision for certain aspects of social care, which particularly affected adults who may lack capacity to make certain decisions. The provisions of Schedule 3, Part 2, Section 11 of the Coronavirus (Scotland) Act 2020 have now expired[37] or been suspended[38]. The Commission's previous commentary on the Scottish legislation can be found here.

Conclusions and Recommendations

Based on our own research and evidence provided by interviewees, the Commission continues to have concerns with regard to the lack of transparency on the use of the powers brought in by the Coronavirus Act, as well as the lack of rigorous monitoring which would enable clearer assessment and scrutiny, particularly by the Scottish Parliament, of the necessity and proportionality of the measures.

We therefore make the following recommendations for action.

1. The Commission recommends that the Scottish Government works in partnership with local authorities who are using, or have used, the powers to gather data on the number and identity of individuals affected by the provisions under s 16 and s17 of the Coronavirus Act 2020. The Commission recommends that the Scottish Government collates, analyses and publishes this information to enable additional scrutiny of the use of these provisions by relevant parties.

2. The Commission recommends that the Scottish Government undertakes research with people affected by these powers, and where appropriate, their families and unpaid carers, to understand more about their experiences and identify if there have been any concerns in relation to their care and support.

3. The Commission agrees with the Scottish Government guidance on social care assessments under the powers that 'arrangements should be made to conduct assessments for people who did not receive a full assessment while section 16 was switched on. For adults with incapacity, a review of those adults subsequently identified as lacking capacity should follow the principles of the AWI Act and the recommendations of the United Nations Convention on the Rights of Persons with Disability.' The Commission recommends that local authorities and HSCPs clearly and proactively communicate with people and their families as to when this assessment should take place.

4. We also recommend that the powers under the Coronavirus Act should not be used in relation to people who had already had an assessment and were in receipt of a care and support package prior to 31st January 2020. People with existing packages should not have these altered without recourse to a full assessment.

5. The Scottish Government should publish a more detailed and transparent account of which Health and Social Care Partnerships and local authorities have made use of powers in relation to assessments under s16 and 17 of the Coronavirus Act, which are intending to use the powers, and the decision-making framework they have used in choosing whether or not to implement the powers. This will assist the required scrutiny of the necessity and proportionality of the use of powers into the future.

5. Challenges to Social Care before the Pandemic

The Commission asked interviewees to provide a summary of the kinds of challenges they and their organisations were facing before the pandemic. This enabled us to establish context for the subsequent impact of COVID-19 and how it was managed.

Interviewees provided a wide range of commentary on the pre-existing challenges facing the social care sector. Many of these have been previously identified by the Scottish Parliament's summary analysis of the 225 responses it received in its initial inquiry into social care,[39] and in response to the Scottish Government and COSLA discussion paper on Reform of Adult Social Care.[40]

Challenges for People who Require Social Care Support and for Unpaid Carers

Interviewees identified a range of challenges to the realisation of the right to live independently, in particular in relation to the availability, accessibility and quality of social care for people who need support, including family carers.

> [The key challenge] "was around having enough support, SDS, decent care packages in place and set up and flexible use of this packages" (Carer organisation)

> "Effective support from local services and that's for the person that they care for, that has always been the number one priority, if that works then a lot of things fall into place for carers as well." (Carer organisation)

This included poor or incomplete information being given to people at the point of attempting to access the social care system, which could at times act as an obstacle to getting the right support:

> "People's access to information and trying to understand how to access support and to social care, and I think a lot of that was your first point of contact was local authorities, the quality of information maybe that people were receiving. There are still a lot of people being told they may not be eligible for SDS, people not be might be signposted to

> other sources of information and support, particularly independent sources outside of the local authority, so people are unfortunately getting incorrect messages, which might make them think 'there is nothing else we can do', or give them completely incorrect information in terms of potential eligibility, which has maybe not really been established at that point." (Umbrella organisation)

As has been well-documented for a number of years, eligibility criteria and care charging were also pointed to as key barriers to accessing social care. As each of these are set by each local authority area, in accordance with the budgets available to them, rather than taking a national approach, many people noted the inequality of different criteria being applied across the country, meaning that the level of support and the amount a person could be expected to pay were contingent on where a person lived.

> "I'm sorry but [Council name] have always been only providing support at the critical end, there is a major problem with the eligibility criteria, major, major problem that we have been trying to work on through the reform process." (Disabled people's organisation)

> "And that's very much linked to eligibility criteria which is quite tight now, that has over the last couple of years become tighter around the country, just the way in which it is described has become quite different, for example in Aberdeen, they don't talk about 'critical' they talk about emergency, now emergency conjures up quite different associations. People say well 'Am I in an emergency?' It's very different to ask, 'Do I feel the support I might need to maintain my independence is critical?'" (Umbrella organisation)

> "One of the other issues would have been on an individual level about social care charging, the disparity between social care charges across the country and the need to kind of at some level to try and at least have proper guidance around that, the existing guidance is not strong enough in terms of trying to manage that balance between localism and asking something which is not massively insulting to people across different local authority areas." (Third sector organisation)

It was noted that the tightening of eligibility criteria often meant that people were not able to get support to help them live independently as is required by the CPRD, and in some cases, they were not able access support until they reached a crisis point, often connected to the worsening of a condition or impairment and/or the ability of a carer to support the person without detriment to their own physical and mental health.

> "There has certainly been in some areas much more focus on providing people with their critical or substantial support needs and there would be concern about the ability to have other types of support that's about quality of life and opportunity." (Provider)

> "The trajectory for people with dementia tends to be that people have no social care until fairly late on. People don't get care until a crisis and when they do it tends to be at the point of requiring a move into residential care rather than in the community." (Third sector organisation)

Many interviewees noted the potential that self-directed support offered to the system, especially in terms of protecting and promoting rights, including respect for autonomy, choice and control:

> [The SDS legislation] "is stronger than previous legislation because there are some rights based principles perhaps embedded in the mainstream through that legislation." (Third Sector Organisation)

However, as has been well-documented through reviews by Audit Scotland,[41] the Care Inspectorate,[42] and current research by the ALLIANCE and Self-Directed Support Scotland,[43] there continue to be a range of challenges to its implementation.

> "We have a Parliament, who on a cross party basis legislated for SDS in 2013, that is the silver bullet, that's it, and why are we looking for something else? It's just never been implemented properly in my view." (Representative body)

> "One of the challenges that we have talked about on an ongoing basis is that frustration of maybe not seeing SDS being available to people in the way that it was promoted and that that has been an ongoing concern for us an organisation." (Provider)

> "Since the introduction of the [SDS] Act, if you looked at the legislation now and at statutory guidance and you looked at practice, there's really a huge gulf between expectation and reality. That covers any aspect of delivery and people's experience of accessing social care." (Umbrella organisation)

These challenges include specific groups being funnelled towards or away from particular of the options, meaning that there is unequal access to particular types of support but also a limit on the amount of choice and control a person can have, based on their impairment, clearly running contrary to the principles of the Act and also to key human rights principles of non-discrimination and autonomy set out in the CRPD, which is based on the presumption of equality before the law:

> "Then with regard to non-discrimination and equality, there are specific groups, as well that have particular problems accessing social care and SDS, you know people with lived experience of mental health problems, people with learning disability and being told that SDS is not for you. Or it just doesn't apply, it's not actually for your group or your condition, which is obviously not…" (Third sector organisation)

> "We spoke to a number of folk with learning disabilities being told 'SDS is not for you,' being told 'Option 1, I'm not sure if you can handle that.' Other areas that I would also highlight alongside the learning disabilities and mental health specific ones is generally speaking women having less choice than men." (Third sector organisation)

The patchy and unequal implementation of self-directed support represents an enormous barrier to the realisation of rights for people and unpaid carers who need support to fulfil their right to live independently in the community.

In summary, before the pandemic, people requiring support and unpaid carers faced challenges to both the accessibility and availability of social care, with inequalities relating to geography, identity and socio-economic status evident.

Challenges for Provider Organisations

The key challenges highlighted by providers and provider organisations were connected to the financial sustainability of their organisations in market-driven environment. Several noted that the procurement practices of services by local

authorities had the effect of driving down costs to a level in which neither the desired quality of care, nor fair and appropriate terms and conditions for staff could be provided.

> "Trying to provide support in a marketplace which has been under a challenge for the last 10 years, the challenge being a downward pressure on costs, repeated tenders, procurement exercises, that takes up quite a lot of my time, trying to manage increasingly complex services with less money." (Provider)

> "In terms of home care staff in particular, the way in which contracts have been developed over time make it virtually impossible to engage in Fair Work practices." (Representative body)

It was noted that procurement by local authorities also created a significant disparity between the terms and conditions of in-house services and those of staff working in procured services.

> "We know there is this huge problem between the disparity between public sector pay and conditions and third and independent sector conditions; again at the heart of this is the procurement process." (Third sector organisation)

> "There's this hypocrisy on the part of local authorities, who commission and celebrate their in-house provision as being fair work compliant and yet externally commission organisations at rates which make fair work practice, continuity of contract…and the use of electronic call monitoring, it makes it impossible." (Representative body)

Recruitment and workforce terms and conditions were also noted as key challenges particularly the disparity between the skilled and demanding nature of social care roles and the relatively low pay available for these. Interviewees noted the competition in the labour market because of low wages was high and that maintaining staffing levels was always a challenge.

> "There is a lot of competition and that's across the board, the Terms and Conditions and the salary isn't one that necessarily encourages people to apply to social care." (Provider)

> "We pay above the Scottish Living Wage but at the same time so do lots of other sectors and jobs and social care is a challenging job, very complex, I think that it is undervalued in terms of the financial payment and the way that it has been seen." (Provider)

Some interviewees noted the gendered dimension of social care, noting that this played into the perception of social care as low-skill, low-value work:

> "Gender is a massive issue and social care is a massively gendered issue. Two thirds of the people accessing social care are women, 85% of the 200,000 plus workforce are women. It's not a coincidence that it's an undervalued and underpaid sector that's predominantly women focused." (Third sector organisation)

In summary, from the perspective of providers, there were rights challenges in relation to providing an adequate quality of care in a competitive market, as well as in ensuring that staff could enjoy just and favourable conditions of work as set out in ICESCR and ILO treaties.

Additional Policy Challenges

Localism v National Approach

Many interviewees discussed the increasing tension and disjuncture between the national policy approach to the delivery and reform of social care, as one which is characterised by implementing the principles of SDS, and taking a human rights based approach relating to the CRPD, at least at a rhetorical level, and the practical implementation of this at local level through strategic commissioning, procurement, assessment and service provision processes.

> "Yes, I mean if you looked at the SDS change map that the Scottish Government developed, that's great, it's got all the outcomes in it. Unfortunately has anybody seen it, does anybody use it, is any practitioner actually aware that they should be meeting these certain outcomes?" (Umbrella organisation)

> "The problem is that there is an intent and will in the Scottish Government particularly to push that rights agenda, and that's why the reform of adult care policy is very rights focused, and it says a lot of the right things but there isn't a competency there in order to translate

> that into practice, and there is a question mark as to the extent to which there is that intention and desire at local authority level, which is where all this stuff actually happens. There is a problem in relation to the relationship between central and local government as there is elsewhere, that needs to be resolved." (Third sector organisation)

Interviewees expressed frustration that the relationship between the centre and the local often acted as a scapegoat for difficult or contentious decisions on either side:

> "If you allow the local authorities to commission without any reference to Government guidance, which the Government are always reluctant to provide, to control from the centre….that's what they say, I think it allows them to pass over responsibility as they go along, they hand the money to HSCPs. They in turn blame the government if anything goes wrong." (Provider)

This tension between policy aspiration and policy delivery has become more evident throughout the COVID-19 pandemic, where Scottish Government guidance has insisted that there should be no reduction in social care support to people[44] but local authorities and care providers at local level have struggled to manage the many pre-existing challenges of workforce capacity and underfunding meaning that people were in some cases, already receiving less support than their assessed need would suggest they required.

Accountability and Transparency

Reflecting some of the concerns discussed above in relation to the powers introduced by the Coronavirus Act 2020, a clear and related thread which ran through many of the interviews was about the need to establish systems which would enable greater transparency and accountability over the activity of public authorities, and in particular local authorities in relation to social care.

> "There isn't really anyone holding local authorities to account, there's very limited accountability in terms of implementing that legislation. Scottish Government don't do that, they expect local people and organisations to do that and local people and organisations don't have the tools to do that." (Umbrella organisation)

With regard to transparency, several interviewees noted that people and unpaid carers attempting to access support were often not provided with the reasons for decision making around their care package. As noted above, the Court of Session has indicated that local authorities should provide an explanation of their reasoning in arriving at an estimate for the cost of care as an important element of procedural fairness, and interviewees agreed that this was an important element of understanding the process which should be seen more often.

> "Transparency [is] generally a common theme problem, and something that's praised when it exists….even if it's not the response that [the person] wants. Clarity of process is held as really important and the flip side of that is that it's a problem." (Third sector organisation)

> "I think there is one thing about definitely transparency in understanding just what to expect from your journey. So as a local authority, yes we are challenged with undertaking that assessment, here's the criteria we use and making that very clear. This is how we are going to work that out, so this is how we score it, this is how we allocate resource, this is how we determine eligibility, this is how we allocate resources on that basis, so people understand." (Umbrella organisation)

It was also noted that there needed to be a more robust system for individuals to challenge decisions made by local authorities about social care. Some interviewees suggested an independent tribunal services as a mechanism to achieve this:

> "A tribunal process would need to enable people to make relevant referrals, you'd have to decide what the processes for that are. That absolutely would bring local authorities into a scenario where they are no longer in control in deciding and that independent body can have scrutiny, can access any relevant information, can make a decision that is legally enforceable and binding. Absolutely, I think also just knowing that people have the ability to take public authorities to that type of environment, might change the way which local authorities deal with people's concerns, to prevent getting into all that time and cost which could be completely unnecessary. So that system is needed, without that we will continue to have a lack of accountability." (Umbrella organisation)

Interviewees noted that the need for greater transparency also extended to the way in which local government allocated and spent resource on social care, and notes that there was little scrutiny of this:

> "The problem is with the implementation, scrutiny and the accountability all around that piece. Despite having been subject to investigation by the Public Audit and Post-Legislative Scrutiny Committee and others, the problem is, is that resource trumps all, and resource availability trumps all and is used as a reason for why x, y and z can't happen without further explanation and investigation of that assumption….and also then the dark tunnel into which funds go, it's impossible to find out, so a quarter of the £15 billion health and care budget we think is allocated to SDS and social care more widely but it's impossible to really to work it out." (Third sector organisation)

This also included the way that budgets are managed where monies are provided from central government to support key policies such as the National Living Wage:

> "There are problems of implementation such as the Living Wage Policy, which everyone supports of course but the way that it was implemented was very poorly thought through, in particular the way that the resources are distributed. It goes from Scottish Government, to local authorities in the local government settlements, to HSCPs then back to local authorities to actually do the procurement, there is no assurance and there is no transparency in the system." (Representative body)

Accountability and transparency concerns are also engaged in relation to the monitoring and data collection about people who use and require social care, and their experiences of it. Two of our interviewees noted that the lack of data available to local authorities on people's take up and experience of social care made it more difficult to see how different groups are affected:

> "At local authority level there is a very little data tracking, there is very little evidence for how they're checking the differences between different population groups, ISD data is very limited in terms of what it can do in terms of ethnicity, no data of whether folk have learning disabilities, so you're relying on quite a range of sources of information for implementation which compounds some of these issues of disparity of experience." (Third Sector Organisation)

Specifically in relation to the collection of data about ethnicity and the experiences of Black and Minority Ethnic groups, one interviewee said

> "I raise this issue at every meeting that I go to and you see their eyes glazing over and it's not an issue for 99% of people, and the interesting thing is that it isn't an issue for 99% of the population and it also isn't an issue for 99% of policy people or anybody else, it is really shocking…" (Umbrella organisation)

Interviewees' conclusions on the need for more robust data are supported by a recent submission of the Office for Statistics Regulation to the Scottish Parliament's Health and Sport Committee Inquiry on Adult Social Care which found that there are important gaps in the provision of statistics on social care, as well as issues of data quality, meaning that 'we don't know how many people currently need social care and whether those needs are being met, how many people might need care in future, and we don't know how well social care services achieve their goals of helping people to live independently and maintain a good quality of life.'[45]

Conclusions and Recommendations

Before the advent of COVID-19, it was clear that all of the different actors in the social care system were facing challenges in ensuring the accessibility, availability, adequacy and quality of social care to people who have a right to the support they need to live independently. The system was not focused on securing rights and was troubled by a lack of transparency and accountability.

The Commission has undertaken a significant programme of work in relation to human rights budgeting. Human rights budget work uses human rights standards and principles to develop, analyse and scrutinise a budget. The Commission notes the potential of a human rights budgeting approach in addressing the lack of transparency and accountability of spending in the social care system.[46]

We make the following recommendation.

6. The Commission recommends taking a human rights based approach to future public finances, which considers the impact of financial decisions on the rights of older and disabled people and closely interrogates claims in relation to limited resources could make a significant shift in the way that budgets are generated, allocated and spent.

6. Impact of COVID-19 on Social Care

The Commission asked interviewees a number of questions about the impact of the pandemic, both on their staff and organisations, as well as on the people they support or act on behalf of. This section considers and summarises the range of impacts reported.

Disproportionate Impact on Older and Disabled People and People with Intersectional Identities

Many interviewees were keen to highlight that some of the early rhetoric about the impact of pandemic as being an 'equaliser' or affecting everyone equally was particularly unhelpful. Instead it was noted that older and disabled people were in the first instance much more likely to be adversely affected should they be infected by the COVID-19 virus.

> "One of the things we have been trying to highlight throughout the course is that people accessing social care, people with long-term conditions, disabled people and carers are being disproportionately affected: a) in terms of they are clinically at greater risk of developing complications as a result of the virus in many cases."

> "Disabled people overall we think are disproportionately impacted by the illness, but we haven't got data, there is no clear data on that." (User led organisation)

There was also recognition of the different impacts on people with intersectional identities, such as older and disabled women and people from Black and Minority Ethnic groups.

> "We always take an intersectional approach, we think that disabled women are probably more likely to be carers, and to be taking on responsibilities for children and now for older people, we've been told that childcare being an issue, childcare and work balance. Additionally BAME disabled people with underlying conditions are more likely to die from the pandemic." (User led organisation)

> "I said at the start that the way in which we respond to the pandemic will either determine whether we are an age discriminatory society or not, and unfortunately, tragically I have been proven right." (Representative Body)

Layered on top of that was the recognition that the policy and practice decisions around managing the pandemic were much more likely to adversely affect the rights of people who required support, especially with personal care and to undertake every day activities such as food preparation.

> "People accessing social care and our members more generally, people with long-term conditions, disabled people and carers are being disproportionately affected: b) disproportionately affected by the adaptations that are taking place to manage the spread of the virus in terms of service changes and lockdown arrangements." (Third sector organisation)

> "Disabled people have fewer resources to support themselves in emergency situations and will be disproportionately affected." (Disabled people's organisation)

The Commission also asked whether in the experience of interviewees, there were any specific groups of people in receipt of social care who, in their view, had been disproportionately affected. Interviewees identified the following groups:

- **People on the autism spectrum who need support.** This related to the challenges some people on the autism spectrum face in relation to the disruption of routine and/or familiar activities and environments.
- **Parent carers of children and young people.** This related to the increased demand on parents, with less support from school or family members.
- **People who manage their own personal assistants.** This related to the lack of clear guidance, access to support and the risk of being left without support if the personal assistant became ill or needed to shield.
- **People who lack capacity to make certain decisions.** This related to moves from hospital or the community into care homes, and restrictive or disproportionate practices in relation to seeing family members.

Care and Support at Home and Support in the Community

Evidence from both our interviewees and from other sources indicates that the most significant impact on social care support has been the large scale withdrawal or reduction of services, affecting both care and support at home, and the provision of day services and activities in the community.

The most recent Information Services Division report on Social Care from 2019 estimated that in 2018, there were 59,809 people in Scotland in receipt of care at home.[47] Of these, just under half (49.2% or 26,798 people) were older people, and a slightly lower proportion (46.6% 25,246 people) were disabled people. More than a third (37%) of people receiving home care had more than 10 hours of care per week. Half of people receiving higher amounts of home care were disabled people under 65.

One of the most significant impacts of COVID-19 across Scotland has been the reduction or complete withdrawal of care and support in the home for older people, disabled people and disabled children and young people. More than half of interviewees commented on this as one of the biggest impacts of the pandemic. This is corroborated by evidence gathered by other organisations. A survey of 800 disabled people by Inclusion Scotland found that:

> almost half of people responding on this issue told us that the COVID-19 pandemic has had an impact on the social care support they get, formal and informal. Around 30% of respondents told us their support had either stopped completely or had been reduced.[48]

An online and telephone survey conducted by the Scottish Commission for People with Learning Disabilities between 14th April and 5th May found that almost two thirds (64%) of people with learning disabilities had experienced a reduction in care and support.[49]

While it is difficult to find consistent, comparable and accurate published data on the impact on home care in each Health and Social Care Partnership Area, a BBC Scotland Freedom of Information request in April 2020 collated information across 23 Health and Social Care Partnerships.[50] They found that in the region of 3,700 care packages had been ceased or reduced across Scotland compared to January 2020, with the biggest reductions as a proportion of the

total number of people supported seen in Glasgow, West Dunbartonshire, Moray, North Lanarkshire and Edinburgh. Inverclyde Council also indicated that it has done 4,589 fewer home care visits since January. It should be noted that Glasgow makes up for more than half of the estimated decrease, and that in some local authorities figures have changed very little or in some cases, there has been a small increase in care packages (Angus, Falkirk and South Ayrshire). However, the total number provided by the BBC Freedom of Information request is likely to be a significant underestimate since 8 Health and Social Care Partnerships failed to provide data, and others provided it in a form that was not comparable.

It is very difficult to provide an accurate estimate of the proportion of people whose care package has been reduced or withdrawn. However, using the data published in 2019 by ISD (n=59,809), it can be estimated that at least 5%, and likely a higher proportion of people who receive care and support in the home have been affected.

There is no quantitative data available on how reductions and withdrawals have affected different groups of people, for example older people, or disabled people, where reductions have fallen in terms of SDS options or how different types of providers (in house, third sector and private) have sought to respond to the pandemic.

Qualitative data from the interviews we conducted suggests that people who receive a direct payment and manage a personal assistant have faced particular challenges, especially at the start of the pandemic, due to not being able to access information and guidance, the fact that personal assistants were initially unable to access PPE, and may themselves have become ill or had to shield.

> "Particularly people who were managing their own support, people who were receiving direct payments on Option 1, where their [Personal Assistants] were having to shield themselves, there was suddenly a very immediate impact on the level of support people had available to them, how they were going to manage that." (Umbrella organisation)

Third sector providers, whose service provision would mainly fall under Options 2 and 3 of SDS, noted that in general, they had not had to withdraw services, but that they had had to provide them in different ways and use support more flexibly:

> "We have not stopped supporting anyone who wanted support. Where we couldn't deliver a lot of that support was because a lot of that support was maybe social support so support to go and do things in your local community, so that support didn't happen. That was the main change...What has been sustained is the contact with the people and workers they know well and they have continued to get support and their support has maybe been much more about trying to find things to do within people's home or new ways of connecting with others. Although it has maybe not been what people would have chosen, it's actually created some really good stuff, so in some ways, for all their limitations, we have seen people's opportunities expanding because they have been willing to try new things that they wouldn't have considered in the past. I think some of our staff have been incredibly creative." (Provider)

> "The sector hasn't reduced a great deal of its visiting services actually, what has happened is that HSCPs, especially in the cities, appear to have removed people's support at a stroke, but I don't think there has been a lot of that in our sector, there's been some adjustments." (Representative body)

One organisation, who supported people with mental health needs noted that for the most part, they had been able to adapt their services by supporting people through phone calls and video calls. Although it was recognised that some people who required more intensive face-to-face support and those who were digitally excluded were not able to benefit from this, it appeared that this had been working effectively, based on feedback from people using the service:

> "So the main impact has been on how many face to face contacts we can provide, so out of our services, [40%] of them continue to deliver more or less what they delivered before and the others have had to switch to technology. It's worked well [because] most people have a smart phone so that in itself is enough to help without having a laptop or any specific technology. I think the people who are getting visiting support, they are the most isolated. The people who are relying on us to pop in and see them every day have felt it most." (Provider)

Reasons for the Reduction in Care and Support at Home

It is important to understand how and why reductions and changes to care packages have been made. Interviewees acknowledged that COVID-19 had had an impact on the availability of the workforce, because members of staff had become ill and contracted the virus, had to care for others in the home themselves or were in the shielding category.

> "In some local authority areas we were told we needed to provide essential support only and that wasn't about not supporting people but it was about managing risk to people and staff, where there was a genuine worry that so many staff might become unable to work because they became infected or had symptoms that it was about the sustainability of support and being able to manage that so we didn't get into a position where there were no staff available." (Provider)

> "Care packages have been withdrawn and the reason given is for COVID reasons, that we don't have the staff and you are going to have to make arrangements." (Umbrella organisation)

Undoubtedly, the initial stages of capacity planning were extremely challenging for Health and Social Care Partnerships and providers. However, as set out in the section on challenges before the pandemic, the shortage of staff in the sector was and had been very well known and understood for a number of years. The strain in the social care system, in terms of underfunding, understaffing has been known and understood for some time. It should be noted that the Scottish Government and the Scottish Social Services Council quickly undertook steps to ensure the rapid re-registration of social care staff who had retired or left the profession.

In some circumstances, the reduction or withdrawal of a care package was related to the express will of the person who would usually receive support and their families and/or carers. We heard examples of people and families who changed their living arrangements, for example by a disabled or older person choosing to move in or back in with relatives. This was often in response to concerns about a person's specific health and support needs, and in response to a desire to minimise contact with the outside world. In some cases, it was motivated by a desire to protect social care staff themselves

> "We've heard from people who might have chosen not to have care at this point because of physical distancing who also chosen to do so because their family members were more able to be around, because of the furlough." (Representative organisation)

> "Some carers have been in touch to say 'I just don't feel confident, these care workers are going around multiple people, plus they are coming in on the bus, they are going to the shops they are doing all the things that they need to do as a person,' that real fear that they would be bringing the virus in. We did speak to a number of people who withdrew from services because of that." (Carers' organisation)

One provider noted that this kind of decision affected around 15-20% of the total number of people they supported in the early stages or lockdown, although, in some cases, the family had come back to reinstitute services where they were not able to support the person themselves on a full-time basis:

> "Some families actually came back very quickly and said actually we are going to need to find a way of doing this, and we have worked with them to find a way that's comfortable for them." (Provider)

It should not be underestimated what a significant decision people and their families made in withdrawing from services, particularly people and services who may have worked together for some years to establish an independent tenancy and support package. One interviewee commented on the impact that the removal of support had on people's independence:

> "So the complete removal for most people of home based support, and off the back of that, a lot of people have really lost their independence, that has been really hard fought for and really hard won. It doesn't come naturally." (Third sector organisation)

It is critical that neither the enjoyment of the right to live independently in the community nor the good will of families and carers in an emergency situation be compromised by assumptions about future care. Half of our interviewees expressed concern that older and/or disabled people and unpaid carers would be judged by local authorities on the way that they had managed during the pandemic and many expressed fears that local authorities might view the temporary changes brought about in care packages as an opportunity to bring in reduced packages:

"I think there is a real anxiety now that the commissioner, or the Health and Social Care Partnership [will say] 'Well you were alright, you got through that alright, you don't really need this, do you, let's talk about how we continue reducing?'" (Representative body)

"That's a fear of disabled people that their support will not be returned to them, and people have additional needs as well, we know of people who have additional impairments since lockdown and have become ill with something, they will need that urgent assessment." (Disabled people's organisation)

"Suddenly family and friends were having to be relied upon and the worry for a lot of people was that this establishes a precedent, that somehow local authorities might think that people really don't need that formal support ongoing, and this is going to be one of the things go forward, where people are a bit worried how well local authorities might view how they have managed to keep themselves well and isolated, whether that review of their needs is going to change people's understanding, eligibility and access to support in the future." (Umbrella organisation)

"I have to say we are hearing a few kind of worrying things around 'You coped' or 'The family coped' and a real concern that that is going to impact on care packages going forward, and this idea that families will care, carers will care and just get on with it, could set carers back, I hate to say decades, but some of the way things have been articulated does feel like it's coming out of the 50s." (Carers organisation)

"And there have been some of those anecdotal discussions around 'People have coped really well during lockdown, they have managed on much less support, isn't that really interesting, I wonder what that means for the future?' and we have had to say, well clearly their circumstances are completely different and people were able to cope on less because there was less to do, less opportunity, it's not a reflection of what people can manage in ordinary circumstances. That this is an artificial situation in which people have been living for some months and decisions can't be made about support levels and needs based on that." (Provider)

> [We need] "clearer guidance about returning to support at previous times." (Third sector organisation)

Processes around the Reduction in Care and Support at Home

While some people and families chose to withdraw from formal service, in other cases, it is clear that the involvement, choice and control of older and disabled people in decisions around their support package has been limited or even non-existent. Many of the interviewees we spoke to referred to reductions or removals of social care at a stroke, without proper assessment of the impact of the removal of care from people, either from a health, well-being, equality or rights perspective.

> "The impact on disabled people has been huge! Support stopped often without much notice and inappropriate communications used, lack of communication from social work department, many people told us little advance notice about having their support stopped or cut down." (Disabled People's Organisation)

Many interviewees chose to comment on the processes through which decisions were made about where care and support packages were reduced or withdrawn and the manner in which this was communicated with people. Interviewees noted that the process for this had often been poor, with no or limited communication about what people could expect.

> "Quite a lot of people had support withdrawn almost overnight…. I have just come across multiple examples where they might have had a phone call, particularly where the support was on the basis of a needs of a carer, the support was withdrawn, "We don't have enough people to provide that support, we're having to refocus, we're having to focus on more urgent need." People didn't really have any kind of say. There was nothing to say how long that would last for, when they would review that, if there was any change in their circumstances whether they could say, something happened, I really do need additional support, so quite a lot of people overnight lost their support and that was quite traumatic for people." (Umbrella organisation)

> "Actually, what has happened is that HSCPs, especially in the cities, appear to have removed people's support at a stroke." (Representative body)

> "In terms of what evidence and research we have it's that people have said that their support was stopped and they didn't hear anything. 'Support has stopped and nobody has contacted us.' It's been like, the support's not happening and people have been told that. One of the things people with learning disabilities kept saying is that "I was expecting to hear from my social worker, to check in." This is maybe what will happen in the future, there will be cases when it does, but it just flat out stopped for people." (Third sector organisation)

Some interviewees reported that in some cases people had been subject to a certain amount of pressure to accept a reduction in services:

> "I have to say I think there's been a bit of central pressure from service providers and others, you play on people's goodness, 'We'll manage, we'll cope.'" (Carers' organisation)

In some cases, it was noted that the power of attorney or welfare guardian of a person who received home care was not contacted or communicated with at all.

> "Someone who was caring for a family member that didn't live with them and went to them about 3 days in, and the person hadn't received any services for 3 days, they had been withdrawn and there had been no consultation with her as a carer and power of attorney about what that meant. His part of the service was about making sure he had food that was cooked and so it was like, to some extent they are things that the local authority thinks are 'low-level', that someone only needs help with cooking and getting up." (Carers' organisation)

This was not the only instance of decisions about reductions in care packages for adults who may lack capacity in some areas, where the welfare guardian or power of attorney was not informed. This is an area of significant concern because of both the obvious potential for a detrimental impact to the person in terms of their rights to health,[51] food,[52] and physical and psychological integrity,[53] but also the failure to adhere to the procedural safeguards set out in the general principles of the AWI Act. Section 1 (2) of this Act requires that 'there shall be no intervention in the affairs of an adult unless the person responsible for authorising or effecting the intervention is satisfied that the intervention will benefit the adult and that such benefit cannot reasonably be achieved without

the intervention.' It is not clear how the removal of essential support could be viewed as of benefit to an adult who lacks capacity to make some decisions, particularly if they also need physical support and personal care.

Section 1 (4) of the Act sets out that where an intervention is to be made account must be taken of the views and wishes of both the adult, their nearest relative, any guardian, continuing attorney or welfare attorney of the adult, where reasonable and practical to do so. While the situation was undoubtedly immensely pressured for both local authority social work departments and provider organisations, there was no enacted suspension of the principles of the AWI Act in relation to the reduction of care packages, and communication with welfare guardians or powers of attorney to discuss and advise of the constraints on the ability to provide support at home would have been both reasonable and practicable steps to take, with a view to ensuring the adult could be supported in a different way.

Several interviewees noted that in relation to decision to reduce or withdraw care packages in general, there appeared to have much less thought given to the proportionality of the decision than there would be in under pre-COVID-19 circumstances, in particular with respect to the kinds of needs a person had and the ability of the person or their networks to provide support to meet these:

> "No real assessment of whether that informal carer was in a position to offer the kind of support the person needed, because there is not really any conversation about that, no kind of checking whether…what do they need to provide that support do they need bits of equipment, bits of PPE. In normal circumstances, a certain amount of support withdrawn from someone, that creates an issues that a person might want to question or challenge in some way and there's got to be a process in terms of a reassessment or review of a person's needs before doing that, that's been dispensed with in many cases, even if that is down to circumstances that organisations have lost 10 staff, if people understand that, people need organisations and local authorities to come back and say "this is our plan for how to address this", it's not acceptable to just do that." (Umbrella organisation)

It appears to be the case that many individuals have had their care and support packages removed suddenly, without dialogue and without the usual assessment processes which would act as procedural safeguards.

Impact on Family Carers, including Respite

Interviewees also almost universally recognised the impact of the reduction or withdrawal of services, whether this was imposed or chosen, on unpaid carers, who were often at short notice required to provided additional care for people, and sometimes for the first time without any access to the social or organisational supports which might have enabled them to care:

> "Increase in caring role, and lessening of support, a lot of people who applied for a grant said that they have an increase in their role because their kids aren't going to school or the normal groups. It's not that those things are designed as respite but they act in that way, a lessening of the informal supports, e.g. 'my Mum would normally have him on a Sunday afternoon but now she can't', that double whammy of more responsibility and the informal stuff disappearing. Being able to plan ahead taking decisions about moving in together and really changing the way that they were living to pre-empt some of those difficulties, everything taking longer, everything being more complicated and difficult, a huge amount of information to get through." (Carers' organisation)

> "We have seen a reduction in community groups and family networks to give face to face support, so that's much more significant in the face of a significant cut and that would include people who are accessing day centres, whose support has been paused rather than cut, so it's a really substantial reduction in the longer term." (Third sector organisation)

Many noted that there had often been almost no dialogue with family carers as to whether they would be able to support the person appropriately, and what they might need to assist them:

> "There was no real assessment of whether that informal carers was in a position to offer the kind of support the person needed, because there is not really any conversation about that, no kind of checking whether…what do they need to provide that support do they need bits of equipment, bits of PPE." (Umbrella organisation)

> "Yes there's an understanding that the pressures of staffing, but that's a different thing, if you have a proper conversation with someone about that you can perhaps come to an accommodation about what might be available." (Carers' organisation)

> "Here's one example from a carer. 'On 18th March, the care provider called me to say they were suspending my brother's care (35 hours a week) from 21st March. That means I have to pick up 3 sleepovers on top of the 4 I already do for my brother as well as providing social support.'" (Disabled people's organisation)

Several interviewees identified significant physical and psychological impacts on family carers as a result of the withdrawal of support and the increase in care:

> "The big impacts are on physical and mental health. I think they're the big ones. People are…. are and will start to break down, and we did some surveying a few weeks ago, and people were struggling at that point and worried about breaking down." (Carers' organisation)

> [There's been] "a huge mental health impact on carers and as well, psychological pressures, increased stress and social isolation." (Disabled people's organisation)

While accessing respite had been a challenging area for family carers before the pandemic, it was noted as an area of particular concern for some groups including parents of disabled, children and young people.

Impact on Day Centres and Community Activities

Alongside the reduction or withdrawal in services identified above came a reduction on opportunities to attend activities in communal and/or community facilities.

> "Where we haven't been able to operate as normal is where our services were focused purely on providing support to do things in the day so where we supported people who had alternative day support who maybe had previously gone to day centres in the past but now didn't do that and had support to do other things ,all of the opportunities to support people were shut down so we couldn't provide the service because community centres and ordinary places to visit were gone so we couldn't do that." (Provider)

As with reductions or withdrawals of care packages, there was little information available in local areas about when day services could recommence:

> "No one knows, what's happening with day centres reopening, we have asked the HSCP can they give us an idea of what's happening, everyone is doing their own things, people are hearing about the phases, but it's being experienced a bit differently." (Carers' organisation)

Impact on Levels of Care and Support

The reduction or withdrawal of care and support at home has led to circumstances in which people were left without essential care, such as assistance to get up and go to bed, to wash and use the toilet and to eat and drink and to take medication.

> "There are people whose social care packages were cut basically overnight, they would usually have 3 daily visits, they have been completely cut, no-one to support them to get dressed or to apply medication, the regressive nature of that is so stark, it's hard to even describe the impact of that on people." (Third sector organisation)

> "It was this gentleman within the community, who had just before COVID, negotiated a new supported tenancy really, and which totally met his needs, he actually had a learning disability but a functional mental illness as well, so this was a good move for him, so he moved, but at the point whereby his community care team would have been settling him in and such like, COVID happened. This man lost hundreds of weight and eventually had lost his mobility, had been found almost catatonic in bed. It will be a long recovery, and essentially the evidence that I was given is that this man, is really a victim of COVID, so it's just really sad because going to urgent care has consequences, he got so frail and lost so much weight." (Legal specialist)

> "A lot of examples of people left in dire situations, we have been told of people being forced to sleep in wheelchairs, unable to get out of bed, unable to wash and dress themselves, keeping up basic chores having to move in with family even though you know family isn't used to providing the care and support they need, family members being forced into caring roles that they haven't done before and some having to give up employment to do that." (User led organisation)

> "One person we work with ended up being left in their wheelchair, [not properly dressed], for hours at a time, no dignity, they ended up having a physical and mental breakdown, no support, so they had a number of PAs but some were shielding…they got a member of the family to complain a and they were just ignored by the local council, or they came back to them saying 'We don't have a list of your current needs and how they have changed', then they were ignored and they followed up saying, 'I emailed you on this date with this information' and they wrote back saying 'we still haven't got a clear idea of what your needs are'. It was disgraceful." (Disabled people's organisation)

The impacts described above have the potential to engage rights to life, physical and psychological integrity as well as to dignity and autonomy, under Articles 2, 3 and 8 of the European Convention on Human Rights.

With respect to Article 8, the removal of certain elements of social care support packages which have the effect of interfering with rights and dignity, without following proper assessment procedures have been found to be a violation of Article 8 rights as in the case of *McDonald v UK*, since such changes were not in accordance with law. It is not clear how the Courts would view the context of the COVID-19 pandemic as a mitigating factor for these decisions, however it should not be taken for granted that such decisions will be regarded as proportionate, especially if there is an unclear rationale for removing certain elements of support.

With respect to Article 3, the European Court has set out that the treatment of a person must reach a minimum level of severity for Article 3 to be engaged.[54] Any assessment of this should take into account the duration of the treatment, its physical and mental effects and the sex, age and health of the person concerned.[55] Jurisprudence under the ECHR has previously found that treatment of disabled people in a prison setting where the person 'risks developing sores because her bed is too hard or unreachable, and is unable to go to the toilet or keep clean without the greatest of difficulty, constitutes degrading treatment contrary to Article 3.'[56] While the setting may not be analogous, the impact on some people due to a lack of support at home will have been similar. It should be noted that there are no circumstances, even in crisis situations, where a state may justifiably not comply with the prohibition on cruel, inhuman and degrading treatment.

As the above evidence from interviewees illustrates, the reduction and withdrawal of care and support at home also have the potential to engage rights to food,[57] health,[58] and independent living[59] under ICESCR and the CRPD, since some people in receipt of social care have not had the support they need to manage long-term health conditions, take medicine in a timely fashion, prepare and eat food and maintain their independence, albeit in a lockdown context.

Conclusions and Recommendations

Our research shows that the reduction and withdrawal of care and support at home, as part of the state response to COVID-19, has had direct and detrimental impacts on the human rights of those affected.

While many local authorities and providers will have been making complex decisions and assessing the risk to people from reducing or withdrawing care with the more limited resources available, sometimes these systems have not worked as effectively as they should have done. They may not have been based on rights based approaches, which take into account the impact of decisions on physical and psychological integrity, rights to health, food and independent living.

We note that any attempt to reduce care packages on the basis of people's experiences during COVID-19 would be highly retrogressive, contrary to the requirements of Article 19 of the CRPD, and would risk challenges under the HRA in particular under Article 8 (private and family life), and in some extreme cases, Article 2 (right to life) and Article 3 (the prohibition on cruel, inhuman and degrading treatment).

The Commission is deeply concerned that people who may lack capacity to make some decisions about their welfare have been left without care and support, without effective communication with the welfare guardian or power of attorney. Failure to communicate with a welfare guardian or power of attorney opens up the potential for serious detriment to rights, including rights to food, health, independent living, and Articles 3 and 8 ECHR, as set out above.

We therefore make the following recommendations.

7. The Commission recommends that the Scottish Government and COSLA jointly commit to the re-institution of care and support at pre-pandemic levels, as a minimum, and that where people indicate that they have increased support needs due to the effects of COVID-19 or of lockdown, that they receive a full assessment. The Commission notes that the new powers brought in under s16 and 17 of the Coronavirus Act should not be used to alter support packages for people with pre-existing arrangements (before January 31st).

8. In planning for the resumption of pre-pandemic services, local authorities and Health and Social Care Partnerships must either recommence the pre-COVID care package, or if the person's circumstances have substantively changed, they must fairly and systematically assess need.

9. It should not be assumed that family supports which have been in place during the crisis are sustainable over the long term. Disabled people, family carers, older people and children and young people must be informed in an accessible and timely manner of the next steps in relation to the resumption of their pre-pandemic care package.

10. In line with the recommendation set out in Scottish Government guidance, people who have had no, or partial social care assessments should have a review within six weeks. Where it is not possible for this to be delivered, local authorities should communicate clearly and proactively with people and their families as to the expected timescale for a full assessment, and any implications this will have for care-charging.

11. The Scottish Government and COSLA should develop an emergency decision making framework for social care which is grounded in rights-based principles of inclusion and participation in decision making, and transparency. This should also meet critical human rights standards:

    - ensure non-regression
    - be temporary and time-limited
    - be necessary and proportionate
    - be non-discriminatory and mitigate inequalities
    - ensure the protection of a minimum core content of rights
    - consider all other options, including financial alternatives.

12. In future situations of emergency where resources are stretched, disabled people, family carers, older people and children and young people must be involved in a meaningful conversation about prospective decisions to cut their care packages. This is especially the case where people need support to make decisions or another person has power of attorney or is a welfare guardian.

13. The impact of COVID-19 on the human rights of older and disabled people who get care and support at home and in the community should be included in any future inquiry into the pandemic. Our separate briefing on the impact of COVID-19 in residential and nursing homes sets out the relevant rights based standards.[60]

14. In order to understand the impact of the pandemic on care and support at home, the Scottish Government should immediately establish data collection mechanisms to monitor the nature and extent of reductions and withdrawals of care and support. This will help support the social care sector to respond effectively in the event of a resurgence in the virus or further complications related to a combination of winter flu and COVID-19. It will also help to ensure the availability and adequacy of social care support during periods of crisis.

15. Where someone has a welfare power of attorney or a welfare guardian, local authorities should ensure that individual is contacted to discuss potential changes in a care package, even in times of crisis and extreme pressure. This can avoid both failures of procedural safeguards and detrimental impacts on rights.

16. The Scottish Government should rethink and refocus social care as a delivery mechanism for realising people's human rights. To address the longstanding inadequacies in the social care system, an integrated programme of reform must take place, explicitly grounded in human rights standards, which makes changes at legislative, budgetary, policy and implementation levels.

7. Guidance

This chapter discusses and assesses issues relating to guidance around COVID-19 legislation, policy and practice.

Introduction

The issuing of regular guidance to support Health and Social Care Partnerships, local authorities, older and disabled people and their families, and social care providers and representative organisations has been essential, not only in supporting understanding of the legislative changes but also changes to policy and practice in the field. Since the end of March, the Scottish Government, and in some cases the Scottish Government jointly with COSLA, have issued a range of advice and guidance on social care funding, provision, clinical guidance and information for unpaid carers.

Views and Experience of Interviewees

The Commission asked a number of questions on guidance during the interviews, including on its timeliness, accessibility, quality and relevance to social care. It is worth noting that different pieces of guidance were of greater or lesser relevance to organisations depending on their role and identity. In general, interviewees noted that initial guidance was slow to appear, making it challenging to advise people affected by the changes, unpaid carers and staff. Participants also noted that people were making decisions about whether to lockdown some time in advance of the official UK Government announcement:

> "Well, to be honest a lot of it came after the fact, or it came really really close to it, so things about employment in relation to shielding, about these sort of things, they came really late in the day. Obviously very challenging to respond to carers, where we were with carers, the period when they started to have a lot of questions, a lot of fear obviously and where people had actually self-locked down, had been before the lockdown itself, we have been trying to advise and support people around that but it had been building already before lockdown actually kicked in." (Carers' organisation)

In some local areas, there appeared to have been a more proactive approach which anticipated the impact of lockdown on for example, family carers and tried to meet information needs:

> "The Carers' Centre worked with the HSCP to get a letter out to everyone on our books, who all got a letter, twofold, partly about what we were expecting to happen, it was quite early, on PPE, it said, you might be struggling to get this, please contact us, the other side of that letter said, it was like a carer identification letter, it said, this person is a carer, if they are out at the shops, please make allowances." (Carers' organisation)

One sector, advocacy, noted that despite its importance in supporting people with mental health issues, learning disability and others, it had not received any official guidance or advice which had had a knock on impact on how well people were able to participate in decisions affecting their rights:

> "Zero. And more importantly, advocacy organisations have had very close to zero from their own commissioners from the local authority or the NHS, some people have said they have had a reassuring phone call from their Commissioner saying are you alright, that has been dependent on the relationships, some people have said they have been out and out obstructed and some people have been asked for their KPIs and their quarterly report. We didn't get any information from Scottish Government." (Advocacy organisation)

In contrast, some guidance was felt to be particularly helpful, especially the Scottish Government guidance on Option 1 and 2 of self-directed support,[61] both in terms of the commitment to make up any funding gap, but also to use budgets flexibly and set out that the pandemic met the exceptional circumstances test for employing family members with a direct payment.

> "Guidance on Option 1 and 2 helped focus the flexibility that people need to make their own choices and manage things as best they can. they can still pay their PAs, they can make a different use for their PA, if they can't come into the home environment, they can do other things. That guidance has supported an increased flexibility and choice and control. So that's been really positive, and that's probably helped local authorities to focus on that, they are not having to work through that themselves, they know they are going to be funded, they are not having to find that." (Umbrella organisation)

Interviewees' commentary on the guidance issued also expressed frustration that people who know and understand social care, including disabled people and older people, had had very little opportunity to inform the development of guidance. It was felt that responses to the pandemic had been almost entirely health-led and that there has been very limited opportunity for disabled people, family carers or social care bodies to contribute to decision-making processes:

> "At clinical levels, various Chief Medical Officer level, Chief Science Officer…..we haven't been anywhere near them at all, and I think that has been the story across the piece, I don't think we're singled out here, this has been a very very clinically led response, you can tell by the slogan, protect the NHS, and the corollary is the rest of you can just….. and that has had an impact." (Representative body)

> "SAGE at Scottish level does not and did not have sufficient presence from social care and from those who were dealing with older people's care and support." (Representative body)

> "One of the things has been that OK it's an infection, it's a virus etc and so there's a medical element to it but it feels like a lot of decisions have been driven by a medical model when they didn't need to be." (Advocacy organisation)

> "I think the really figural thing for me was the complete and utter lack of involvement of the care sector in pandemic general planning, so operation Swan or whatever it was, the care sector wasn't included in that at all which shows the lack of parity of esteem." (Third sector organisation)

This had also caused some interviewees to reflect on how well understood the social model of disability still was in policy and legislative circles. The lack of understanding of the social model of disability was felt to be particularly visible in relation to the decision of the Chief Medical Officer to issue a letter to people with specific health conditions as at higher risk from the guidance. However, as many interviewees noted, many people who were not medically at higher risk from the virus still required support and access to live their day to day lives and suddenly faced increased barriers to doing so.

> "I mentioned before the shielding with no letter thing, so not everyone has that CMO letter because their condition is not on the list and many disabled people are choosing to shield based on their own expertise and personal circumstances and likelihood of attaining treatment so they know that's the right thing, but they are not getting that access to food and medicine, employment protection that comes with a shielding letter. Two thirds of the people who responded to our survey who were shielding and had no letter said they had difficulty accessing food." (Disabled people's organisation)

Conclusions and Recommendations

Guidance plays an important role in enabling rights to be realised in an emergency situation.

We make the following recommendations.

17. The Commission recommends that social care experts, including disabled people, and unpaid carers, should be involved in the development of guidance going forward, and in particular in planning for future crises, including a resurgence of the virus.

18. The Commission recommends that the Scottish Government undertake a review of how a social model and human rights approach to decisions taking under the pandemic could have improved practice, particularly in terms of ensuring that disabled and older people faced fewer barriers to living their everyday lives.

8. Personal Protective Equipment (PPE) and Testing

This chapter discusses and assesses issues relating to PPE and testing in the context of social care.

Introduction

As key infection control measures, the use of appropriate PPE and testing in line with guidance is a vital tool to protect people's right to health, right to life, and to ensure just and favourable conditions of work in the workplace.

Views and Experiences of Interviewees – PPE

Two thirds of interviewees reported that either they, or the people they support, had difficulty accessing both PPE and information about the types and use of PPE in the early stages of the circulation of the disease. This affected people receiving support, social care staff, including personal assistants, family carers and staff in mental health settings.

> "I think accessing PPE was an issue at first, people were worried about it, they didn't know what they needed to be getting." (Carer organisation)

> "At the beginning not knowing how to get PPE, not knowing what appropriate PPE was." (Disabled people's organisation)

Interviewees also noted that to begin with, the information and guidance about PPE was often confusing, and changed quickly.

> "The information on what PPE people should be wearing it was a little bit vague." (Carer organisation)

> "I don't think it was clear enough at the start…. Also information has changed very quickly, certainly in the early part of information coming out, you could see something being published one day, it might be removed and changed by the next day or even in the same day, that created a bit of muddling." (Provider)

In addition, several interviewees commented that important changes to guidance on PPE were often communicated before there was any infrastructure in place to supply the relevant items, which led to anxiety among front-line social care staff and families:

> "The First Minister announced that all social care staff could self-assess if they needed a fluid resistant face mask. It was said without the resource being there to back that up, and that took a bit of work in terms of getting supplies to meet that commitment from the First Minister." (Provider)

> "It was a mess, the guidance was issued, telling people how they should comply, before any real consideration had been given about the ability of these organisations to access the equipment which the guidance said they needed." (Representative organisation)

Several participants articulated the concern that information and guidance on PPE had been written with clinical settings in mind, and that there was little understanding and awareness of how care and support are provided in either residential or home care settings, which in turn affected the relevance of the guidance to the way their organisations worked:

> "The first iteration of guidance for care homes, this has clearly been nowhere near anyone who actually either lives or works or runs a care home, the impression is that there a lot of clinical experts telling people how they think they should behave, there's been no insight into what it's actually like." (Representative organisation)

> "So at times there was a fundamental misunderstanding about what would be needed, from people who were looking at the need for PPE in different settings. I think there was initially some real misunderstandings about the sorts of support situations that go on within people's own homes and the fact that social care would need particular access to bits of PPE that wasn't part of their everyday ordinary supplies and there were real difficulties accessing. But it has been, there have been times where particularly some of our colleagues in health, might have perceived the guidance that we should be following as the guidance for care homes and we have had to be that's not the case for us, that's where there has sometimes been a bit of muddling." (Provider)

> [We need] "the development of Infection Prevention and Control practices which are appreciative of the fact that a care home is not a unit, it's not an institution, it's somebody's home so we have to get better and that's partly design." (Representative Organisation)

Some participants also raised concerns that in the early stages of the pandemic PPE resources were being diverted away from certain parts of the social care workforce in preference for both the NHS and for public authority provided services:

> "I know a number of examples across the country where people were trying to access PPE, couldn't go to the local hub or to the place that was designated for agency staff, were refused PPE, so we are talking hundreds if not thousands of people across Scotland who are managing personal assistants who don't have the same access to the same level of support and to the same level of equipment that other people were getting."

> "Care providers were finding the local hubs impossible to access. They didn't even know where they were, they were closed for four days over bank holidays, this was right in the middle of the initial outbreak, it was very very poor, there was also an issue, whereby because they were run by the local statutory agencies, it appeared to us that they were prioritising scarce supplies for their own use."

> "There was an issue around care homes not getting access to PPE. One of the things apparently holding that up was the partnerships basically wanted to insert themselves into that process and be distribution hubs, and there was all sorts of toing and froing going on."

> "So in the early days, PPE was a challenge, the usual routes, all PPE supplies would have been purchased by a provider, and that supply dried up overnight, partly because of a lack of production in China, where most our supplies come from, but also significantly but the prioritisation of the NHS in the UK."

> "Some suppliers have told us that they had been told that they had to divert their stock to the NHS, which we were probably ultimately getting back through the hubs but so there have been things which have made accessing PPE quite difficult."

Views and Experiences of Interviewees – Testing

The Commission asked participants a number of questions around the timeliness of guidance and information on testing, and about access to testing itself. Three interviewees felt that the guidance had been confusing and insufficient. One noted that the guidance had put provider organisations in a difficult position:

> "It's the one area where there has been a problem. I think there has been an issue where small care homes are low priority and even the government guidance isn't clear and the HPS guidance isn't very clear. It leaves it down to providers to determine whether they should or shouldn't test." (Provider)

Several interviewees pointed out that, as with PPE, there was or had been a significant gap between policy statements on testing and the actual infrastructure available to achieve this.

> "Capability and capacity wise they don't seem to be able to do it, even though the policy is to do it, they can't seem to do it." (Representative organisation)

> "It's working really well now, very early doors it was slower, I think the communication had come out but the arrangements hadn't been established so the test centres were still being set up um so that early doors." (Provider)

Others stressed that here had been or were inequalities in access to testing between health and social care workers, between different types of social care workers, and between family carers and health and social care workers.

> "What you might ideally see as needing to be done in social care, which for us, would be routine, regular testing of staff, that doesn't seem to be on the agenda." (Representative organisation)

> "One of the early issues for us was about the consistency of testing, what we had said and tried to push for, was priority testing of people with learning disabilities and family carers and support staff, the reason being that we were hearing so much anxiety from family carers about having to provide personal care, really concerned that they were going to give something to somebody." (Third sector organisation)

> "Lack of testing for personal assistants. We are aware that there was someone who can't have her PAs in because she's at high risk, but not on the shielding list. She gets personal care from PAs, but because she can't get her PAs tested because you can only get tested if you have got symptoms, they can't come in." (Disabled people's organisation)

Two interviewees noted the significance of policy decisions to cease testing and the later impact that this had on the spread of the virus in residential and nursing care settings, and therefore on the right to life, the right to health and just and favourable conditions of work:

> "Testing was a critical failure. In March we were arguing that testing should not have been removed." (Representative organisation)

Two interviewees who commented on testing acknowledged the importance that it would have in containing and minimising the incidence of the virus in social care settings:

> "We think that routine and regular testing of staff in visiting services is also a priority, and particularly when you think if we are moving to phase two, the care at home or the visiting services risk ratchets up a bit more." (Representative organisation)

> "There are three routes to protect people in a residential and a nursing environment. One is the appropriate use of PPE, the second is infection control measures and practice (IPC), and the third is the stringent testing of individuals, because care home residents aren't going anywhere but the staff who come in clearly carry a risk, you can only reduce that risk through universal mask wearing IPC and by testing." (Representative organisation)

However, it was noted that there had been little consideration given to the implications of the test and protect scheme on social care, for example that it could lead to the closure of an entire services or cause someone's support to be completely removed with the potential rights impacts outlined above:

> "If you contacted disabled people to say that their PAs have contracted it, imagine the fear not having that support, losing that for 2 weeks and not being able to get somebody else to do it." (Disabled people's organisation)

Conclusions and Recommendations

All people using social care, and all employees providing social care, have the right to life (Article 2 ECHR), the right to health and the right to just and favourable working conditions.

19. The Scottish Government should take steps to ensure that in the event of future resurgence of the virus, personal protective equipment and testing is available to everyone who requires or provides personal care in a social care environment.

9. Workforce

Many interviewees took the opportunity to praise the contribution of social care staff during the pandemic:

> "One of the brilliant, brilliant things about our sector, is the extent to which they have continued, they have maintained service delivery, they have been brilliant, they have done it and the staff have been extraordinary, extraordinary." (Representative organisation)

Interviewees noted the fear, stress and anxiety which had faced social care workers throughout the pandemic, and the importance of employers and organisations supporting their mental health:

> "It's increased the sense of fear, people have been very, very anxious, folk have been worried about the risk to themselves and their families about being out and working and travelling to work and travelling between people's homes and going into situations where they don't quite know what people we support might have been doing and who they have had contact with. But also there has been quite a large fear about taking something in to people they support, that has been a real anxiety." (Provider)

> "The psychological threat, catastrophic thinking, and if we don't think as staff what is going to happen, am I going to be alive, what will happen to my loved ones, those sort of things it is quite normal and natural to have. So managing your own feelings, those of your staff, allowing them to speak, 'You are not alone, I am here too.'" (Mental health professional)

It was also noted that many staff had experienced profound trauma and bereavement as a result of the care and support they had provided to people during COVID-19:

> "People that work in care homes have spoken about the grief and bereavement they are going through, that's the policy and practice, that's people in home-like settings, and it's an extended, not necessarily functional family of sorts." (Third sector organisation)

It is noted that the Scottish Government introduced a Scottish Statutory Instrument during the pandemic to ensure that all social care staff were entitled to the National Living Wage. Interviewees welcomed this change but warned that in some cases, such pay rises could create cuts elsewhere, for example in sick pay policies, in a competitive market.

> "If you isolate one element of a service budget, and make it sacrosanct, then the other things have to be sacrificed to it, if you have to pay people the living wage, you will cut their sick pay."

Conclusions and Recommendations

20. The Commission recommends that all social care staff should have access to adequate and appropriate mental health and trauma support, in light of the nature of the experiences they have been exposed to during the COVID-19 pandemic.

10. The Convention on the Rights of Persons with Disabilities (CRPD)

As described in section 3, the Convention on the Rights of Persons with Disabilities (CRPD) interprets already existing human rights standards in the context of the lives of disabled people.

Much emphasis has been placed in recent years in Scotland on understanding the role of the CRPD and thinking about how it could be embedded into social care. However, less emphasis has been placed on approaching the problem from a different perspective – understanding social care as a critical delivery mechanism both of the social model of disability, and of the rights enshrined within the CRPD. That requires more than interpreting the system that we have in a way amenable to the CRPD. It requires rethinking the whole system of social care so that it is capable of delivering the support required to dismantle exclusionary structures.

The incorporation of the CRPD directly into Scots law would be an important step forward in this respect. The 2018 report of the First Ministers Advisory Group on Human Rights Leadership recommended a new framework human rights law for Scotland which incorporated international standards [62]. A National Taskforce on Human Rights Leadership is now taking this work forward and will make recommendations for a new Bill in spring 2021. This is an opportunity to advance the incorporation of the CRPD.

New legislation could have an important impact on both the way people are assessed, and the kinds of social model-based outcomes people can seek support for.

Duties under new framework legislation would apply equally to all public authorities. A rights based approach does not distinguish between the nature of public authorities with respect to the duties they have towards respecting, protecting and fulfilling the rights of older and disabled people and unpaid carers. All of these responsibilities are properly located at both local and national level. In this way, the incorporation of the CRPD could help to bridge the gap between policy set out at the centre and delivery which takes place locally.

Incorporating the CRPD would also provide an additional accountability mechanism where older and disabled people wish to challenge decisions about their care. It could have a significant impact on the way in which courts assess claims brought by individuals against local authorities. At the moment, there is little opportunity for individuals to set out how actions or omissions of public authorities affect their rights in social care. If courts were required to interpret legislation in a way that is compatible with CRPD rights, their reasoning with respect to the allocation of finite resources may change. In particular, the right to independent living could be a significant factor in enabling people to challenge packages which are lower cost but require a move into residential or nursing care or alternatively, a top up charge.

Conclusions and Recommendations

Incorporation of the CRPD would provide a concrete way to secure people's rights in a social care context, and would act as an accountability mechanism for decision-making by local authorities and health and social care partnerships, both at a policy level and in relation to decisions about individual situations.

The Commission recommends the following steps.

21. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) should be incorporated into Scots law and therefore into policy design and delivery. This would be an important step in ensuring that the negative impacts on people's rights that have happened during the pandemic do not happen again.

22. Incorporation of the CRPD should include duties on public authorities to have due regard to Convention rights to ensure rights-based decision making, as well as a duty to comply with the Convention. This could help to resolve some of the differences in approach between local and central government, as well as providing a more robust mechanism for people to hold public authorities to account for decisions in relation to their social care. It would also provide the domestic courts with clearly articulated rights-based norms and standards when considering complex cases in the context of finite resources.

23. The National Taskforce on Human Rights Leadership, established to take forward recommendations for new human rights laws in Scotland, should take the opportunity to advance the incorporation of the Convention on the Rights of Persons with Disabilities into Scots law.[63]

11. Conclusions and Recommendations

This chapter collates all of the conclusions and recommendations reached through this impact monitoring research.

Conclusions

Evidence from this research, assessed against the relevant human rights standards, shows the following:

1. COVID–19 has had a profound impact on the way in which social care support has been delivered in Scotland, leading to significant gaps in the realisation of rights for people who rely on such support, including unpaid carers.

2. A considerable proportion of people who use social care support at home have experienced either a reduction or complete withdrawal of support. In many cases, the withdrawals and reductions seen in the early months of the pandemic happened rapidly, without either adequate communication or assessment of the proportionality of such decisions.

3. The impact of this policy and practice has had a direct and detrimental effect on people's rights, including those protected by the European Convention for Human Rights and by international instruments such as the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of Persons with Disabilities. This includes potential unlawful interferences with people's rights to physical and psychological integrity, and negative impacts on people's rights to a private and family life without recourse to the normal assessment and review procedures.

4. The Commission is deeply concerned about the future social care support available to people whose packages were reduced or withdrawn over the period, and the potential impact that this could have on how their rights are realised, both now and in future.

5. The COVID-19 pandemic has also exacerbated pre-existing inadequacies in the models of social care access, funding, procurement and commissioning, which are unable to provide people with the support which best and most appropriately fits their life.

6. Legislative changes as a result of the pandemic have been poorly explained, and implementation of the legislation lacks transparency. This is confusing for people accessing the system for the first time and detrimental to proper scrutiny and use of public funds. Without further information as to the factors influencing the decision to adopt the provisions of the Coronavirus Act 2020, there is very little opportunity for scrutiny by relevant parties, including the Scottish Parliament.

7. It is clear that there is a need to strengthen the framework of decision making in social care, through applying a rights based approach. This would ensure stronger protection and respect for people's rights as we continue to deal with COVID-19, including any potential second wave of infections.

8. There is an opportunity to invest in a social care system, based on human rights, capable of delivering the outcomes which are enshrined in the Convention on the Rights of Persons with Disabilities.

9. The international human rights legal framework should inform the provision of social care much more strongly, including through the integration of health and social care. This has the potential to inform the development of more robust accountability processes, both in relation to individual complaints and accountability mechanisms, but also in connection with budget scrutiny and transparency, through human rights budgeting.

Recommendations

To address the concerns and issues highlighted in our conclusions, the Commission makes the following recommendations.

Resumption of care and support

1. The Scottish Government and COSLA should jointly commit to re-commencing care and support at pre-pandemic levels, as a minimum. Where people indicate that they have increased support needs due to the effects of COVID-19 or of lockdown, they should receive a full assessment. The new powers brought in under s16 and 17 of the Coronavirus Act should not be used to alter support packages for people with pre-existing social arrangements (those in place before January 31st).

2. In planning for the resumption of pre-pandemic services, local authorities and Health and Social Care Partnerships must either recommence the pre-COVID care package, or if the person's circumstances have substantively changed, they must fairly and systematically assess need.

3. It should not be assumed that family supports which have been in place during the crisis are sustainable over the long term. Disabled people, family carers, older people and children and young people must be informed in an accessible and timely manner of the next steps in relation to the resumption of their pre-pandemic care package.

4. In line with the recommendation set out in Scottish Government guidance, people who have had no, or partial social care assessments should have a review within six weeks. Where it is not possible for this to be delivered, local authorities should communicate clearly and proactively with people and their families as to the expected timescale for a full assessment, and any implications this will have for care-charging.

Involvement in decision making

5. The Scottish Government and COSLA should develop an emergency decision making framework for social care which is grounded in rights-based principles of inclusion and participation in decision making, and transparency. This should also meet critical human rights standards:

    - ensure non-regression
    - be temporary and time-limited
    - be necessary and proportionate
    - be non-discriminatory and mitigate inequalities
    - ensure the protection of a minimum core content of rights
    - consider all other options, including financial alternatives.

6. In future situations of emergency where resources are stretched, disabled people, family carers, older people and children and young people must be involved in a meaningful conversation about prospective decisions to cut their care packages. This is especially the case where people need support to make decisions or another person has power of attorney or is a welfare guardian.

Ensuring lessons are learned

7. In order to understand the impact of the pandemic on care and support at home, the Scottish Government should immediately establish data collection mechanisms to monitor the nature and extent of reductions and withdrawals of care and support. This will help support the social care sector to respond effectively in the event of a resurgence in the virus or further complications related to a combination of winter flu and COVID-19. It will also help to ensure the availability and adequacy of social care support during periods of crisis.

8. The impact of COVID-19 on the human rights of older and disabled people who get care and support at home and in the community should be included in any future inquiry into the pandemic. Our separate briefing on the impact of COVID-19 in residential and nursing homes sets out the relevant rights based standards.[64]

9. The Scottish Government should publish a more detailed and transparent account of which Health and Social Care Partnerships and local authorities have made use of powers in relation to assessments under s16 and 17 of the Coronavirus Act, which are intending to use the powers, and the decision-making framework they have used in choosing whether or not to implement the powers. This will assist the required scrutiny of the necessity and proportionality of the use of powers into the future.

A rights based social care system

10. The Scottish Government should rethink and refocus social care as a delivery mechanism for realising people's human rights. To address the longstanding inadequacies in the social care system, an integrated programme of reform must take place, explicitly grounded in human rights standards, which makes changes at legislative, budgetary, policy and implementation levels.

Human rights based budgeting

11. The Scottish Government should take a human rights based approach to future public finances, which considers the impact of financial decisions on the rights of older and disabled people and closely interrogates claims in relation to limited resources. This could make a significant shift in the way that budgets are generated, allocated and spent, with a corresponding significant impact on how people's rights are realised.

Legislative powers

12. The Commission recommends that the Scottish Government works in partnership with local authorities who are using, or have used, the powers to gather data on the number and identity of individuals affected by the provisions under s16 and s17 of the Coronavirus Act 2020. The Commission recommends that the Scottish Government collates, analyses and publishes this information to enable additional scrutiny of the use of these provisions by relevant parties.

13. The Commission recommends that the Scottish Government undertakes research with people affected by these powers, and where appropriate, their families and unpaid carers, to understand more about their experiences and identify if there have been any concerns in relation to their care and support.

14. The Commission agrees with the Scottish Government guidance on social care assessments under the powers that 'arrangements should be made to conduct assessments for people who did not receive a full assessment while section 16 was in force. For adults with incapacity, a review of those adults subsequently identified as lacking capacity should follow the principles of the AWI Act and the recommendations of the United Nations Convention on the Rights of Persons with Disability.' The Commission recommends that local authorities and HSCPs clearly and proactively communicate with people and their families as to when this assessment should take place.

15. We also recommend that the powers under the Coronavirus Act should not be used in relation to people who had already had an assessment and were in receipt of a care and support package prior to 31st January 2020. People with existing packages should not have these altered without recourse to a full assessment.

16. The Commission recommends that the effect of Schedule 3, s11 (3) (b) of the Coronavirus (Scotland) Act 2020 should only be revived where it is absolutely necessary and proportionate to do so and that it apply for the shortest time possible, given the impact that these provisions have on the length of guardianship orders and the opportunities to review or appeal these.

17. Where someone has a welfare power of attorney or a welfare guardian, local authorities should ensure that individual is contacted to discuss potential changes in a care package, even in times of crisis and extreme pressure. This can avoid both failures of procedural safeguards and detrimental impacts on rights.

Guidance

18. Social care experts, including disabled people and unpaid carers, should be involved in the development of guidance going forward, and in particular in planning for future crises, including a resurgence of the virus.

19. The Scottish Government should undertake a review of how a social model and human rights approach to decisions taking under the pandemic could have improved practice, particularly in terms of ensuring that disabled and older people faced fewer barriers to living their everyday lives.

Personal Protective Equipment and Testing

20. The Scottish Government should take steps to ensure that in the event of future resurgence of the virus, personal protective equipment and testing is available to everyone who requires or provides personal care in a social care environment.

Workforce

21. The Commission recommends that all social care staff should have access to adequate and appropriate mental health and trauma support, in light of the nature of the experiences they have been exposed to during the COVID-19 pandemic.

Convention on Rights of Persons with Disabilities

22. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) should be incorporated into Scots law and therefore into policy design and delivery. This would be an important step in ensuring that the negative impacts on people's rights that have happened during the pandemic do not happen again.

23. Incorporation of the CRPD should include duties on public authorities to have due regard to Convention rights to ensure rights-based decision making, as well as a duty to comply with the Convention. This could help to resolve some of the differences in approach between local and central government, as well as providing a more robust mechanism for people to hold public authorities to account for decisions in relation to their social care. It would also provide the domestic courts with clearly articulated rights-based norms and standards when considering complex cases in the context of finite resources.

24. The National Taskforce on Human Rights Leadership, established to take forward recommendations for new human rights laws in Scotland, should take the opportunity to advance the incorporation of the Convention into Scots law.[65]

Closing remarks

The COVID-19 pandemic has exposed and exacerbated the inadequacies of the ways in which social care is accessed, funded, procured and commissioned in Scotland. The current social care system is unable to provide people with the support that fits their life best and most appropriately, and to ensure their rights are respected, protected and realised.

Short and longer term change is needed to address the significant human rights concerns we have identified, and to ensure the level of level of decline in the realisation of people's rights that has taken place never happens again. The Commission hopes that this impact monitoring research will now be acted upon by the Scottish Government, COSLA and other relevant public authorities.

Endnotes

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19. General Comments are the authoritative view of the Committee which oversees a particular human rights treaty as to the substance of the rights.
20. Supra 1
21. Supra 1, para 28
22. Supra 1, para 39
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24. Joint Statement: Persons with Disabilities and COVID-19 by the Chair of the United Nations Committee on the Rights of Persons with Disabilities, on behalf of the Committee on the Rights of Persons with Disabilities and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility, available at https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25765&LangID=E
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