



Inclusion Scotland

Submission to the Independent Review of Adult Social Care

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Summary of recommendations

Recommendation 1: If it is to have credibility the Independent Review must identify and address longstanding barriers to progress and come forward with new, achievable recommendations for positive change to the Social Care Support system that really deliver human rights, independent living, choice and control, equitably for all who need it.

Recommendation 2: Action should be taken to declutter the strategic landscape and ensure coherence between vision, strategy, outcomes, indicators, delivery, monitoring and evaluation.

Recommendation 3: Should the Independent Review not recommend the re-opening of the Independent Living Fund in some shape or form, despite hard evidence of its many merits, the reasons for this must be unambiguously explained.

Recommendation 4: The Independent Review should investigate and report on the whereabouts of the £100 million allocated by Scottish Government for Social Care Support and propose transparency and accountability mechanisms with regard to the funding of Social Care Support

Recommendation 5: The Independent Review should support calls for the incorporation of the UN Convention on the Rights of Persons with Disabilities into Scots Law and the rights to independent living this would enshrine. To make these rights real, mechanisms must be established to hold all responsible for delivering Social Care Support accountable, with redress where rights are shown to have been breached. These mechanisms should also include an independent complaints system as well as investing in Independent Advocacy, particularly collective, peer advocacy.

Recommendation 6: Develop a Charter as per the social security Charter against which all involved must be publicly and annually held to account against clear expectations and monitoring mechanisms that place the lived experience of those using Social Care Support at the heart.

Recommendation 7: There should be a programme of investment in user-led support organisations such as Centres for Inclusive Living.

Recommendation 8: All four SDS options must be promoted, with disabled people informed and empowered to have meaningful choice and control over their care and support.

Recommendation 9: In the context of health and social care integration, the Independent Review should assert the importance of the role played by Social Care Support, distinct from the role of healthcare and that Scottish Government money for social care must be ring-fenced. This distinct role must be evident in any recommendations for a national care service.

Recommendation 10: Scrap the unfair tax on disabled people that comes from local authorities charging people for their right to receive the support they need to live independently as equal citizens.

Recommendation 11: As argued by the Scottish Independent Living Coalition of Disabled People's Organisations¹ (SILC) human rights do not cease in times of crisis, they are even more important. We must learn from disabled people's experiences during the pandemic to create more robust systems and to ensure this never happens again.

Recommendation 12: A national Social Care Support system must be established based on the principles set out in the joint open letter to the Cabinet Secretary, "Radical action needed to build a Social Care Support system worthy of the name²".

Recommendation 13: Whatever the Independent Review group produces must go beyond high-level aspirations to follow through into how this will be delivered in practice and transparent mechanisms for holding those responsible to account.

¹ SILC (2020) Call for Immediate Action: Disabled people's human rights to life and health under threat https://inclusionscotland.org/wp-content/uploads/2020/04/SILC-Statement-on-NHS-and-rights-of-Disabled-People_17.04.20.pdf

² Please see: Inclusion Scotland (2020) Call for radical action to transform Scotland's Social Care Support System <https://inclusionscotland.org/call-for-urgent-radical-action-to-transform-scotlands-social-care-support-system/>

1. Introduction

This submission sets out Inclusion Scotland's contribution to the Independent Review of Adult Social Care, announced in the Programme for Government on 1st September 2020. Inclusion Scotland's mission is to achieve positive changes to policy and practice, so that we disabled people are fully included throughout all Scottish society as equal citizens. Inclusion Scotland is a 'Disabled People's Organisation' (DPO) – led by disabled people ourselves. This is important because, like anyone else, we have the right to speak for ourselves and because we know best, through our own lived experience, what we need, what works and what does not.

Social Care has long been a critically important issue to disabled people. Inclusion Scotland has a long track record of making the case for improvement to provision, so that disabled people are not only able to stay alive but have a life, in accordance with their human right to independent living. Throughout this submission we refer to social care as 'Social Care Support'. This is in recognition of the fact that its purpose is not just, or in some cases at all, to look after and protect people but to support and empower them to exercise choice and control over their lives as equal citizens.

This submission also centres and draws on the work of the People-led Policy Panel (PLPP)³ on adult Social Care Support, administered and supported by Inclusion Scotland. We are grateful to the PLPP for their very active involvement in developing this submission. The PLPP has made a separate submission to the Review, which we refer to throughout. The PLPP is currently made up of 28 people from across Scotland who need adult Social Care Support as a supported person or an unpaid carer. It reflects the range of people who need adult Social Care Support, their locations and circumstances.

The submission also draws on findings from Inclusion Scotland's recent surveys on the impact of COVID-19, and responses to it, on provision of Social Care Support and hence on disabled people's lives. It is no

³ For further information on the PLPP see: <https://inclusionscotland.org/what-we-do/policy/people-led-policy/>

exaggeration to say that this has been devastating. However, it is also no exaggeration to say that Social Care Support was already in a state of crisis well before the arrival of COVID-19.

This submission begins with an overview of the context for the Independent Review, and evidence of long-term systemic problems with the current system. The impact of COVID-19 is then discussed and its immediate consequences for Social Care Support. What it so starkly underlined is how far away the current system is from the often articulated visions for it. In light of the preceding evidence, the final section sets out the case for a national Social Care Support service and key features that a Social Care Support system worthy of the name should possess. Recommendations for action are made throughout.

2. Overview

2.1 Strategic incoherence

The gap between the rhetoric of Scottish Government and COSLA, and the reality experienced on the ground, had long been vast and was widening well before the advent of COVID-19. This is not for want of effort on the part of many people. A great deal of time has been devoted down the years to successive reframing of vision statements, dating at least as far back as 2009, all saying much the same thing. There was a 2020 Vision for Health and Social care, and recently officials initiated discussion on another one for 2030. Similarly, the production of outcomes, indicators and standards has proliferated. There has been little if any cross-referral between them or vision statements, despite Inclusion Scotland's frequent efforts to raise the need for coherence.

Inclusion Scotland has been involved in most of the following exercises:

- Independent Living – A Shared Vision (2009)⁴. This was signed by the Scottish Government COSA and the Independent Living in Scotland (ILiS) Steering Group.

⁴ Scottish Government, COSLA and ILiS (2009) Independent Living – A Shared Vision <https://www2.gov.scot/resource/doc/935/0093260.pdf>

- Vision for Independent Living (2013)⁵. This was signed by Jim Elder-Woodward OBE (chair of the Scottish Independent Living Coalition), Cllr Peter Johnson (COSLA spokesperson), Alex Neil (then Cabinet Secretary for Health and Wellbeing), and Derek Feeley (in his then roles with Scottish Government, NHS Scotland and as Independent Living Programme Champion).
- Our Shared Ambition for Social Care (2016)⁶. This was developed and endorsed by numerous organisations.
- National Health and Wellbeing outcomes framework⁷ (2015)
- Review of targets and indicators for health and social care in Scotland (2017)⁸. This exercise was led by Sir Harry Burns. It is unclear what became of it following its publication.
- Health and social care standards⁹ (2017)

The key flaws in the Social Care Support system are well-known and have been repeatedly discussed in numerous Scottish Government stakeholder advisory groups such as the Integration Implementation Group, the Transformational Change Programme, and the Health and Social Care Partners Group, among many others. These have often been populated by much the same cast of organisations that form the membership of the Independent Review advisory panel.

In 2015, the Cabinet Secretary launched a National Conversation on the Future of Health and Social Care. The output from this appeared to amount to nothing more than a leaflet with some quotes. Shortly

⁵ Scottish Government (2013) Our Shared Vision for Independent Living in Scotland <https://www.webarchive.org.uk/wayback/archive/20170112131056/http://www.gov.scot/Publications/2013/04/8699>

⁶ Inclusion Scotland (2016) Our Shared Ambition for Social Care <https://inclusionScotland.org/wp-content/uploads/2018/05/Shared-Ambition-for-social-care-final.pdf>

⁷ Scottish Government (2015) National Health and Wellbeing Outcomes Framework <https://www.gov.scot/publications/national-health-wellbeing-outcomes-framework/>

⁸ Scottish Government (2017) Review of targets and indicators for health and social care in Scotland <https://www.gov.scot/publications/review-targets-indicators-health-social-care-scotland/>

⁹ Scottish Government (2017) Health and social care standards: My support, My life <https://www.gov.scot/publications/health-social-care-standards-support-life/>

afterwards, in 2017, a Health and Social Care Delivery Plan¹⁰ was published. It made no reference to the National Conversation (and contained nothing more than a paragraph on social care). The examples are numerous. Meanwhile, there is no obvious reason to those outside why solutions that have been shown to actually work for people who use Social Care Support are not pursued. The re-opening of the Independent Living Fund (ILF), or some version of it, is a case in point. This is despite the commitment in the Programme for Government in 2018/19¹¹ to explore a top-up system, what looked like good progress towards it and the fact that Northern Ireland looks to be on the verge of re-opening it¹². There is strong evidence that the ILF can deliver the kind of system we need, bringing social and economic benefits¹³. Indeed, the ILF could provide a model upon which to build a National Social Care Support System with rights, dignity and empowerment at the core.

The People-led Policy Panel, made up of people with lived experience of needing Social Care Support, was in its third year of working with the Scottish Government and other stakeholders on the reform of adult Social Care Support. At the point the Independent Review was announced, the PLPP had been working for well over a year on named work streams that came from the Programme Framework launched by Jeane Freeman, Cabinet Secretary for Health and Social Care, along with (another) Shared Vision,¹⁴ in June 2019. This looked promising.

¹⁰ Scottish Government (2016) Health and social care delivery plan
<https://www.gov.scot/publications/health-social-care-delivery-plan/>

¹¹ Scottish Government (2018) Delivering for Today, Investing for Tomorrow: the Government's Programme for Scotland 2018/19
<https://www.gov.scot/publications/delivering-today-investing-tomorrow-governments-programme-scotland-2018-19/pages/7/>

¹² Newry Times (2020) Northern Ireland Residents to have their say on reopening of Independent Living Fund <http://newrytimes.com/2020/05/29/ni-residents-to-have-their-say-on-reopening-of-independent-living-fund/>

¹³ For example, please see: <https://ilf.scot/wp-content/uploads/2020/07/44188-ILF-NI-Impact-Evaluation-Report.pdf>.

¹⁴ Scottish Government (2019) Social Care Support Reform: Partnership Programme Framework <https://www.gov.scot/publications/social-care-support-investment-scotlands-people-society-economy-programme-framework-partnership-programme-support-local-reform-adult-social-care/>

Even though it covered topics that had been much explored before, there was coherence between a vision statement and workstreams. The methods of developing this were highly innovative and proving to be highly successful, with the new PLPP model of co-production. This was in line with the commitment in 'A Fairer Scotland for Disabled People'¹⁵ that disabled people should be at the heart of social care developments. It was in that context that the Independent Review was announced. There were reassurances that the reform programme would work closely with the Independent Review and add to any work done previously rather than replicating it.

We had deep concern that, having spent many years successfully gaining recognition of the vital contribution of lived experience to development of policy and strategy, no one with lived experience of using Social Care Support was included among members of the Independent Review advisory panel. However, we were pleased that Derek Feeley, Chair of the Independent Review, prioritised meeting with the People-led Policy Panel as one of his very first engagements in that role, and subsequently we were delighted when this resulted in the absence of lived experience on the review group being rapidly remedied with the appointment of Jim Elder-Woodward, OBE.

Despite recent innovation and progress cited above, overall there is a picture of long-term strategic incoherence. There have been no obvious join-up between visions, outcomes, activities and delivery plans. There appears to have been no evaluation of what has gone before, no transparent analysis of blockages to progress, even where solutions look obvious. Stakeholder input has been sought but not always integrated or even referenced in what then ensues. Strategic exercises are not followed through to implementation, and are frequently merely replaced

Scottish Government (2019) Social Care Support Reform: Vision
<https://www.gov.scot/publications/social-care-support-investment-scotlands-people-society-economy-shared-vision-adult-social-care-support-including-support-carers-partnership-programme-support-local-reform-adult-social-care/>

¹⁵ Scottish Government (2016) A Fairer Scotland for Disabled People: Delivery Plan
<https://www.gov.scot/publications/fairer-scotland-disabled-people-delivery-plan-2021-united-nations-convention/>

by another iteration, as if the previous one had never happened. There is no transparency and no accountability.

The case for reform has been extremely well-rehearsed and there are concerns that the Independent Review will transpire to be little more than the latest opportunity to rehearse them yet again.

Recommendation 1: If it is to have credibility the Independent Review must identify and address longstanding barriers to progress and come forward with new, achievable recommendations for positive change to the Social Care Support system that really deliver human rights, independent living, choice and control, equitably for all who need it.

Recommendation 2: Action should be taken to declutter the strategic landscape and ensure coherence between vision, strategy, outcomes, indicators, delivery, monitoring and evaluation.

Recommendation 3: Should the Independent Review not recommend the re-opening of the Independent Living Fund in some shape or form, despite hard evidence of its many merits, the reasons for this must be unambiguously explained.

2.2 Transparency and accountability

There are a vast number of bodies involved in policy-making and delivery of Social Care Support in what is a highly complex overall system. From the perspective of people using Social Care Support, or indeed any external party, it is very hard to identify who has responsibility for what and who is responsible if things go wrong. Even if that can be discerned, lack of transparency makes accountability near-impossible, let alone redress. There is also no independent complaints system or ombudsman (please refer to PLPP submission for more on this). Yet, while the Care Inspectorate has a critically important role to play in gathering data and upholding standards, there is remarkably little data publicly and accessibly available about the inner workings of the overall system.

As will be discussed below, the lack of transparency and accountability mechanisms, and the adverse consequences for those relying on Social Care Support, were graphically illustrated by the fact that no one to this day appears to be able to account for where £100million emergency

funding allocated by Scottish Government to enable the continuance of care packages during the COVID pandemic has gone¹⁶. This has not been seen by third sector providers or users of Social Care Support who, instead, experienced care packages being cut or withdrawn altogether, without consultation, sometimes overnight. Unsurprisingly the consequences were devastating. If ever a neat illustration was required of this utterly dysfunctional, unaccountable system, this is it.

In its submission to the Independent Review, COSLA made great play of the need for local democratic accountability. This is a nonsense. No such thing exists in any meaningful sense for the users of Social Care Support, whether at a local authority policy level or with regard to individual care packages. While of course there is a need to co-ordinate and ensure a smooth interface between Social Care Support and other local authority services, and healthcare, the same can be said of any services, employment or activity delivered by anyone. The repeated refrain over at least a decade that service providers should work together to ensure seamless holistic support has not delivered this. Social Care Support is a fundamental underpinning to equal citizenship and as such spans all that is required to exercise this.

Recommendation 4: The Independent Review should investigate and report on the whereabouts of the £100 million allocated by Scottish Government for Social Care Support and propose transparency and accountability mechanisms with regard to the funding of Social Care Support.

2.3 Human Rights

While there is much talk of the importance of rights to Social Care Support, the reality currently is that it can be extremely hard to exercise whatever supposed rights to Social Care Support exist of any kind. With the arrival of COVID-19, the abuse of disabled people's human rights has been unequivocal, notably with regard to Social Care

¹⁶ Health and Social Care.Scot (2020) What happened to emergency social care cash? <https://healthandcare.scot/default.asp?page=story&story=2023>

Support failures¹⁷, as will be evidenced in more detail below. This must be a great disappointment to Scottish Government and COSLA, as it certainly has been to third sector signatories to vision statements placing human rights centrally – something which COSLA repeats in its submission to the Independent Review.

For rights to be real – in fact to be rights at all – entitlements must be transparent and consistently and equitably applied; it must be possible easily to challenge when rights are not respected and to get redress.

Currently people can only complain to the social worker who often made the decisions in the first place, or their manager. Again, this points to the necessity of an independent complaints system, with sufficient powers to redress. Also, to the fundamental role of Independent Advocacy within a national Social Care Support system.

The devolved social security system is a good illustration of rights. But any supposed ‘rights’ to Social Care Support bear no resemblance to this. Moreover, while entitlements to social security assistance are determined at a national level, as necessary to ensure rights-based equitable treatment, and in that respect it is a national ‘top-down’ system, recipients are able to spend the funds they are entitled to however they choose. In that essential respect to equate a national system with top down imposition, as COSLA is wont to do, is completely false. Moreover, to suggest, as COSLA appears to do in its submission to the Independent Review, that an appropriate route to exercising and enforcing rights is through the intervention of elected members, is absurd. A person’s right should not be contingent on another person’s willingness and capacity to intervene effectively and human rights should never be contingent on local priorities. If they are, then they are not rights of any kind.

As highlighted by the PLPP in their submission there is no case law in Scotland about Social Care Support, local authorities prefer to pay off individuals rather than risk that a legal precedence is created through case law that could be used by everyone. Local authorities have huge

¹⁷ See for example: <https://www.scottishhumanrights.com/news/commission-calls-for-immediate-return-of-social-care-support-to-address-human-rights-concerns/>

legal teams and it can be difficult to access legal aid to take a case to tribunal. The ability of people using Social Care Support to enforce their human rights might change through the current work of the Human Rights Taskforce, led by Alan Millar. This offers the prospect of a Human Rights Bill incorporating various human rights conventions into Scots Law. There could be a possibility of incorporating the United Nations (UN) Convention on Rights of Persons with Disabilities (CRPD). Article 19 provides that:

States Parties to the present 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.

This clearly has a direct bearing on rights to Social Care Support. Thus, were the UNCRPD to be incorporated into Scots Law, it would presumably give people a judicial basis for challenging failures to respect human rights. This would have significant implications for the current system and its many failures and underlines why a new system must be capable of consistently delivering on human rights.

COSLA's record on disabled people's rights has more generally been disappointing. Following the launch of its co-produced delivery plan for UNCRPD in 2015¹⁸, and despite our repeated requests for reports in how it was being implemented, none have been forthcoming and it appears to have been rapidly dropped after publication.

Recommendation 5: Independent Review should support calls for the incorporation of the UN Convention on the Rights of Persons with Disabilities into Scots Law and the rights to independent living this would enshrine. To make these rights real, mechanisms must be established to hold all responsible for delivering Social Care Support accountable, with redress where rights are shown to have been breached. These mechanisms should also include an independent complaints system as well as investing in Independent Advocacy, particularly collective, peer advocacy.

Recommendation 6: Develop a Charter as per the social security Charter against which all involved must be publicly and annually held to account against clear expectations and monitoring mechanisms that place the lived experience of those using Social Care Support at the heart.

2.4 Self-directed Support

The Scottish Government's 10-year strategy for Self-Directed Support¹⁹, published in 2010 described Self Directed Support as follows:

the ways in which individuals and families can have informed choice about the way support is provided to them... Through a co-production approach to agreeing individual outcomes, options are considered for ways in which available resources can be used so people can have greater levels of control over how their support needs are met, and by whom.

Scottish Government's Self-directed Support strategy, 2010

¹⁸ COSLA (2015) UNCRPD Scottish Local Government Delivery Plan 2015 -2018 <https://www.lothiancil.org.uk/wp-content/uploads/2015/09/uncrpd-cosladeliveryplan.pdf>

¹⁹ Scottish Government (2010) Self Directed Support: A National Strategy for Scotland <https://www2.gov.scot/resource/doc/329971/0106962.pdf>

However, the Scottish Human Rights Commission²⁰ point to “patchy and unequal” implementation of SDS and how this is an enormous barrier to realising the rights of supported people and their unpaid cares/supporters. Recent research²¹ by Self Directed Support Scotland (SDSS) and The Alliance into the experiences of people using SDS in Scotland illustrates that despite examples of good practice, urgent work is needed to ensure systematic good practice and complete transparency in the delivery of SDS. The research also shows that far more needs to be done to ensure everyone is offered genuine, meaningful choice between all four SDS options. Option 3 continues to be the most commonly used, indicating little has fundamentally changed since SDS was introduced and begging deeper, systemic, questions about why this is the case. Moving forwards, we want disabled people to be genuinely informed and empowered to choose meaningfully between **all** four SDS options. In our surveys of the impact of the COVID 19 pandemic on disabled people, there is emerging evidence that being on Option 1 of SDS has positively impacted on the experiences of some:

“I receive SDS option 1 and I think this is the difference. I am paid directly and therefore carried out all checks on my PA [personal assistant] myself. Local authorities cannot withdraw care and send the staff elsewhere, e.g. care homes”.

July 2020 Short survey respondent

As far back as the year 2000, as well as the overwhelming benefits to disabled people (many different impairment groups) in achieving choice and control over their support and thereby their lives, the vital importance of support organisations, such as Centres for Inclusive Living, in supporting people with direct payments, was identified²². Yet availability of such disabled-people-led support organisations and

²⁰ Scottish Human Rights Commission (2020) Covid 19, Social Care and Human Rights: Impact Monitoring Report <https://www.scottishhumanrights.com/media/2102/covid-19-social-care-monitoring-report-vfinal.pdf>

²¹ SDSS and The Alliance (2020) My Support My Choice: User experiences of self directed support in Scotland, <https://www.sdsscotland.org.uk/mysupportmychoice/>

²² Witcher et al (2000) “Direct Payments: the Impact on Choice and Control”, Scottish Executive

user/peer led groups generally across Scotland remains extremely patchy²³. Overall, while the ethos and ambitions of SDS remain sound, after 10 years of delivery of these still falls a long way short, and the inequities across Scotland are extremely problematic and unfair.

Recommendation 7: There should be a programme of investment in user-led organisations such as Centres for Inclusive Living.

Recommendation 8: All four SDS options must be promoted, with disabled people informed and empowered to have meaningful choice and control over their care and support, with support to make informed decisions if they need it.

2.5 Health and Social Care integration

It was back in 2011 that the Christie Commission report²⁴ called for “a radical, new, collaborative culture throughout our public services”. It is clear from the way that health and social care integration was set up and has played out that ensuing dynamics – competition for budgets, etc. – have been counterproductive to such a goal. While no one would dispute the importance of a seamless interface between health care and Social Care Support services, the integration of health and social care in 2014²⁵ introduced a new set of extremely counter-productive tensions and dynamics, which served to focus attention on structures and relationships between health boards and local authorities. In contrast to COSLA’s claim that the establishment of a national care service would drive a focus on structure, it is extremely clear that this has been the result of the current arrangements and any focus on people using/needing Social Care Support has faded from view in consequence.

²³ Disability News Service (2019) User-led groups discuss how to turn back the tide of closures <https://www.disabilitynewsservice.com/user-led-groups-discuss-how-to-turn-back-the-tide-of-closures/>

²⁴ Scottish Government (2011) Christie Commission on the Future of Public Services <https://www.gov.scot/publications/commission-future-delivery-public-services/>

²⁵ Public Bodies (Joint Working) (Scotland) Act 2014 <https://www.legislation.gov.uk/asp/2014/9/contents/enacted>

Along with tensions inherent to integration structures, further complications have been ambiguity and competing interpretations of what health and Social Care Support actually means. For some it means subsuming both into one 'care service', with Social Care Support nothing more than a minor adjunct to healthcare, with only health-related goals – largely related to easing 'bed-blocking' in acute settings. There are nods towards its role in terms of preventing healthcare needs from arising, and it does have an important role to play here, though even then this has not been followed through with investment of resources. For others, integration concerns smoothing the interface between the two different services of health and Social Care Support, which may overlap somewhere in the middle, but which otherwise have distinct goals and meet different needs for different people. In particular, as flagged above, the role of Social Care Support goes a great deal wider than any relationship to healthcare.

Recommendation 9: In the context of health and social care integration, the Independent Review should assert the importance of the role played by Social Care Support, distinct from the role of healthcare and that Scottish Government money for social care must be ring-fenced. This distinct role must be evident in any recommendations for a national care service.

2.6 Care charges:

Charges for Social Care Support continue to vary enormously across Scotland. Inclusion Scotland believes that charging disabled people for the support they need to exercise their rights to independent living is discriminatory as it amounts to a tax on disabled people to enable them to have the same freedom, choice, dignity and control at home, at work and in the community as other citizens. Out of 32 Scottish Local Authorities, 21 charge above 10% of a person's income. Local Authorities can also vary the tax they charge on income remaining after allowances, and this can be up to 100%. We believe that healthcare is free at the point of delivery and Social Care Support should be too. Jeane Freeman, Cabinet Secretary for Health and Sport, recently made

a pledge to end care charges²⁶ as part of a commitment towards a national care system - we urge the new Government elected in 2021 to honour this pledge and stop driving disabled people into poverty with unfair care charges.

Recommendation 10: Scrap the unfair tax on disabled people that comes from local authorities charging people for their right to receive the support they need to live independently as equal citizens.

3. The impact of COVID

Inclusion Scotland surveyed disabled people and their family carers about their experiences during the pandemic. We ran a baseline survey²⁷ about the impact of COVID-19 asking a range of questions, and then two short surveys, one about the experiences of people who were shielding²⁸ and one on Social Care Support and charging during the pandemic (report pending). Our survey findings were shocking and stark. The pandemic has exposed long-term, deep rooted flaws in the system and the devastating impacts on disabled people and unpaid carers/supporters are clear to see. According to our surveys the pandemic has created new inequality fault-lines and loss of basic rights.

Many people had their care support packages cut, sometimes overnight as demonstrated in the quotes from survey respondents below. This left some people without support to get out of bed or get essential food and medication, and violated many basic human rights, such as Articles 19 “living independently and being included in the community” and 28 “adequate standard of living and social protection” of the UN (United Nations) CRPD (Convention on the Rights of Persons with Disabilities:

²⁶ Health and Care.Scot (2020) Freeman: SNP “will create” national care service <https://healthandcare.scot/default.asp?page=story&story=2313>

²⁷ Inclusion Scotland (2020) Rights At Risk -COVID 19, Disabled People and emergency planning in Scotland, a Baseline Report <https://inclusionScotland.org/rights-at-risk-covid-19-disabled-people-and-emergency-planning-in-scotland-a-baseline-report-from-inclusion-scotland/27>

²⁸ Inclusion Scotland (2020) Shielding Report <https://inclusionScotland.org/shielding-report/>

“I have gone from 20 hours of care (seven hours of which were personal care) to ZERO. I am now bedbound completely because of this.”

“my son was in Residential care where he was getting 2 to 1 support but they sent him home and he now gets no support”

“we don't have any support at all at the moment, we are normally supported 5 days a week”

“Support was withdrawn to a point that I could not cope. Family are now carers 24/7”

“My support package has collapsed. I am sleeping in my wheelchair instead of in bed, no help getting washed and dressed. It's a nightmare.”

July 2020 Social Care short survey respondents

People across Scotland have still not had their care packages reinstated and some people are still paying charges for care they are not receiving.

Inclusion Scotland's Social Care and Charging Survey (July 2020, report pending) asked if people had been involved in the decisions made about changing or stopping their Social Care Support as a result of COVID-19. Of those who said they had experienced a loss or reduction in their support/care during the crisis 51 responded (67%) that they were not involved in discussing the changes. This shows that there was limited (if any) involvement in decisions that could have significant negative impact on the lives of both disabled people and unpaid carers/supporters. Serious concerns were also raised around how people were informed of the changes to their Social Care Support. In particular, being informed by voicemail, text or letter with no follow up to check these had been received or to discuss the potential impact of this decision, and without regard to accessible communications/ information for individuals that required it

“12 weeks on and a phone call from council to ask if support can continue to be stopped for another 12 weeks. It's a very anxious experience and for my family member to be left a voicemail

informing them was incredibly disappointing and completely inappropriate way to treat a vulnerable person.”²⁹

July 2020 Social Care short survey respondent

The COVID-19 pandemic has highlighted concerns around how decisions are made about Social Care Support needs and how they will be met. There appears to be an assumption that spouses or other family members would be able and willing to step in to fill the gap when Social Care Support was withdrawn or reduced. This has put additional pressure on both disabled people and family members and a worrying concern that this will be made to continue as people have been seen to have “coped”. Disabled people and their unpaid carers/supporters are also concerned that because they have been able to ‘survive’ with less support any underspend on their individual budget this year will be clawed back by the local authority and/or that their individual budget for the next year will be cut:

“I’m really fearful for the future of social care. It has reduced me to just feeling like a burden. The emotional, financial and wellbeing cost to my family of having to take over my care has been huge. They feel they have no support either. It feels like we’ve been dumped and forgotten about.”

July 2020 Social Care short survey respondent

“It [support] has been non-existent as the support workers were unable to work. My daughter had to move in with us and give up work. The support is not perfect or even good but it is better than nothing.”

July 2020 Social Care short survey respondent

²⁹ N.B. Inclusion Scotland advises against the word ‘vulnerable’ as it assumes a constant state, and would rather those disabled people at increased risk of contracting the virus and succumbing to it be referred to as ‘at risk’ in reference to the virus.

It is painfully clear that the real life experience of disabled people and their unpaid carers/supporters does not fit well with the expectations contained in the Scottish Government and COSLA guidance issued in May 2020 to local authorities, health and social care partnerships and care providers delivering self-directed support Option 2.³⁰ This guidance says that:

It is critical that Social Care Support is maintained with minimal interruption during this period to ensure the safety, dignity and human rights of people who already have support in place and for those who will need it, taking into account their strengths, family and community assets at this time. Scottish Government and COSLA expect that local systems will act to do what is right to deal with the virus and to protect people's health and wellbeing, recognising that funding is available to meet both existing and new demand in social care during this period of unprecedented pressures.

Scottish Government (2020) Coronavirus Covid 19 Guidance on Self Directed Support.

Recommendation 11: As argued by the Scottish Independent Living Coalition of Disabled People's Organisations³¹ (SILC) human rights do not cease in times of crisis, they are even more important. We must learn from disabled people's experiences during the pandemic to create more robust systems and to ensure what happened to people never happens again.

³⁰ Scottish Government (2020) Coronavirus COVID 19 Guidance on Self Directed Support
<https://www.gov.scot/publications/coronavirus-covid-19-guidance-on-self-directed-support/>

³¹ SILC (2020) Call for Immediate Action: Disabled people's human rights to life and health under threat https://inclusionScotland.org/wp-content/uploads/2020/04/SILC-Statement-on-NHS-and-rights-of-Disabled-People_17.04.20.pdf

4. The case for a national system

4.1 Summary

While vision statements stretching back to 2009 have made human rights central, and while COSLA's submission to the independent review does likewise, the evidence set out above is unequivocal that human rights have not been met when it comes to the delivery of Social Care Support, and not just recently. There have long been wide variations in criteria for support, charges and availability of SDS options. This is profoundly unfair and damaging to people in Scotland who rely on Social Care Support to exercise equal citizenship and human rights. The evidence that the current system is irretrievably dysfunctional – and that while more resources are part of that it is not that alone – is overwhelming. We need a fundamentally different system and have clearly needed this for a long time.

4.2 Letter to Cabinet Secretary

On 28th August 2020, a coalition of DPOs and carer organisations, coordinated by Inclusion Scotland, wrote an open letter to the Cabinet Secretary for Health and Social Care ³²calling for radical action to build a Social Care Support system worthy of the name and to re-open the Independent Living Fund Scotland (ILFS) to new and wider applications as a first step towards this. We asked for a National Care Support Service based on the following principles:

- a. **A system that is no longer based on 'life and limb' support** to keep people alive, but which enables those with Social Care Support needs to access the resources and support they need, with **genuine choice and control** over who provides it and how they use it to live their lives; **in order to achieve independent living, equal citizenship and fulfil their human rights**. This also includes **ensuring that unpaid carers/supporters have the support they need** to provide care and, critically, the choice on

³² Inclusion Scotland (2020) Call for radical action to transform Scotland's Social Care Support System <https://inclusionScotland.org/call-for-urgent-radical-action-to-transform-scotlands-social-care-support-system/>

- what support they are willing and able to provide; in partnership with the person they provide support to;
- b. A system that is **transparent and accountable** to ensure that Scottish Government money designated for Social Care Support is spent on Social Care Support;
 - c. A **system of national, rights-based entitlements** that gives people rights to resources to meet assessed needs, thereby enabling portability and **putting an end to the post-code lottery**;
 - d. **A Social Care Support system that is clearly distinct from the healthcare system**;
 - e. **An end to competitive tendering** that drives down quality, reliability, user satisfaction and wages;
 - f. A system that is **free at the point of use**;
 - g. **A system that is co-designed with people who use Social Care Support and unpaid carers/supporters**: with participation supported by capacity building to boost knowledge, confidence and accountability at local, national and provider-levels.

This provides a concise summary of the key features we want to see in a National Social Care Support system. To date no reply to this letter has been received.

Recommendation 12: a national Social Care Support system must be established based on the principles set out in the letter to the Cabinet Secretary.

5. Next steps

For the independent review to make a series of recommendations, no matter how good, is not the point. It is what happens next and the impact that has on the lives of people using or needing to use Social Care Support that is. This means that whatever the independent review group produces must go beyond high level aspirations to follow through into how this will be delivered in practice, accountability mechanisms, etc.

We very much hope that the independent review will not just be yet another forum where much the same organisations have much the same discussions about much the same issues, leading to much the same recommendations that lead to no positive change for the users of Social Care Support. It must not, as so often before, simply skate round the fact

that this is a fundamentally dysfunctional system. It will take courage to break through the longstanding log-jam of powerful, competing vested interests. Ultimately, though, all involved must confront the unpalatable fact that allegedly shared visions for Social Care Support have unequivocally failed to be realised and, if Social Care Support is not delivering what its users need and want, we have all been wasting our time.

None of us have any more time to waste.

Recommendation 13: Whatever the Independent Review group produces must go beyond high level aspirations to follow through into how this will be delivered in practice and transparent mechanisms for holding those responsible to account.