Independent Review of Adult Social Care in Scotland Evidence Submissions

Volume 3

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Independent Review of Adult Social Care in Scotland

From September to November 2020, there was an open call inviting individuals and organisations to submit views, papers and evidence to the Independent Review of Adult Social Care. These four evidence documents contain some of those organisations’ and representative bodies’ submissions.

Only where permission has been given have submissions been published. Responses from individuals, and any responses containing personally identifying information, have not been published. The Chair of the review and members of the advisory panel are very grateful for these submissions, all of which were taken into account during the review.

This volume contains supporting files from I to R and the Appendix links directly to organisations’ and representatives bodies’ submissions where they were published on their own websites.

In Control Scotland

November 2020

Report

Make Your Views known About the Future of Social Care in Scotland

in Control Scotland

Make Your Views known about the Future of Social Care Scotland

Introduction

Independent Review of Adult Social Care in Scotland

The Scottish Government have recently set up an independent review of adult social care in Scotland. The review is being carried out by a short life group, with the aim of developing recommendations to improve the way care and support is delivered and experienced in the future. There are three phases to the review process, the first of which is an open call to gather the lived experience, thoughts and ideas of people using social care.

Have Your Say

In Control Scotland wanted to give people an opportunity to talk about the review and share their views, so we set up two zoom meetings, which took place on Thursday, 29th October and Friday, 6th November 2020 and sent out an open invitation, so that anyone interested could have their say. These zoom meetings were attended by a mix of individuals accessing social care support, family carers and people working to support others in either a paid or advisory role. We have now collated the information, feedback and comments from both these meetings in this short report.

Structure

We wanted to find out what people who use the social care system thought about the services they currently receive, and structured the meetings using the following headings:

- What is working well?
- What is not working well?
- What matters to you?
- What are the key things that need to change and how can this happen?

You can find out what people thought and their views around social care in Scotland on the following pages:

Views on the Future of Social Care Scotland

These are just some of the comments shared by people who attended our '*Make Your Views Known*' sessions:

What is Working Well and What Matters to You?

"Having choice, and flexibility around what works well for you, being able to recruit your own team of support workers"

"Having flexibility around how you use your support and adapt to changes around Covid-19"

"Being able to be responsive and creative during Covid-19"

"Having the opportunity to work with local authority staff and plan with individuals creatively around what works best for them. Families and individuals sharing what works for them with others"

"Social Workers having knowledge and understanding about self-directed support and them being supported by their own managers to implement this in the way it is meant to work"

"Having good guidance from the Scottish Government which describes the values and encourages flexibility is very helpful"

''Local systems that provide information, advice and support''

What is Not Working Well?

"It should be everyone's right to manage their budgets in a way that makes sense for them and this doesn't happen"

"Good legislation exists, but it is not being implemented. The Covid-19 pandemic has highlighted the lack of core values and people are losing control of their budgets"

“Social care is moving more and more towards being process-led, rather than people-led. It should be values led with just enough process, rather than the other way around’’

“There is no consistency with something which is a national policy and legislation. There should be a reasonable level of entitlement to support everywhere”

“There are issues with flexibility around funding during this current pandemic and also lack of community resources – how can we support these?”

“There seems to be an unwillingness from Local Authorities to be flexible around people’s budgets (during the Covid-19 pandemic) and some people have had some of their budget clawed back, sometimes without any conversation taking place around this”

“People are being judged on what they are spending budget on”

“Lots of anxieties with parents during this time, specifically those with grown up children with complex needs having little or no support and feel like they are being forgotten! Many people say they feel like they are on their knees”

“There is no consideration of admin costs included in budgets and there is still an issue with support just being calculated in hours”

“Self-directed support legislation has the right values and is clear around what should be happening, but it differs in individual areas with what is actually happening”

“Training and education around self-directed support is not always available in local areas and it can be costly for people who need to provide travelling costs to support staff to attend training”

“Depending on what option you take, can be the difference on how creative and flexible you can be”

“Some work needs to be done with some providers/agencies around how they interact and work with people”

“Some people are not having choice and control over their support and are being offered residential care as this is seen as a cheaper option of support”

“People higher up in organisations get involved and make decisions about individual’s without having any conversations with person or the people who know them best, sometimes decisions are made specifically around the person’s diagnosis”

“People are being forced to take a ‘direct payment’ in order to get what they want”

“Supported people can sometimes feel threatened if they don’t do something that is suggested by Social Work, they will lose some of their support”

“There is a definite power imbalance and there needs to be a power shift from professionals thinking they have all the answers and the person requiring support does not”

“Although there is national guidance around self-directed support, it seems to be implemented in 32 different ways across local authority areas”

“Rural areas are not taken into account when looking at support budgets, and people feel forced into Option1. It is also harder to recruit support staff/PA’s when it costs more for people to travel a distance for work”

“Family members can feel anxious and stressed when forced into an ‘unpaid team manager’ role when there is not enough support available”

“Support does not work when there is no trust in the social care system”

Our Priorities for the Future of Social Care Scotland

- Ensure HSCP's/local authorities implement self-directed support as it is intended and follow the national legislation and guidance
- Where necessary, support healthy and appropriate challenge to inconsistent local implementation and hold local authorities to account for implementation in their area
- Ensure there is a clear shift of power from organisations to people. This includes people who are needing support being proactively made aware of their entitlements and the choices available to them so they don't have to argue to get a local response in line with national legislation and guidance
- Improve consistency of what is available so that there is a good variety of support available without unnecessary variation
- Improve and increase training for Social Workers so they have a better knowledge and understanding about self-directed support
- Develop local practice to ensure there is trust and openness working both ways with Social Workers and the individual needing support, so that the person is being trusted to spend their budget wisely and in a way that makes most sense to them
- Ensure that the conversations with people about social care support are conversations about what matters most to them

We would like to take this opportunity to thank everyone who attended our sessions to make their views known on the future of social care in Scotland.

Independent Living Fund Scotland

Independent Living Fund Scotland

Supporting independent living in Scotland & Northern Ireland

Discussion paper **05 November 2020**

Options for a National Independent Living fund

Introduction

This paper has been produced following a meeting on 30th October 2020 between ILF Scotland and representatives of the panel leading the Independent Review of Adult Social Care in Scotland.

At the end of this meeting Derek Feeley, the Chair of the review, requested a short submission that considered the potential role of ILF Scotland in providing a national system of self-directed support. He specifically asked for a rights based approach, aligned with the value base of his review, focusing on the needs, rights and preferences of people who use care services in order to develop a system that reflects a collaborative approach with citizens, and one that enables people to live well.

In order to reflect the complexity of where ILF Scotland sits currently and aspires to be in the future, this paper lays out four options. It should be noted that these options are not unrelated: rather, each builds on the previous option, creating a pathway to an increasingly sophisticated level of independent living support for Scotland's disabled people, which can be tailored to fit within the eventual vision for a National Care Service as developed by the review.

As a starting point ILF Scotland believes that any work to develop rights based national care or independent living services needs to embrace the Independent Living in Scotland (ILiS) definition of independent living:

"Independent living means all disabled people having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not necessarily mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life."

Equally, ILF Scotland believes we must strive to uphold the commitment of Article 19 of the UNCRPD, recognising:

“the equal right of all persons with disabilities to live in the community, with choices equal to others”.

This human rights and independent living focus has been central to the work of ILF Scotland to date, and we will strive to maintain this into the future. Our priority at ILF Scotland is always to achieve the best possible outcomes for Scotland’s disabled people in relation to achieving independent living.

The following options are presented at the request of the review panel, and we hope they are of interest. We welcome the request from the panel for further discussion.

1a Re-open a modernised ILF Scotland 2015 Fund

Disabled people and their organisations have been calling for the immediate re-opening of ILF for some time, and these calls have intensified as a result of the experience of disabled people through the COVID pandemic. A re-opening of the 2015 fund, with some policy modernisation, provides a low risk but effective first step in addressing these calls and, significantly, provides a sound platform from which to build radical progress.

Re-opening ILF using the existing policy suite is possible. However we know that there are a few anomalies within the existing policies. As these anomalies are easily fixed, it makes sense to rectify them as part of any re-opening process. In particular the ILF Scotland charging policy is not currently fit for purpose.

A re-opened and modernised ILF would operate as a national support to local Self Directed Support (SDS) practice. To date referred to as a “National Top Up Scheme”, it developed from the 2018/19 Scottish Programme for Government commitment to consider a potential new national scheme for people with the highest support needs to ensure they could live independently. In partnership with our Sponsor Team and Scottish Government (SG) colleagues we have made significant progress in designing such a potential scheme. It is essentially a modernised ILF designed to provide a national mechanism to enable independent living for disabled people who are significantly impaired and to protect HSCP's from high cost packages of care. It has the potential to incentivise improved assessment and SDS practice, an enhanced independent living focus, and to promote preventative interventions.

This option is relatively straightforward for ILF Scotland to implement. It's core feature is a “Threshold Sum” above which an ILF Direct Payment to the individual disabled person can be made in order to enhance their independent living outcomes. Eligibility is triggered when the HSCP funded care and support reaches the threshold. Some or all of the costs of care above this threshold are then met by ILF Scotland, with certain conditions and incentives attached.

The threshold sum, depending on its level, will define the size of the eligible population. It broadly allows a targeting of a national resource to those in greatest need - a subset within the general social care population – as determined through existing SDS assessment processes.

At present, ILF provides additionality, up to a maximum ILF award, over and above the HSCP responsibility to meet assessed eligible need. The ILF focus is on independent living, and we know that this focus produces life transforming outcomes for disabled people. This option, despite its relative simplicity, is therefore in itself very worthwhile and is something that disabled people are already asking to happen as soon as possible.

The primary duty of the HSCP as set out in the SW Scotland Act 1968 (and its amendments) remains in place. Consequently, the HSCP is the lead social care assessor while the contribution from ILF Scotland is supportive and complementary.

1b Remove the ILF award limit in a re-opened 2015 Fund

This is a development of option 1a.

At present ILF Scotland should not be the majority funder of any jointly funded package of care and support. This recognises the distinct purposes of the two funding sources and the primary role of the HSCP in relation to statutory social care duties. ILF Scotland's role is to compliment this statutory provision with a focus on additional independent living outcomes – what we refer to as additionality. The maximum award reinforces this HSCP responsibility, but was also used by ILF UK as a budget control mechanism.

The seemingly simple act of a policy amendment to remove the ILF maximum award, and the associated expectation that ILF Scotland is not the primary funder, could have a transformational impact with the potential to create a genuine national social care and support service.

In the face of an unquantifiable upper HSCP liability for meeting need the ILF threshold sum will mark the reasonable limit of HSCP financial liability to any one person, so allowing more manageable redirection of local resources to lower levels of need. ILF Scotland as a national service would assume responsibility for all need above this local limit.

In Scotland at present it is largely only substantial and critical needs that are considered eligible, and ineligible, or unmet need, is largely unrecorded. If we remove the current existence of an ILF maximum award so that none exists, with ILF funding all (affordable) need over the threshold, we have instantly flipped the current situation on its head (HSCP being main assessor and funder with ILF complimenting this) and ILF becomes a comprehensive national independent living service.

This option would also transform the social work/SDS assessment process. Significantly, it would lead to the assessment of all need, the recognition of unmet need, and transparency in relation to resource allocation relative to the level of need. It would enable us to recognise the limit of local resource whilst providing the mechanism for making available national provision for those in greatest need. It is a model that recognises the needs, rights and preferences of individual disabled people. It recognises that for a relatively small number of people, who have extremely high support needs, options other than residential or institutional care are available, unless such a care model is their expressed personal wish.

Option 1 (a and b) is essentially a modernised ILF designed to provide a national mechanism to enable independent living for disabled people who are significantly impaired and to protect HSCP’s from high cost packages of care. It has the potential to incentivise improved assessment and SDS practice, an enhanced independent living focus, to address current challenges with eligibility criteria, and to promote preventative interventions (particularly when delivered in parallel to the ILF Scotland Transition Fund). It is low risk and relatively straight forward for ILF Scotland to implement (1b being more complex in practice than 1a). No revision of statute would be required.

2 A National Direct Payments Service

In practice ILF Scotland operates as an SDS option 1 payment service to disabled people, already paying approximately one third of all Direct Payments in Scotland. A natural development stemming from a re-opened and expanded ILF would be a National Direct Payment Service (NDPS), where ILF Scotland assumed responsibility for the management of all Direct Payments. Such a service would recognise and consolidate the Self Directed Support strategy of the Scottish Government, and indeed the achievements of the wider international Independent Living Movement, by placing this form of support on a consistent national basis. It would support increased Direct Payment uptake, providing national consistency, portability, and flexibility.

Initially the HSCP would retain its assessment role as entry point while, over time, current and future Direct Payments would pass to ILF Scotland to fund and administer. It would likely be attractive to disabled people to be supported by a single source and one stop shop, especially if ILF Scotland further developed its existing but informal welfare rights role.

Built as an extension of ILF Scotland’s 2015 scheme, this approach could also offer improved alignment of social care with other public services, removing some of the duplications and streamlining support to disabled people. This is now more possible than ever with the devolution of social security to Scotland. For the first time a Scottish Government has the opportunity to align funding streams and achieve long term efficiencies through reduction in current costly multiple bureaucracies. Caution will be needed so as not to confuse the distinct purposes of social security support and social care support.

HSCP’s would be relieved of the cost of the Direct Payment (and the further cost of its administration), helping to redirect limited local resources into other social care priorities. National models of care currently exist within the NHS in Scotland where Health Finance at the Scottish Government allocate (top slice) a national budget in relation to the national service which is then delivered across the country.

Note that some revision of statute would be required, as at present assessment of need and allocation of personal budgets is the sole responsibility of the HSCP. This could be achieved through a review and extension of existing legislation taken through the Scottish Parliament.

Note it is also possible that existing ILF Scotland policies could also enable a faster track development of SDS Option 2, as a means of addressing the well documented challenges of implementation of this SDS option, it being more compatible with long standing ILF practice. The HSCP would initially remain as entry point into this Option also.

3 An Independent Living Scheme within a National Care Service

It is too early to speculate what a NCS may look like and, therefore, what role, if any, ILF Scotland may have to play in it. We are however interested in exploring the distinction, if there is one to be made, between a National Care Service and a National Independent Living Service. This may simply be a question of use of language, however many of our recipients have told us that they do not want or need “care”.

What disabled people have told us they want is the fulfilment of their human rights and assistance to enable them to live independently. Disabled people are consistently clear about not wanting to be automatically categorised as vulnerable and in need of care. Whatever form a national care service might take, it will be important to evidence within its structure an embodiment of Independent Living values.

The form of delivery could be no less than what disabled people have already achieved within social care in the years since the development of the Independent Living Movement from 1970. This entails, as a minimum, a national form of direct payment or similar means by which disabled people can exercise direct choice and control over how they are supported within a service. Without a feature of this kind a National Care Service is at risk of being seen as a significantly retrograde step by disabled people and Disabled People’s Organisations, with further likely risk of being resisted by disabled people. However, we at ILF Scotland have listened long and hard to disabled people and believe options 1a, 1b and 2 are all likely to be fully compatible within the context of a nationally administered National Care Service.

ILF Scotland as an NDPB and Limited Company wholly owned by Scottish Ministers is a pre-existing vehicle for delivery of any potential national independent living scheme within a developing national care service. ILF Scotland is already a National Independent Living Service, and one that is highly regarded and respected by disabled people. We operate consistently across the whole of Scotland. Indeed this is one of the things disabled people like about our model. It is portable, and not subject to local variations of any kind, including local charging policies and eligibility criteria.

ILFS has gained the confidence of many disabled people and their organisations (as recent public calls for re-opening have evidenced). It would be costly and confusing to create another body any better placed to deliver the kind of independent living that a national care service would require. ILFS is well placed to offer Scotland wide support for any future work in this direction.

Conclusion

At ILF Scotland we take engagement and involvement of disabled people very seriously. We therefore talk to them, and their representatives, consistently. What we hear is that the organisational culture of ILF Scotland is appreciated by the disabled people who we work for and a wider group of disabled people who we come into contact with through partnership discussions. What we hear is that: -

- Our relationship with disabled people is built on trust
- We offer real choice and real control, empowering people to make decisions for themselves
- We offer real flexibility
- We are responsive and reach decisions quickly
- We are light touch with limited bureaucracy
- We always listen to what people have to say
- We carry out holistic, independent living focused assessments in partnership with the individual, rather than narrow needs based assessment linked to rigid eligibility criteria

In essence, our culture, and the practice which stems from this culture, leaves people feeling like they are being treated as equals, with dignity, and with respect.

ILF Scotland has been successful in gaining the trust and respect of disabled people and their organisations since its creation in 2015, building solidly on the previous work of the inherited UK ILF. We offer a tried and tested national service, which, despite its flaws (as discussed at out meeting and which are easily rectified), is seen as an opportunity to start the process of much needed reform of social care in Scotland.

It is time, in our view, to take forward the values and aspirations of the independent living movement by re-opening ILF as championed by disabled people and subsequently further building independent living in Scotland on this national platform. This first element can be achieved at pace within a matter of around 6 months to build the infrastructure needed. The latter can be built as part of the future outcomes of this review of adult social care should it define a more radical change going forward for independent living for disabled people in Scotland.

Peter Scott OBE
Chief Executive ILF Scotland

Susan Douglas-Scott CBE
Board Chair ILF Scotland

Inspiring Scotland

Building Forward Differently – an opportunity for authentic inclusion in a COVID-19 society

Through discussions with our Learning Disability Portfolio, other voluntary sector organisations in the sector and from Inspiring Scotland's experience as a member of the Scottish Government's COVID 19 Stakeholders, Inspiring Scotland would like to propose and initiate a strategic conversation about how our stakeholders can contribute to public services reform as we move forward to the next phase of the pandemic.

The COVID19 crisis has transformed how many voluntary organisations operate. We believe, this experience could be a 'once in a generation' opportunity to really make change happen for vulnerable people across Scotland in the longer term.

Most third sector organisations we have contact with have had to pivot their business models overnight, accelerating the use of digital and virtual solutions on a scale never before imagined. This has been done to ensure that the people these organisations work with and for, continue to be served.

The speed, resilience, adaptability, and flexibility of the voluntary sector to change their approach has, as a result, significantly eased the burden on statutory sector services and also filled gaps in provision caused by the pandemic.

As a significant part of 'the system' in Scotland, we want to ensure that we are truly recognised as equal partners and are central to the next phase of not only systems improvement but system redesign.

Inspiring Scotland want to work with the voluntary and statutory sector in Scotland to develop a radical reassessment of what is required; fundamental changes which will enable us to 'Build Forward Differently' rather than 'Build Back Better'. There is a significant risk that moving back to move forward will only further enshrine the discrimination faced by the people we work with. We believe that our approach will ensure that future systems and services are grounded in a human rights approach and are integrated, transparent, effective, and efficient as well as value for money. Those who rely on services to support them must be genuinely front and centre in design, planning and implementation.

We also understand that because the voluntary sector pivoted overnight in response to the crisis, now is the time to pause and reflect. Constantly being in response mode is unsustainable. Time must be taken to redesign systems that work for everyone.

Due to the third sector's relationship and role in supporting those who are at most risk, no matter the complexity of their issues or disabilities, we can ensure that by working with those individuals the system redesign works both now and in the longer term for all.

We would like to propose working with the voluntary and statutory sector as equal partners to:

- **Involve and engage both the individuals themselves and the voluntary sector** in the development of planning and strategy from the outset.

- **Start planning from the position of people's reality and not underestimate the trauma inflicted during this period**, which builds on multiple past traumas and experience of discrimination. Everyone, at all levels has to recognise that anxiety is increasing all the time and levels of trust are plummeting.

- Redesign systems in terms of processes such as **collaboration, community, co-production and co-design.** Community and society have responded creatively to the pandemic and we must change the narrative moving forward to ensure their involvement in the planning of a way forward.

- Agree that **timeframes are critical**, and this is **a long-term process of recovery for the whole country**. This will not be achieved in weeks or months.

- **Ensure authentic inclusion**. Many of the positive responses to the pandemic have come from communities and third sector organisations and it is essential that this is not lost moving forward. There is a **growing fear of the risk of a 'back to normal' mentality** rather than an acceptance that many of the changes borne out of necessity should be enshrined in service delivery and practise going forward.

- **Avoid the risk of resources all being pulled back to the centre**. How do we ensure that this does not happen at the cost of the voluntary sector, the community and individuals?

- **Consider a plan for moving forward which is fully systemic in approach**, ensuring that the voluntary sector is an equal partner within this system. Without significant and continued support from the voluntary sector and the other networks of support mentioned above people with learning disabilities and other high risk groups risk being further excluded from access to work, education, culture, leisure and suitable living environments all of which are essential for achieving and maintaining health and well-being.

The Changing Face of Technology in Building Forward Differently

Given the prominence and capabilities of technology and digital communication in a new COVID 19 world, we also propose that digital and technology is considered in our whole system approach.

We collectively need to rethink and redesign how our digital world works. People with Learning Disabilities are generally excluded from communicating digitally either through lack of access to hardware, or broadband or mobile data. This is compounded by the fact they may also lack the skills and agency, which means that they currently have no voice.

We also need to rethink and redesign how technology is used. It is central to the development of systems and services, in access to and use of data. Until now, public service systems have been developed around the needs of organisations, not the needs of the individuals they serve. This mismatch means that public services have a huge barrier in terms of achievability, availability and affordability. It also means that the potential for vibrant, sustainable and effective services are held back by the institutional structures that have grown up around the collection and use of data of the individuals they serve.

We have an ideal opportunity to use technology to:

- inform people who use social care and support organisations and families about what support services they are entitled to and that are tailored to their circumstances (i.e. how to navigate the system).
- enable people to engage directly with support organisations and for agencies to respond directly to them.
- gather evidence /intelligence about peoples' experiences to better inform and evaluate policy, planning and commissioning decisions.
- facilitate peer support and networking.
- give people with learning disabilities a voice.

Both digital exclusion and traditional systems design restricts citizens, their health and economic opportunities, which increases the friction, effort, risk and costs of service delivery across all sectors. This ultimately undermines public trust. With its Smart Entitlement and Attribute Prototype work, the Scottish Government has already recognised the importance of this issue in the arena of personal data collected and stored by Scottish Government, and a number of public sector bodies and likewise in the third sector. We would like to see this go further.

Summary

The third sector has shown through this crisis how flexible and committed it is in ensuring that the people it serves are at the forefront of everything it does. Through working closely with statutory services, it can act as advocate, driver and broker for individuals and families in the intelligent redesign of systems both on the ground and digitally to ensure that Scotland is a leader in the new COVID-19 world.

Let's use this opportunity to Build Forward Differently and start a conversation.

Contributors to this paper

Inspiring Scotland
Kirsty Gilchrist, Performance Advisor, Learning Disability Group
Elaine Crichton, Performance Advisor, Learning Disability Group

Learning Disability Portfolio
Jenny Miller, CEO, PAMIS
Charlie McMillan, CEO, SCLD (Scottish Commission for people with Learning Disabilities)
Eddie McConnell, CEO, Downs Syndrome Scotland
Julie McKenzie, Development Manager, musicALL
Norma Curran, CEO, VIAS
Marion Smith, CEO, Get2gether
Heather Hall, CEO, The Usual Place
Rhona Neill, Service Manager, People First

Other
James Fletcher, Arc Scotland
Alex Stobart, Director, Mydex CIC[1] (Partner in SG Digital Identity Scotland prototype development)
https://blogs.gov.scot/digital/2020/05/13/digital-identity-scotland-prototype-draws-to-a-close/

- [1] As a community interest company with a mission to empower citizens, this gives us the ability to speak more broadly about the change state that could be possible following the pandemic and how Scotland could be renewed.

Iriss

Iriss submission to the Independent Review of Adult Social Care

Iriss
November, 2020

Purpose

We welcome the recognition that our current system of social care requires reform. Work over the last decade has demonstrated a threadbare system held together by the commitment of the social care workforce, the creativity and resilience of supported people, and the best efforts of leaders with a vision for a future that prioritises people over process.

As review panel members you will have already received substantial input on the challenges of the current system and a range of perspectives across supported people, representative groups and the workforce. From this, ideas for the future will emerge.

Our submission to the review focuses on a different but equally important concern -

How can we practically reform social care for the better? What are the tools and improvement support we need to make the change we want to see stick?

The problem with reform

'*Policy rarely goes to plan, and there is often a gap between aspiration and reality*' [1]

Significant efforts and positive intent have gone into changing social care in Scotland, notably the introduction of Self-directed Support in 2013[2] and attempts to improve how social care is planned and purchased (commissioned and procured.)[3] Despite this effort, success has been limited and implementation problems persist.[4]

Making change in social care is deeply challenging because social care is a complex system. The system comprises differing perspectives, professions, organisations and purposes set in a complex, and sometimes conflicting, operating context of legislation and guidance. To effectively change social care for the better we need to:

- Make best use of evidence
- Work in real co-production and partnership to build an innovation friendly environment
- Invest in large scale, ambitious systems change
- Use digital, design and communication tools strategically to embed change

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[1] Dickinson H. (2020) The Elephant in the Room – Public Servants and Implementation: An Introduction. In: Sullivan H., Dickinson H., Henderson H. (eds) The Palgrave Handbook of the Public Servant. Palgrave Macmillan, Cham. https://doi-org-443.webvpn.jnu.edu.cn/10.1007/978-3-030-03008-7_107-1

[2] https://www.gov.scot/publications/guide-social-care-self-directed-support-scotland-act-2013/

[3] http://www.ccpscotland.org/wp-content/uploads/2018/11/Procurement-reform-and-social-care-guide.pdf

[4] https://www.audit-scotland.gov.uk/report/self-directed-support-2017-progress-report

Evidence-informed practice

There appears to have been a widening gap between the aspirations of rhetoric in policy and the reality of the lived experiences of people using care and support. Huge progress has been made over the last three decades in how we think about good care, with the emergence of rights-based approaches, person and relationship-centred care and the central role of co-production in social care.

However, despite these advances, we still face considerable challenges with the adoption and implementation of evidence in frontline practice and management. We acknowledge that a raft of contextual issues present barriers to evidence use in social care. These include ongoing funding debates and shortages, how the workforce is valued, volatility in the sector, and the tensions between managerialism and professionalism in social work and social care. While these are significant, our experiences have highlighted some specific challenges and promising developments associated with mobilising and implementing research evidence in social care. Our starting point is that evidence implementation is not a transaction but rather a social, dynamic process that takes place with existing complex systems. The effective and sustained use of evidence 'in practice' relies on an embedded use of evidence in first-line management, system design, strategy development, commissioning and policy. Research has shown that there is little point in having evidence-informed tools and resources for practitioners delivering care and support, without a supportive policy and culture to let them flourish in engaging with more progressive ways of working. It is therefore important to produce targeted outputs and engagement opportunities.

We have developed a number of resources (Navigating Evidence: A tool to support evidence use in practice), services (Evidence Search and Summary Service) and programmes of work (Leadership stories: developing effective supervision) that have looked to close the distance between evidence and practice and to make 'evidence of all types' useful and meaningful to practitioners across social care.

Coproduction and innovation

Over the last seven years, Iriss has been working with the sector using principles of coproduction. Coproduction is a process that creates change and is a way of working with, rather than doing to, people and communities to achieve better outcomes.

A co-production approach sees people who access support as assets and builds on people's existing capabilities. In addition, it breaks down the barriers (and hierarchies of evidence) between people who use services and professionals. The outputs of a coproduction process can be huge, such as services, processes and pathways, or small, such as improving individual relationships or changing local policies. Done well, the coproduction process can support organisations and individuals become agents for change and provide both an ethical process for achieving change, but also tangible results within a more innovative landscape of delivery. This requires an environment that can spend time building trust and relationships, and has the ability to absorb and shape progressive change.

Iriss has used this approach in a number of pieces of work (Pilotlight - Self directed support and Hospital to Home Pathways) to explore how these processes work and to develop tools and resources for the workforce to be able to use these approaches themselves (Coproduction Project Planner and Working Together Apart).

Investing in systems change

Studies[5] suggest that only very few attempts at reform are fully effective. To create change across social care requires a collaborative systems-based approach to change. This requires us to:

- Be clear on the future we want to see
- Be realistic about the system as is; the different interests; the effectiveness of legislation and guidance; and the pull towards the status quo
- Develop consensus on where to focus our efforts
- Co-ordinate and network individual and local change efforts to create a critical mass of people working in the way we want to see ('systems acupuncture')
- Track and evaluate complex change responding flexibly to emerging issues and learning

Digital and design

Large scale systems change requires thoughtful and effective approaches to communication, digital and design, to reach the wide range of people, organisations and professions that need to be part of the change.

The approach needs to be based on the principles of encouraging diversity, enabling connection, and being accessible; thinking about online design alongside what we want to communicate, and how the audience can engage with the material.

Iriss has over a decade of experience in developing innovative, accessible and appropriate digital content, exploring issues of digital exclusion, and engaging with the workforce to

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[5] Change failure issues are summarised in s.3: https://www.england.nhs.uk/wp-content/uploads/2017/09/practical-guide-large-scale-change-april-2018-smll.pdf

develop confidence and skills. Embedded in the organisation is a dedicated knowledge media and communications team working in collaboration with evidence-informed practice and innovation and improvement colleagues. We deliver not only digital, design and online solutions for Iriss, but also to support the wider sector. This includes elements such as website design (Secure Care Pathways and Standards Scotland), digital learning resources (Finding Evidence Online) and the production and running of multimedia platforms (Iriss.fm - Scotland's Social Services Podcast). Crucially, and in recognition of the challenges we currently face as a society and as a sector, this also encompasses projects that examine key ways for the workforce to engage with those who receive care and support, such as the work we lead on with the Scottish Government exploring the use of Near Me video consulting in social services.

Conclusion

The social care future we want to see is centred on the person; collaborative and innovative. To get there we need to develop an operating context that supports quality social work and social care to flourish. This requires an evidence-informed, coproduced and complexity friendly approach to change.

Iriss is well placed both in terms of expertise and experience to help. We would be delighted to talk to the review about practical planning for making the change stick.

We ask the review to consider *how* long term, sustainable change in social care will be planned and delivered as they consider the options for the future of social care.

About Iriss

Iriss is a charity that has supported the social services workforce in Scotland since 2008. Our work involves working with people and services across the sector — local authority, third sector and private — to improve the knowledge and skills of the workforce and ultimately, improve the quality of social services. By improving services we improve the lives of people across Scotland.

www.iriss.org.uk
enquiries@iriss.org.uk
@irissorg

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Key and Community Lifestyles

Independent Review of Adult Social Care
Submission from Key and Community Lifestyles

Key and Community Lifestyles welcome the opportunity to submit evidence and contribute our experience as a third sector social care provider to the review. We are pleased to offer this written submission on some of the key review themes.

About us

Key was established in 1978 by a group of families who wanted their sons and daughters to live full lives at the heart of their local communities. Some of those family members remain involved with Key and we continue to be shaped by the experiences of families and people with disabilities. We provide individualised support to people in 16 Local Authority areas.

Community Lifestyles is a subsidiary of Key, set up in 1995 to support disabled people and people long-term conditions across Glasgow.

Together we offer personalised support to over 2000 disabled people, and people with long-term conditions, across Scotland. We provide support in the person's own home, their family home or in their local community. Support can range from just a few hours per week, a few hours a day to 24-hour support, including overnights.

We employ over 2000 staff largely in direct support or local service management roles. They have flexible working patterns across a range of part-time and full-time contracts, to ensure each person receives support at the time that best meets their individual outcomes.

We work in close partnership across all our work with TAG (The Advisory Group). TAG was originally set up by Key in 1996 to enable people with learning disabilities to have a stronger voice in the services they use and in their local communities. TAG became a Scottish Charitable Incorporated Organisation in 2012 to promote the talents of people with learning disabilities, break down discrimination and promote an inclusive Scotland. TAG has service level agreements in place with Key and Community Lifestyles.

Defining ‘adult social care’

The review presents an ideal opportunity to reach a more inclusive and comprehensive definition of adult social care: one which reflects the diversity and complexity, of social care provision in 21st century Scotland. Alongside this we should seek to engage wider Scottish society in understanding the value and range of modern-day social care. Social care is something that we should all have a vested interest in shaping, given the increasing numbers of people who are likely to need to access it, either for themselves or a family member, at some point in their lives.

In our experience many still view social care through the prism of care homes, older people’s services and more traditional forms of supports such as home care and those which are buildings-based.

This view of social care doesn’t accurately reflect the lives of people we support and the part we play in them. Most of the people we support either have a self-directed support budget, primarily using Options 2 or 3, or receive ‘supported living’ as commissioned by their local HSCP. Therefore, for us social care means listening carefully to each person we support, and the important people in their lives, to understand how they want to live their life, play their part in society, and then get alongside them to help make that happen.

We believe that SDS, where its properly implemented, provides the mechanism and value base by which people across care groups in Scotland can access support that guided by their experiences and delivers on their needs, wants and aspirations.

Dimensions of high-quality social care

1. Person-led and human rights based

In the ALLIANCE’s report[1] of their engagement event with people with learning disabilities, one of the participants is quoted as saying:

“Social Care should be a springboard not a safety net”

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[1] **Health and Social Care Alliance Scotland** Social Care Review Engagement Activity- Learning Disability Session, 13 October 2020.

We believe that starting from this point of listening to the person, being led by them and finding out how support can be a means to them achieving their potential is absolutely the foundation of high-quality support.

This quote is pertinent, also, in that it firmly recognises support as a human rights issue. Good support should be built around recognising people as citizens with rights and empower them to enjoy similar opportunities as those who do not require social care support.

2. SDS

Many of the people we support use individual SDS budgets and in our experience, this provides a framework for people to be at the centre of decision-making about their support and how they want to use it. SDS also provides an environment within which flexibility and creativity can thrive, meaning the person can be free to try things, take supported risks, change and adapt their support as needed and, importantly, explore other solutions outside of formal, paid support.

3. Equal partnerships and relationships

It is our experience that trusting collaborative relationships and shared responsibilities between all parties involved in a person's life are crucial to delivering truly person-centred support.

4. A valued workforce

As an employer to over 2000 staff, largely in direct support or local service management roles, we have no doubt that a skilled, valued and motivated workforce is central to the delivery of excellent social care support. A job in social care should be a career of choice which recognises the great skill required to do the job well and provides a path for progression and continuous development.

Early in the pandemic there were some promising signs that social care workers' value was being elevated in public perception with the focus on key workers. However, this early momentum has stalled somewhat, and the focus has returned to the NHS and the very real public health challenges it faces.

5. Community connections

Our experience also shows that community development approaches can offer real benefits to disabled individuals, their families, local agencies and the wider communities[2]. For example, TAG is helping to develop a new sporting initiative in Renfrewshire, where a new partnership with St Mirren Football Club is establishing a sustainable sports resource. Prior to this, the only football opportunity was run by one of the day centres and in order to be able to attend their sessions, each individual was required to undergo a social work assessment, meet the eligibility criteria, be in receipt of support funding, and also attend the day centre.

TAG's Community Development Worker has brought together 30 disabled people and created a fully sustainable resource with people paying a very small amount each week to cover the costs for the coaching and the venue. All day centres and local providers have supported the initiative and several younger people who do not meet the eligibility criteria for funding also attend.

The initiative has created a community-based resource, run as part of the local professional league football club. It has facilitated access to excellent facilities and coaching, the national league, and a more rewarding and enjoyable experience for participants. It has also helped the local Health and Social Care Partnership make best use of available resources and reach a wider group of people who need support.

Needs, rights and preferences of people using social care services and supports

Any future social care system needs to have the rights and views of the people with experience of using it at its very heart. We would urge the review to consider a system reset which delivers a framework reflective of the diversity of the individuals and groups accessing it and which provides person-led, based around their choices and preferences, as opposed to needs and service-led support.

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[2] *Community development, community connections, community life; Independent evaluation of a Community Development partnership between Key, Community Lifestyles and* TAG, G Reekie (Greyhound and Wren), 2017 – available on request.

The experience of staff working in the social care sector

Many of our workforce would say that what they value most about their job is the personal relationships they have built with the people they support and their wider social network. It is a job that means you truly are part of people's lives and often workers will know the individuals they support almost as well as they know members of their own families.

Enjoying such a privileged position in people's lives requires a great deal of skill. At each level of providing support whether as a support worker or local manager, staff must have excellent interpersonal skills and a real commitment to nurturing warm relationships which are based upon empathy, compassion and respect.

They work in partnership with the important people in each individual's life, which can be family or professionals, and can often be pivotal in ensuring that a person's views are heard, acknowledged and acted upon, especially where there could be conflicts of interest, power imbalances, safeguarding concerns, or disagreements over an agreed course of action.

This is, of course, neither a replacement nor alternative to independent advocacy and we would welcome increased availability of these vital resources. However, we do recognise that when access to advocacy is scarce, it is often direct support staff who can be key to people expressing their preferences.

These often so-called 'softer skills' are accompanied by a set of highly professionalised and, often specialised, practical skills which will be tailored to each person our staff support. This can range from preparing food to specified diets and supporting people with their nutrition (including PEG feeding), administering medication, assisting with communication through a range of communication aids, moving and assisting and other health and safety related aspects; in other words activities which in other spheres are likely to be undertaken by staff classified as specialists.

Additionally, at manager level, the staff member will have a range of regulatory, contract monitoring and legislative responsibilities with associated activities.

The move to formal registration of all staff and the requirement that they have relevant SQA qualifications has impacted third sector providers too.

Our workforce is made up of people from many walks of life, many of whom came into their roles several decades ago when these formal expectations didn't exist.

The workforce demographics are changing too, as we welcome increasing numbers of younger people who are choosing this work as a career and may be frustrated that there are few career pathways available to them. It is important that the priorities, skills, knowledge and experiences of these groups are carefully balanced in any future system, alongside emphasising that this is a role that comes with the expectation that people are able to work towards a set of professional standards, regulations and qualifications.

This is against a backdrop where staff in these roles are often deemed as low-skilled whereas highly skilled, highly professional, is a more accurate description. Like providers across the third sector we strive to be an employer which attracts people with the right values, skills and experiences, and keeps them. Resource limitations make it increasingly difficult for all of us to do this through good terms and conditions, and fair work practices.

Regulation, scrutiny and improvement of social care

At local management level, inspection and regulation may not always feel like a co-operative process which is focused on supporting improvement.

For staff in support roles too, inspection conversations may not always be framed in language and ways that are meaningful to them. This can prevent them talking confidently about their role and how they support people. Having an inspection approach which is supportive and enables them to share their considerable knowledge would undoubtedly lead to richer and more robust inspection and quality assurance data.

We would welcome the opportunity for inspection, regulation and contract monitoring to become more focused on having constructive, and yes critical where this is necessary, conversations with providers and, most important of all, with the people who have direct experience of receiving support.

Commissioning and procurement

Current competitive tendering processes can undermine the potential to provide good person-centred support in several ways:

- They can act as a disincentive to collaborative working and partnership building among third sector providers and others.
- They can create a culture of decision-making which is risk averse and stifles innovation.
-

- They divert energy, resource and time away from organisations' core purpose to deliver excellent support.
- They categorise, or codify, people based on group characteristics which can lead to service-based rather than person-led decisions.
- They make it challenging for people and communities to take control of the planning and delivery of their support.

As a provider we are also witnessing procurement approaches which are not grounded in the principles of SDS and in some cases are moving away from it entirely.

Potential national aspects of a social care system

We would advocate that greater and more consistent implementation of existing Self-directed Support legislation across all Scottish local authorities could deliver on a national framework for social care which has individuals at the heart of the planning, delivery and review of their own support. In our experience there is disparity across local authorities in the implementation of SDS. Where SDS is embraced we have numerous examples of how outcomes-based support planning and creative use of individual budgets (which includes tailored support, harnessing community opportunities and technology) has helped people live great lives and achieve their goals. Even where SDS has been less consistently applied, the tenacity of the person and those in their life alongside working closely with creative and committed colleagues has led to positive results in people's lives.

We would urge the review to consider the great benefits of localism in providing excellent support to individuals and the role that local communities can play in planning local solutions which are responsive to local needs and wants.

Such approaches have the potential to harness local talents, ideas and opportunities and make the best use of resources such as technology, infrastructure, and social housing.

Social and health care services already share a national framework of standards, the National Health and Social Care Standards. They offer the potential for everyone involved in social care to be very clear about what to expect from the support they receive or provide but perhaps would benefit from greater awareness raising of their existence and how they can be used to ensure support is truly person-led.

We would also urge the review to consider how we can achieve increased parity of charging policies across all local authorities, and more transparency around eligibility criteria, commissioning and procurement.

As an employer of almost 3,000 staff across Key and Community Lifestyles providing support to over 2,000 individuals living in 15 local authority areas we welcome the opportunity to contribute to this momentous review of Adult Social Care and extend an invitation for members of the Review Group to engage with people we support and work alongside to further envisage the way forward for adults requiring support in Scotland in the years and decades ahead.

Key and Community Lifestyles November 2020

Key and Community Lifestyles
The Square
70 Renton Street
Glasgow, G4 0HT
0141 342 1890

A society registered under the Co-operative and Community Benefit Societies Act 2014, company number 1938 R (S) and with the Scottish Housing Regulator, registration number 141. Key, Key Support and Key Housing are names used by Key Housing Association limited, a charity registered in Scotland, charity number SC006652. Community Lifestyles Limited, Company No SC186901. A subsidiary of Key Housing Association and a charity registered in Scotland, No SC028041.

Leuchie House

Dear Derek,
I enjoyed participating in your recent engagement event, organised through the Alliance. So many instances of issues raised were being raised in my last period of employment in social care over 10 years ago. Hopefully though this is empowering rather than overwhelming for your Review, all power to your elbow.

I am deliberately being brief, in the hope that in so doing the status of **respite care** is specifically referenced in your findings. I am of course happy to provide further detail as required, perhaps in your nest stage.

To remind and provide context: Leuchie House provides short breaks of 4-11 nights to around 300 people with neurological conditions, from 28 of the 32 Local Authority areas in Scotland. Over half have MS and the average age of guest is 62 years old. This give us a small population sample with great diversity of location, condition and experience of social care. That diversity of experience is perhaps the single biggest comment to make and in our view is inconsistent with the intent and spirit of (legislative) right to assessment, for carers, which was to ensure provision of required service. Once again fine and universal policy intent has not been felt at individual level.

COVID has underlined the importance of respite care. Despite very obvious and real concerns regarding COVID risks for our target population, Leuchie has been inundated with requests for respite care, driving the organisation to re-open on 28th September after a short pause in our usual service delivery. Behind every booking for respite care is a story of desperation, a carer and their love done unable to cope to the extent that they will take the COVID risk of entering a group social care setting, for respite.

We have received numerous calls for social work and health professionals concerned about the exhaustion of carers, the unintended harm to those being cared for and the increased pressure on higher tariff services for want of preventative respite care.

The old faithful’s remain:
Transition from adult to older people remains awful for most, across Scotland. Generally this means starting again with health and social care, lack of allocated/ named Social Worker/ large reduction in service assessed as required. *‘Ageing by one day does not diminish the disease or needs nor does it reduce the burden of care on loved ones.’*

There is great inconsistency across Scotland which leaves people with very similar care and support needs in receipt of very different care and support
‘The legal right to assessment for social care support and for separate carers assessment is only as good as the spending priorities and skill of the assessing authority, which is massively varied.’

The concept and management of task based/ short interval care packages entirely undermines the dignity and of individuals and the very concept of person-centred care
‘If a user of support services cannot vary the task from cleaning a kitchen to making a drink, it isn’t person centred or responding to the needs of the individual’

A respite break is funded to give the carer a break, most options ignore the experience of the individual in receipt of care
‘The quality of experience of the person receiving care is crucial to the carers choice to use a short break service. A temporarily vacant bed in an older people’s home is not a positive choice for a 50 year old’

We could re-imagine respite in the context of the above by making available the technology which will increase independence of the cared for person and their unpaid carer, with benefits to both. This will enable the disabled person and carer to gain multiple short moments of independence throughout the day, adding up to as much as an hour a day, equivalent to a full day over a week.

In the hope that this brief note may be considered in your review and with all good wishes.

Mark

Mark Bevan | Chief Executive Officer
Leuchie House | North Berwick | EH39 5NT

Luminate

Evidence for the Independent Review of Adult Social Care

Luminate, Scotland’s creative ageing organisation

SUBMITTED 6th NOVEMBER 2020

Introduction

Luminate is Scotland’s creative ageing organisation. Our mission is to ensure that all older people in Scotland can access high quality arts and creative activities, whatever their background and circumstances and wherever they live.

There is growing evidence of the positive impact of being involved in creative activities as we age, bringing opportunities for enjoyment, social connection and self-expression which are important for people’s wellbeing and quality of life.

We believe that creative ageing approaches have an important role to play in developing a social care system where people are supported to live independently; be active citizens; participate and contribute; and maintain their dignity.

Both the arts and social care sectors have made huge strides over the past decade in understanding the impact and value of engagement with arts for older people.

This evidence provides some insight into creative practice in Scotland’s care homes before the pandemic. It demonstrates the commitment and energy of social care staff who recognise its benefits, but also the challenges they face in terms of confidence, skills, capacity and funding to ensure creative practice is sustainable and the quality and quantity of provision consistent across Scotland.

This evidence also highlights the crucial role of professional artists in high quality creative ageing practice. However, this professional group are also facing huge financial challenges.

The impact of Covid-19 has made delivery of, and participation in, arts and creative activities very difficult, particularly in care homes. And yet, the benefits of participation have never been more needed and social care professionals and artists have shown determination and ingenuity throughout this pandemic to adapt activities and help keep people connected.

Any major review of social care in Scotland should recognise the wide-ranging benefits to be gained from embedding creative ageing practice in its delivery. Care is not just about physical care, but individuals’ quality of life and arts and creativity are integral to that.

In this document:

Creative activities in Scottish care settings before Covid-19

In 2018 Luminate mapped creative provisions in Scottish care settings. You can read the full report here.

We found a huge amount of arts and creative activity happening in care settings across Scotland, almost all of it universally acknowledged as positive and beneficial. However, there is inconsistency in provision across Scotland and most settings had limited resources which reduced their capacity to include arts and creativity within their programmes.

The following information provides an overview of our findings after surveying 93 care homes in Scotland.

Who facilitated creative activities in care settings?

- Social care service staff (73%)
    - Activities coordinators, who may or may not be a member of staff (a sizable sub-set of the above group, identified through additional information provided)
- Amateur or volunteer artists (42%)
- Professional artists (26%)
- Registered arts therapists (20%)
- Activities coordinators, who may or may not be a member of staff (42%)

How were creative activities funded?

The creative activities were most often paid for by the core budget of the care service provider (38%) or through fundraising (37%). 16% said they have a variety of ways of funding these activities.

What creative activities were offered and how often?

The care settings offered an average of around five different kinds of participative creative activities, with craft the most popular (90%), music (86%), painting, drawing or sculpture (78%) and shared reading activities (65%). Just over half of settings said they offered these kind of activities daily, and just under half said they offered them weekly.

Almost all (91%) offered audience-based creative activities such as music, theatre and dance performances; museum visits and film screenings. These were most offered monthly.

Impact of participation in creative activities for residents, based on observations from the social care staff who worked with them

The following observations from social care staff provide insight into the benefits of engaging in arts and creative activities:

A right to access arts and culture

"Being creative, in whatever form, shouldn't stop or not be offered just because someone is in care."

"Residents still have a life when they live in a Care Home and it is important that they can still take part or enjoy activities."

Self-expression and agency

"It helps [residents] express themselves when they may have lost the ability to communicate. It helps them explore their reality and condition. It helps others understand their needs better."

Experiencing joy and improved wellbeing

“We see increased levels of happiness and contentment in our participants when they are engaging with creative activities.”

“When we do any of these activities with our clients we can see a rise in their mood. Afterwards they may not all remember the activity they have participated in but they are always in good spirits afterwards.”

Improved self-esteem and self-confidence

“There is a chance to try something new and feel proud of achievements.”

“Opportunity to try new things to feel fulfilled and content.”

Beneficial for people living with dementia

“Creative work allows people, especially with dementia diagnosis to work in the moment as opposed to reminiscence approaches where they are asked to remember, and often can't.”

“Can be particularly useful if a participant has a tendency towards agitation or distress.”

Improving relationships between residents and also between staff and residents

“Some of our projects bring several residents together to work as a team helping with bonding and friendships.”

“Takes the focus away from the care relationships.”

“Sharing an experience together without the barriers of care giver and care recipient.”

Challenges to overcome

Despite these benefits for individuals using social care services, as well as commitment and enthusiasm amongst care staff, care settings reported challenges which made delivering consistent, high quality creative practice difficult. These included a lack of:

- Funding
- Staffing
- Skills, knowledge and confidence amongst care staff
- Inspiration and new ideas
- Training opportunities

The role of the professional artist in social care

There are many examples of innovative projects in Scotland over the past few years, which have demonstrated the positive impact that professional artists can make on the quality of creative arts in social care.

The Care Inspectorate has recognised this in its Arts in Care resource pack, created in partnership with Luminate. The resource seeks to strengthen the relationships between professional artists and care workers.

There are however many obstacles still to overcome, including a lack confidence, awareness, staff time and resources in the social care sector.

The projects outlined below provide insight into the development of creative ageing practice in recent years, which has been made possible through the financial support of numerous trusts and foundations. A crucial question going forward is how this work will survive and thrive going forward.

Luminate and Erskine: Unforgotten Forces Artists in Residence (2017-20)

Luminate has worked in collaboration with residents at Erskine Care Homes over a three-year period (2017-20), many of whom are living with dementia. Two freelance artists facilitated a broad range of creative activities, such as film-making and sculpting. One of the projects involved creating art outdoors and culminated in an outdoor exhibition.

The extended length of the residency enabled the artists to build strong relationships with residents and staff, and design activities that are personalised for each individual they were working with.

Bandrum Nursing Home Artist in Residence (2019)

Fiona Hermse was an artist in residence for nine weeks at Bandrum Nursing Home, Fife. Her residency included nine full-day visits, once per week.

Staff noted that residents were relaxed and focused during activities and uplifted afterwards. In the dementia unit in particular, arts activities prompted a greater than usual level of engagement, smiling and conversation.

After working with Fiona, staff at the care home were inspired to initiate additional creative activities beyond the life of this project.

"[The artist] got residents engaged, staff became engaged, and they created other projects themselves. She got relatives talking – there was a buzz! I think the residency worked well because there was time, she had the time. If she came in for an hour some of them wouldn't have engaged and she wouldn't have achieved a tenth of this. It has been a success and increased our confidence in engaging with creative work."

Bandrum Nursing Manager

Live Music Now

Live Music Now's programmes for older people have included live music sessions in hospitals, hospices, and care homes. In 2013 the organisation embarked on *Composing with Care*, a project for Luminate in which older people in the Hebrides (in residential care) contributed to the creation of a suite on songs by composer William Sweeney, inspired by Hebridean culture and the residents' personal stories and memories.

Their work has continued to develop and the team have contributed significantly during the pandemic. You can find out more about their work here.

Living Voices

Initiated by the Scottish Poetry Library in partnership with the Scottish Storytelling Centre, *Living Voices* began as an 18-month pilot in 2014 in care settings across Scotland, in which professional artists (storytellers, poets and musicians) led monthly sessions with older people. Poet Ken Cockburn said: "I think the thing I enjoyed most was going into care homes… people realise they maybe do have a story to tell and that people will be interested." You can read more about this project here.

Read about more projects like these in *Late Opening: Arts and Older People in Scotland (2017)* here.

Creative activities during the Covid-19 pandemic

Care homes in particular have been hit especially hard throughout this pandemic, with the threat to staff and residents' lives leading to grief and tragedy.

The impact of extreme health protection measures on residents' wellbeing has been profound, particularly the restrictions on visitors, which has affected residents' ability to connect with family and loved ones. Physical contact has been greatly missed, for example through hugging and dancing together, as is contact with younger people.

The ongoing restrictions mean artists are unable to work face-to-face in care settings and engaging with social care staff remains difficult.

Despite this arts and creativity have continued throughout this pandemic, boosting spirits and bringing joy in very dark times.

Through Luminate's Creative Ageing events in August, September and October, professionals from across the arts and social care sectors have shared stories of determination and ingenuity where creative activities have been adapted, or completely reimagined, to help keep residents connected.

Here are some examples:

- SEALL produced and live streamed concerts for residents, staff, family and friends of Home Farm care home, in Skye, during June and July. Residents' families joined in remotely.
- CrossReach' Heart For Art project sent personalised art and craft packs to those who previously participated in their weekly arts groups, as well as to residents of their 16 care homes. The packs were complemented by virtual group sessions.
- Both Equal Arts and Impact Arts used one-to-one telephone calls to help sustain connections with those they work with – to talk about doing creative activities at home and/ or to talk generally.
- Luminate's programme of online films Luminate@Home offer creative activities that can be done by an older person living at home alone or in a care home. The programme is continuing to evolve to reach people who are not online. For example, we will shortly be launching a dementia inclusive singing resource to help people to sing at home on their own or with their family, which will be available in hard copy as well as online.

The role of arts and creativity in improving adult social care in Scotland

We believe that arts and creativity have a central role to play in improving people's experience of social care in Scotland and the outcomes they achieve.

Creative ageing is cross-disciplinary and cross-sectoral. When care staff and artists work together effectively, the results can have a transformative effect for older people.

Both the arts and social care sectors have made huge strides over the past decade in understanding the impact and value of engagement with arts for older people. Despite this, a recent report from the Baring Foundation – *Key workers: creative ageing in lockdown and after* – shows that there is UK-wide concern about the financial viability of the artists and cultural organisations at its heart (read the full report here). Likewise, for those working in social care, there were challenges relating to funding, capacity, skills and confidence that made creative practice patchy across Scotland even before the pandemic. The impact of Covid-19 has only exacerbated those challenges.

Plans to improve social care services for older people should consider how to make creative ageing practice sustainable, so that arts and culture is truly accessible for all.

Reform should include a programme of work that reinforces the rights of older people to access the arts, and in particular seeks to embed arts, culture and creativity in care services. This should include:

- Improved access to creative ageing training opportunities for both social care staff and professional artists who work with older people. Specifically:
    - The inclusion of arts and creativity in the training of care professionals, both those who are currently working in the sector and the students who are training to join it

- Structured and funded opportunities that enable professionals in the care and arts sectors to come together on a regular basis, to share experience and learn from each other.

This would require joint working at all levels, from Scottish Government to Health and Social Care Partnerships to local care providers and arts organisations.

Any new training or CPD opportunities should reflect the challenges and opportunities that the pandemic has brought, for example the inclusion of digital opportunities for those who are online, and the need to continue to support those who are not online – whether individuals or care settings – through imaginative approaches to remote connections.

Luminate, Scotland's creative ageing organisation
Website: luminatescotland.org
Twitter: @LuminateScot
Facebook: @LuminateScotland

Marie Curie

Marie Curie Evidence

Scottish Government Independent Review of Adult Social Care

Introduction and overview of current palliative end and of life care landscape

1. In 2019, there were 58,108 deaths registered in Scotland[1]. It is estimated that around 44,000 of those who died would have had a palliative care need. But, one in four people still miss out on this support across the country[2]. Palliative and end of life care supports people who have a terminal illness. By terminal illness, we mean a disease or condition which will likely result in the person's death. Someone can live for years, months, weeks or days with a terminal illness following their diagnosis.

2. Social care is an integral part of palliative and end of life care helping terminally ill people to live as well as possible right up until their death and supports an end of life experience which reflects what is most important to them. This includes being able to die in their place of choice, when possible, which is often at home or in a community setting.

3. Care at home services can support terminally ill people with daily tasks, housework, prepare meals and take the person shopping or out for day trips. They can also support with tasks such as getting dressed, washing, going to the toilet and shaving. Care workers use hoists and sliders to move people with limited mobility and are also trained to administer medication.

4. Care homes currently vary in the extent to which they provide end-of-life care. Some have specialist teams on site and others draw on community-based resources, primary palliative care or hospice outreach teams to support residents.

5. Social care services can also provide valuable respite for those caring for someone with a terminal illness allowing them to have a break from care, sometimes even just for a few hours.

6. Long standing, fundamental issues in social care have been exacerbated by the Coronavirus pandemic including; lack of sustained financial support; workforce challenges; and compromised, reactive health and social care systems with complex and overwhelming caseloads. When combined with more specific Covid-19 related issues such as lack of Personal Protective Equipment (PPE) and a sudden shift towards more deaths in the community, the pandemic has significantly impacted the care that terminally ill people receive and placed already exhausted social care workforces under further, intense pressure.

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[1] National Records of Scotland: Vital Events References Tables 2019

[2] London School of Economics, Equity in the Provision of Palliative Care in the UK: Review of Evidence (2015)

7. Everyone will be affected by dying, death and bereavement and we welcome this independent review as urgent reform of care for those with palliative and end of life (social) care needs should be a high priority to enable people to die well with the right support.

Marie Curie Evidence

Dimensions of high-quality social care

8. Shift to from hospital to community settings for place of death projected by 2040 (Dec 2019)– Marie Curie led research to help inform decisions around:
    - Community palliative care dimensions and needs (research demonstrated that up to two thirds of people could be dying in community settings by 2040)
    - Specific community care models/funding allocation

9. Palliative Care in Scotland: Research into Practice (2017) – A report from a seminar hosted by Marie Curie, Scottish Government and Research Seminar. The seminar explored what palliative care research exists in Scotland and how this can help inform and improve the reach and quality of palliative care, as well as decisions on strategy and policy. It also identified gaps in the research and suggested possible future areas of study. The event also explored how the scoping review's findings could inform the progress towards meeting some of the ten commitments set out in the Strategic Framework for Action.

10. Consultation on National Health and Social Care Standards (Jan 2017)

11. The Care Inspectorate and Health Improvement Scotland consultation on National Care Standards (Dec 2015)

Needs, rights and preferences of people using social care services and support

12. You Matter (2018)– This report was created following a realistic care event with Scotland's former Chief Medical Officer Dr Catherine Calderwood, to encourage people to think about the care they would want at the end of their life (including social care).

13. Dying to Care; A Report into Social Care at the End of Life (2017) - Good social care is fundamental to people achieving the outcomes they want as they approach the end of their life. This report looks at the barriers in Scotland to people receiving social care and how they can be overcome.

The experience of staff working in the social care sector

**We strongly believe this category should also include informal (family) carers - this is reflected in the below Marie Curie evidence.*

14. Life After Death; Supporting Carers after Bereavement (2020). A collaboration between Marie Curie, Sue Ryder and Reform Scotland which calls for more recognition of the impact of death on the carer and the effect on the carer's

physical and mental health, their relationships, their ability to work and their finances.

15. Scotland Carers Report (2018) - A study from Marie Curie and Macmillan Cancer Support identifying the support needs of carers as well as barriers and triggers for identification of their caring role.
    a. **Parliamentary briefing here**

16. Scottish Government; Carer's Strategic Policy Statement (Dec 2019)

17. Timescales for Adult Carer Support Plans and Young Carer Statements for carers of terminal people (April 2020)

18. Immigration and Scottish Care Sector (prepared for a Members Debate in March 2020 which did not go ahead due to Covid-19)

19. Scottish Labour: Health Debate (Nov 2017)

20. Scottish Conservative: Health Debate (Nov 2017)

21. Scottish Labour NHS and Social Care Workforce Commission (April 2018)

22. Green Party Debate: Carers and Social Care (April 2017)

Regulation, scrutiny and improvement of social care

23. Scottish Parliament - How well is the Care Inspectorate fulfilling its statutory roles? (Aug 2020)

24. Scottish Labour: Carers Allowance Supplement (Feb 2019)

25. Health and Care (Staffing) (Scotland) Bill 2018
    a. **Parliamentary briefing here**

26. Consultation on draft regulations under the Carers (Scotland) Act 2016 (Sept 2017)
    b. **Parliamentary briefing here**

27. Consultation for Non-Residential Social Care Charges (Jan 2016)
    c. **Parliamentary briefing here**

Human rights and ethics in social care

28. Members Debate: Right to Die at Home (Jan 2020)

29. Enough for Everyone: Challenging Inequities in Palliative Care (2016) – A report discussing barriers as to why people may not be able to access palliative care in addition to highlighting certain other groups of people receive less palliative care than others with a comparable need (including social care).
    a. **Parliamentary briefing here**

30. Palliative and End of Life Care for Black, Asian and Minority Ethnic Groups in Scotland; Exploring the Barriers (2015). Black, Asian and minority ethnic groups (BAME) are underrepresented among those using palliative care services (including social care) in Scotland according to this report.

The below Marie Curie evidence covers all of the listed categories above in addition to commissioning and procurement; finance; potential national aspects of a social care system

1. Social Justice and Fairness Commission; Reform of Social Care (Oct 2020)
2. Scottish Labour National Care Service (Aug 2020)
3. Scottish Parliament Health and Sport Committee Social Care Inquiry (Feb 2020)
4. Covid-19 supplement to Scottish Parliament Health and Sport Committee Social Care Inquiry (July 2020)
5. Adult Social Care Reform (Oct 2018) **joint submission with Hospice UK*
6. Scottish Liberal Democrats Social Care Consultation (April 2018)

About Marie Curie

Marie Curie provides care and support for people living with a terminal illness and their families and carers. We provide support through our two hospices in Glasgow and Edinburgh, as well as our community nursing services across 31 local authority areas, and our volunteer led services.

We also provide nationwide support through our information and support service including our national helpline. Marie Curie is also the biggest charitable funder of palliative care research in the UK. In 2019-20, we provided care for 8,534 people living with a terminal illness, as well as their families and carers across Scotland.

Our vision is for a better life for people living with a terminal illness, their families and carers. Our mission is to help people living with a terminal illness, their families and carers, make the most of the time they have together by delivering expert care, emotional support, research and guidance.

Further information:

Richard Meade
Marie Curie
Head of Policy & Public Affairs

Ellie Wagstaff
Marie Curie
Policy and Public Affairs Manager

Mental Health Foundation

Submission to the Independent Review of Adult Social Care

The Mental Health Foundation

Our vision is for a world with good mental health for all.

The Mental Health Foundation works to prevent mental health problems.

We drive change towards a mentally healthy society for all, and support communities, families and individuals to live mentally healthier lives, with a particular focus on those at greatest risk. The Foundation is the home of Mental Health Awareness Week.

The Mental Health Foundation is a UK charity that relies on public donations and grant funding to deliver and campaign for good mental health for all.

Website	www.mentalhealth.org.uk/scotland
Twitter	@MHF_tweets
Facebook	www.facebook.com/mentalhealthfoundation

Mental Health problems among people in need of social care

People with disabilities, long-term health conditions, and/or frailty in later life are at greater risk of having a mental health problem for a variety of reasons that relate to the social determinants of mental health. Mental health is influenced by the circumstances in which we are born, grow, work and live. People with disabilities, long-term health conditions, and/or frailty in later life may face the kind of social circumstances that bring a higher risk of mental health problems if they are relatively isolated either at home or in congregated settings, in impoverished circumstances, in unsuitable housing and/or without opportunity to participate in work, social or civic life.

People with long-term health conditions are two to three times more likely to experience mental health problems, with anxiety problems or mood disorders being particularly common.(1) Despite this, in 2008 a systematic review showed that non-psychiatric health professionals' detection of depression in patients with physical illness was low,(2) while a qualitative study published in 2011 suggested that wider discussion and treatment of emotional problems in the context of physical illness was also low.(3) Co-morbid mental health problems have a number of serious implications for people with long-term conditions, including poorer clinical outcomes and lower quality of life.(4) Perhaps most worryingly, people with co-morbid mental health problems are more likely to die, and die sooner, from physical health conditions such as cardiovascular disease, diabetes, chronic obstructive pulmonary disease (COPD) or asthma.(1)

Based on these inequalities in health outcomes, the King's Fund has recommended as a priority that people with long-term physical health conditions should receive support for the psychological aspects of their condition as a standard part of their physical health care.(5)

While not inevitable, having a physical disability can increase the risk of experiencing mental health problems and low wellbeing. There is consistent evidence of an association between physical disability and depression,(6) although Jenny Morris has pointed out that studies have sometimes presumed that having an impairment will cause a mental health problem.(7) Morris points out that many people with adult-onset physical disabilities have a quality of life equivalent to their non-disabled peers. While people with physical disabilities may experience pain and fatigue that negatively affects their mental health, she also locates some of the potential causes of their mental health problems in the disabling attitudes of non-disabled people, as well as the disabling environments they must face on a daily basis.

Individuals experiencing sensory impairments have also been found to be at a much higher risk of having mental health problems across the life course; however, the needs of this group tend to be underrepresented in research. We do know that deaf children are more likely to experience mental health problems: estimates suggest a 40% prevalence rate of mental health problems in deaf children, compared to 25% prevalence in children without hearing loss.(8) For older adults who are visually impaired, the prevalence of major depressive disorder (5.4%) and anxiety disorders (7.5%) is significantly higher compared to their normally-sighted peers. The most prevalent anxiety disorders are agoraphobia and social phobia.(9) Again, it is reasonable to conclude that many of the mental health problems experienced by people with sensory impairment arise from the social isolation they experience due to inaccessible environments.

People with learning disabilities have an increased risk of developing a mental health problem (between 25 and 40% of those with learning disabilities experience mental health problems)(10) due to social, economic, psychological and emotional factors as well as some biomedical factors. A 2007 study found that children with learning disabilities were at higher risk of exposure to social disadvantage, while lower exposure to social disadvantage reduced the risk of mental disorders between 33% and 51%, depending on the disorder. (11) This suggests that measures to reduce social disadvantage among children with learning disabilities could significantly reduce the prevalence of mental disorders in this group.

As evidenced by a 2015 report by Public Health England, children with learning disabilities, when compared with their non-disabled peers, are more likely to be exposed to a number of inequalities that are risk factors for mental health problems, including: living in overcrowded housing, living in housing in a poor state of repair and housing that was too cold in winter; being at increased risk of exposure to violence, including bullying, physical, sexual, emotional abuse or neglect; being less likely to have a close relationship with their mother; being more likely to be exposed to inconsistent and harsh parenting and more chaotic family environments; and being more likely to be exposed to a greater number and wider range of potentially adverse life events.(12)

For older people a particular mental health risk is loneliness, although this affects people with disabilities of all ages as well. Research commissioned by the Mental Health Foundation and Age Scotland in 2017 found that more than 100,000 older people in Scotland were “chronically lonely” even before the pandemic, and at that a quarter of older people said they experienced depression due to loneliness.(13) Loneliness is a risk to mental health and one of the leading public health challenges of our time. It can lead to stress, anxiety, depression, paranoia and cognitive decline including dementia, and it is a well-known factor in suicide. It can be both a cause and effect of mental health problems. The Office for National Statistics has found that two key risk groups for loneliness are:

- widowed older homeowners living alone with long-term health conditions, and
- unmarried ‘middle-agers’ with long-term health conditions(14)

It is clear that social care recipients and those who would benefit from social care are among the high-risk groups for experiencing loneliness which in turn can lead to mental health problems.

How social care can help to prevent mental health problems

When social care fulfils its aim to support people to live independently, stay socially connected and participate in community life, it can serve as an important means of preventing mental health problems. In order for social care to fulfil this aim, it is important that promoting mental wellbeing and preventing the negative mental health effects of inadequate social care are given due weight in the social care system.

Recommendation: The scope of future adult social care services should incorporate a mental health prevention function, providing emotional and social support and taking into account the negative mental health effects of lack of inclusion, participation and connectedness.

Recommendation: Assessments of need for social care should take into account the potential negative mental health effects of the absence of social care provision for each individual assessed.

In general, a review has found that there is good evidence to support empowerment strategies to improve mental well-being among disadvantaged groups such as women, older people and people at risk of HIV/AIDS.(15) This research shows that programmes employing an empowerment approach have had a positive effective on psychological well-being, self-esteem, self-confidence and sense of self-efficacy.

As loneliness has been identified as a risk factor, fostering social inclusion of people at risk of loneliness, for example older people and people with disabilities, would be one way of supporting their mental wellbeing and reducing their risk of developing mental health problems. For example, The Foundation's Standing Together Project was a three-year Big Lottery-funded initiative to address loneliness, social isolation and poor mental health in residents living in later life housing. Over the course of its delivery, 19 peer support groups, with a combined total of more than 300 participants, were set up in retirement and extra-care housing schemes around London. These groups were facilitated for six months by project staff, and 10 of the 19 groups sustained themselves beyond this period through investment by housing associations, volunteer support, and self-facilitation. The results of the project evaluation indicated that Standing Together groups were successful in fostering a greater sense of social connectedness among participants.

Recommendation: Specific interventions that support social connectedness among people with disabilities, long-term health conditions and/or frailty in later life should be readily provided.

Given the high prevalence of mental health problems among people with long-term physical health conditions, improving the detection and treatment of conditions such as anxiety and depression among this group would be likely to reduce the prevalence of mental health problems in this group as well as improve their overall health outcomes. For example, one study found that people with coronary heart disease who were offered stress management training with their cardiac rehabilitation programme showed reduced stress and improved clinical outcomes when compared to patients who received cardiac rehabilitation alone.(16) Mindfulness programmes have also been shown to have a positive impact on people with diabetes and people with chronic health conditions.(16)

Recommendation: Social care staff should be trained so that they can identify mental health need and refer their clients for appropriate support.

Loneliness in our care homes, particularly among people with mental health problems remains a real challenge. A study by the University of Bedfordshire found that 80% of people with mental health problems have felt lonely in their care home. Care settings must strive to improve the standard of social connectivity, not only through the provision of social activities but ensuring that staff have sufficient time to get to know and converse with residents.

Recommendation: Build relationships of care between care staff and older people through training and quality standards.

Conclusion

It is clear that the social care system can play a vital role in preventing mental health problems by improving social connectedness and participation. The scope of social care should incorporate this mental health prevention function so that it becomes a priority throughout the social care system.

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MND Scotland

MND
Scotland
Supporting people affected by **Motor Neurone Disease**

MND Scotland welcomes the opportunity to provide an open submission to the Adult Social Care Review. We have been engaging with the Scottish Government, MSPs and Scottish Parliament Committees over the last few years to highlight the problems in social care and the impact these have for people with Motor Neurone Disease (MND).

Motor Neurone Disease (MND) is a rapidly progressing, muscle wasting, terminal illness. MND stops signals from the brain reaching the muscles. This means the muscles start to waste and weaken, and eventually stop working. This may cause someone to lose the ability to walk, talk, eat, drink or breathe unaided. Some people may also experience changes which affect their behaviour and ability to think and plan. Not everyone will develop all symptoms and how it affects individuals can vary significantly.

There is currently no cure or effective treatment for MND and the average life expectancy from diagnosis is just 18 months. Almost 200 people are diagnosed each year in Scotland and there are around 400 people in Scotland currently living with MND.

*data from the Scottish MND Register.

Almost everyone with MND needs social care. As people with MND quickly become more and more disabled, they correspondingly need increased levels of care and more complex care. While we acknowledge that many people receive excellent social care, provision is patchy across the country and poorly resourced statutory services can be slow to respond to the rapid progression of MND.

Below we have outlined what we believe are the key issues affecting people with MND and their families, issues which are crucial to reimagining how social care can work for people with MND and other terminal illnesses in Scotland which we hope will be given consideration as part of this review.

Fast-track access to social care

People with MND and other terminal illnesses need fast and easy access to social care that fully meets their needs and can quickly change when more support is needed.

Local authorities follow national guidance on eligibility criteria to social care which sets out the time someone should wait based on any potential risks to them. The ‘critical’ and ‘substantial’ criteria within this do not explicitly reference people with terminal illness and practice appears to vary across local authorities in terms of whether or how they may prioritise someone with a terminal illness, within this existing framework. Feedback from social care staff suggests that prioritisation does not always happen or is difficult to achieve in practice as services may have competing priorities.

Long delays mean that by the time a care package is in place, the person with MND’s condition may have deteriorated so much that more care is already needed. Most local authorities are unable to provide information on waiting times specifically for people with a terminal illness but for those who do, it can take over 5 weeks for any care to be put in place.[1] Recent research carried out by MND Scotland found that as MND progresses and people need increased levels of care (from, for example, one carer once or twice a day to two carers four times a day) this takes even longer and is too often not put in place before the person dies, creating a huge burden for them and their family.

Anticipatory Care Plans (ACPs)

Anticipatory Care Planning is an essential tool for people with a terminal illness like MND and it must be embedded within social care including mandatory training. People with MND can lose the ability to communicate therefore it is essential that the wishes of the individual are easily accessible when providing care and support. Having an ACP in place early can help ensure that people are receiving person-centred care, with the opportunity to review their ACP as and when their condition deteriorates. Sadly, the outcome of MND is inevitable so ACPs for people with MND must note that, due to the rapidly degenerative nature of the disease, it is almost inevitable that a significant increase in care will be needed and this should be planned for.

Currently too many people with a terminal illness do not have these in place. A study led by Marie Curie found that 61% of those who died with an electronic Advanced Care Plan (Known as the Key Information Summary or KIS) died in the community compared to 30% of those who died without one. The chances of dying in the community were found to be 3.7 times higher for those with an electronic advanced care plan.[2]

The eKIS, in its current form, is too limited as only some GP practices will allow District Nurses to upload this vital information about patients. The system is not user-friendly and reliant on GPs updating information when they have time to do so. There is a huge

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[1] MND Scotland Freedom of Information request, 2018

[2] https://www.mariecurie.org.uk/globalassets/media/documents/policy/briefings-consultations/scotland-briefings/marie-curie-briefing-right-to-die-at-home-january-2020.pdf

need and demand for all Allied Health Professionals and others to have access to update the system.

Night-time and 24-hour care at home when needed

As MND progresses, those with the illness can be left unable to move, talk, eat, or breathe without help. Care all day and night becomes critical. Until very recently almost no-one with MND received night-time or 24 hour care. Due to the hard work of our Advocacy Team this is slowly changing. However, advocacy is not a long-term solution for a system that isn't working for people with MND. We believe that night-time and 24 hour care should be provided to people with MND who need it by incorporating the patient's wishes at each stage of their ACP rather than our Advocacy Workers having to advocate for them on a case-by-case basis.

This is equally true in care homes where night staff cannot always give people with MND the attention they need and many with the illness can find night-time particularly frightening. This is often due to their paralysis, as they are unable to press 'call' buttons or shout for help when they need it.

The biggest obstacle to people with MND accessing this level of care is cost. When care packages are assessed, people with MND can be told they are at the maximum level of their budget with very little room for flexibility. There needs to be a greater recognition in the budgeting process that caring for people with MND can become intensive but it is a terminal illness. This level of care should not be seen as a luxury but as a right. Without it, people with MND are at risk and their families face potential burn-out caring 24/7.

Practical support for Self Directed Support

Self-Directed Support (SDS) has the potential to provide solutions in social care to help people with MND. We have seen examples of how SDS can be used to provide personal assistants and pay family members to look after their loved ones.

In Aberdeenshire, Cornerstone helped a family to facilitate a really good package of SDS care which suited both the person with MND and their family. The carer had lots of support in place, including respite and was able to get help for caring through Personal Assistants. Her son gave up his job to care for his father at night and was paid to do this through SDS. While this is a good example of how SDS can work well, we know from other people that they are not always given enough information and support on how SDS works and many say they are actively advised against choosing SDS. Some carers have been devastated to learn only after the death of their loved one that they could have employed a family member to provide some of the care.[3]

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[3] MND Scotland Feasibility Study, Dias, 2018 (Internal Report).

A wider report on experiences of SDS by The Health and Social Care Alliance, published in October 2020, also made some key recommendations which we believe are vital for people with MND who choose the SDS route.[4]

Regularity of care workers

High staff turnover and high levels of sickness absence in the care sector mean that care is not always delivered consistently. Different care workers turn up on different days and it can leave a person feeling unsettled by the constant change.

Building relationships with (and between) care workers is important for the cared for person as it helps build trust between the care workers and cared for person. Most importantly, it creates a safe environment at home where people can receive the best care.

In our research, which looked specifically at the key issues with social care for people with MND, one family recalled how they had 69 different carers in 11 months. [5] This was particularly distressing for the family who regularly opened their door to strangers who were there to carry out personal care.

Finally, without MND training, informal carers/family members can provide invaluable ‘training’ to care workers on what the person with MND needs as they are providing it 24/7. This is impossible if care workers keep changing and made even more difficult in the confines of a limited 15 minute care visit.

An end to time and task commissioning

Time and task commissioning needs to be replaced with a person-centred, rights-based, outcomes focused commissioning process for social care. This should also include specific commissioning arrangements to support fast access to responsive and flexible social care for people with complex palliative care needs.

Too often, care is commissioned using the “time and task model”. This is usually 15-minute visits which gives little time for interaction with the carer and the care worker and makes the vital ‘training’ described above even more challenging. Given the short and restricted time slot, the care worker is solely focused on the task they have been assigned to do. This also means there is no time to build a relationship between the care worker and cared for person which can be really crucial for people who might feel uncomfortable receiving personal care from ‘a stranger coming into the house’.[6] For

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[4] Health & Social Care Alliance report ‘My Support, My Choice on People’s experience’s of Self Directed Support’, October 2020 https://www.alliance-scotland.org.uk/blog/news/my-support-my-choice-major-report-on-peoples-experiences-of-self-directed-support/#expanded

[5] MND Scotland Feasibility Study, Dias, 2018 (Internal Report).

[6] Ibid

people with MND this can be even more challenging when they are unable to communicate verbally with their care worker.

15-minute care visits are simply not long enough to support people with MND, many of whom have complex care needs including wearing specialist ventilation masks which help them to breathe, and essentially stay alive.

In 2018, a Freedom of Information request found that one third of Scottish councils commissioned 15-minute visits for the provision of personal care.[7] This is exacerbated by the lack of funding for local authorities in the provision of social care.

While the impact of short visits is detrimental to the cared for person and their family, it can also have a huge impact on the care worker too. Previous research has suggested that these models of care provision can be stressful for care workers, who are sometimes required to rush between appointments. A report by the Coalition of Care Providers in Scotland found that short visits were a problem for some care workers. In the survey, one care worker reported:

"Some folk only get allocated a certain amount of time and we go in and say 'we can't possibly do it in that time', and we're running over our time with them. We'll keep phoning and saying that 'they need more time', so (our team leader) phones social work, and hopefully it gets allocated. If we don't say anything, it won't get changed. Other service users get upset because they think you have forgotten about them and it can take the rest of the day to catch up."[8]

Another commented:

"We did have a home care contract, a large home care contract which we don't have anymore, and that involved call monitoring by the minute, so we were getting paid literally by the minute. That wasn't fair to colleagues, because of pressure that they were under. It's not helping someone live a valued life."[9]

A sustainable care workforce

All of the needs highlighted above, require much greater capacity in the social care sector. To achieve this, we need an ambitious strategy for the development of a sustainable care workforce which includes:

Making care work an aspirational career choice with opportunities for career progression, fair pay and conditions

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[7] Leonard Cheshire Report https://www.theguardian.com/society/2013/oct/07/15-minute-care-visits-too-short-charity#:~:text=Leonard%20Cheshire%20said%20some%20local,her%20not%20to%20talk%20publicly.n 2018

[8] https://www.fairworkconvention.scot/scr/SCT02196524681-04.htm

[9] Ibid

Care is not viewed as a viable “career choice” because there is no set path for career progression. In practice, this leads to people being trained up and leaving their roles quickly. The pay which current care workers receive is on a par or, in some cases, lower than supermarket workers.

We would like to see social care become an aspirational career choice, like working in the NHS. There should be clear journeys for those who wish to progress and undertake training to enhance their knowledge and skills.

According to the Coalition of Care Providers in Scotland, the introduction of the National Living Wage has faced “significant operational challenges causing financial difficulties for providers.”[10]

According to their research, “implementation in workplaces has resulted in pay compression with workers in supervisory positions or with greater experience finding themselves paid almost exactly at the same level as new starts. Ultimately, “the wage floor has been increased as a result of introducing the Living Wage in care, no mechanism has been devised for undertaking job evaluation and for upgrading the wages for those with greater skills and experience. This has caused difficulties in recruiting and retaining senior posts and managers, with existing workers reluctant to take on additional responsibility for limited financial reward.”[11]

Workforce training

Caring for someone with MND can be incredibly complex. Care staff need the appropriate skills, training and time to deliver specialist care to people with MND at home and other settings. Staff with these skills are not always available and temporary solutions, such as using a family member as the second ‘care worker’, or even local health professionals such as District Nurses, are being used to fill a shortage in care on a long term basis

The problem with specialist training starts at the recruitment stage. Staff are trained at basic levels to deliver basic care very quickly. There is very little time for staff to undertake additional training because of the shortages. Entering social care at entry level means low pay in return for delivering an extremely important service with staff feeling overwhelmed and undervalued.

Long term strategy on Recruitment and Retention

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[10] http://www.ccpscotland.org/wp-content/uploads/2018/11/Univ-of-Strathclyde-Living-Wage-implementation-research-November-2018.pdf

[11] Ibid

A report by the Care Inspectorate and the Scottish Social Services Council published earlier this year has shown that the number of vacancies in the sector remains at 38%, the same as the previous year.[12]

Care companies/agencies are in a constant "recruitment cycle"[13] with no long term strategy on how to retain staff. They expect to spend money to train staff knowing that staff will eventually leave, only for them to have to recruit again. It is costly and ineffective. People leave the care worker role because the role/responsibility vs the pay and reward does not match up. Too often we are told that staff can be paid the same or more, but with better pay and conditions, in supermarkets. Staff are told there is no time for training because they are busy working (sometimes overtime) to cover shifts for those who are off sick.

The Health and Care (Staffing) (Scotland) Bill has set out improvements in this area but recent vacancy levels are showing that more needs to be done to recruit and retain staff. In addition to these challenges, funding is undoubtedly the biggest challenge in transforming care.

Postcode lotteries

We have also found, through our research and feedback from our advocacy workers, that the quality of social care, and how quickly it can be accessed can be determined by where you live. Our research established that this was particularly difficult in rural areas and cities like Edinburgh.

There are different reasons for a lack of care being available in both rural areas and cities but the key problem is the same: long-term recruitment and retention of the workforce. The geography of rural areas means care workers have to make long journeys from client to client, sometimes unpaid, with their clients sometimes feeling their visit is shortened as a result. Due to the lack of care provision in rural areas, some people with MND's only option is to source care through SDS. However, recruiting people willing to take on the work can prove impossible, leaving families struggling to cope on their own. In a city like Edinburgh, it can be a struggle to survive on low pay, and it is less appealing when there is a greater choice of work available with better pay and conditions.

Unless there is recognition of these issues, many families will continue to be left to plug the gaps themselves. Allowing family members to take on huge caring responsibilities is neither a temporary nor long term fix for the problems in the social care system.

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[12] https://www.careinspectorate.com/images/documents/4766/Joint%20CI%20&%20SSSC%20staff%20vacancies%20in%20care%20services%202017.pdf

[13] Ibid

We know that this burden is very difficult for carers who suffer under the extreme pressure of caring for a loved one with MND. Many have had to give up much needed paid employment and we know of young carers of people with MND whose education has been seriously impacted. In addition, carers' own physical and mental health can decline, and coupled with their grief, this can be very difficult to bear. It is not sustainable for family members to provide such complex and intense care when a skilled workforce could be doing this instead.

Investment in social care and the 'Neurological Workforce'

The Accounts Commission backed Scottish Care's view that the current system of social care in Scotland is "unsustainable", reporting that an additional £667m would be needed by 2020 just to maintain current levels and called for a "frank and wide-ranging" debate on the issue.[14]

Last December, the Scottish Government Neurological Framework for Action showed promising signs for the development of a neurological workforce and social care should be key to this ambition. There are 1 million people in Scotland living with a neurological condition, and those with MND, will rely on a robust neurological workforce.

Commitment 16 of the framework sets out the key objectives as follows:

"We will discuss a national or regional approach to workforce planning with stakeholders, to test the extension of existing workforce planning tools and their application to the wider neurological workforce in Integration Authorities and NHS Boards; supporting review of job plans for Consultant Neurologists and Neurophysiologists to make posts more attractive, while recognising the national approach to consultant contracts. We will support a programme of innovation and the development of a phased approach to implementation where emerging evidence supports changing models of workforce, such as testing new roles of Advanced Practice for nurses, allied health professionals, general neurology keyworkers and healthcare scientists working in neurological care and support services."[15]

This will be a key development for the future of the neurological workforce and one which we welcome. However, we must ensure that staff are adequately trained, paid appropriately and supported in their roles.

We believe that any review of Adult Social Care must include the ambitions of the Neurological Framework and its commitments to improving care for people with neurological conditions in Scotland.

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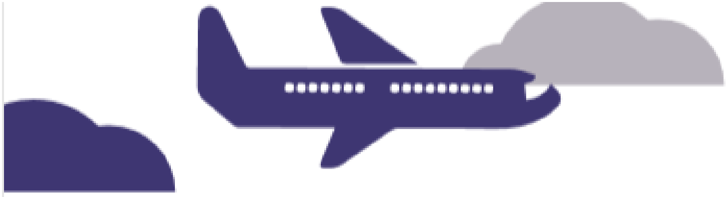
[14] https://www.audit-scotland.gov.uk/uploads/docs/report/2016/ir_181205_social_work.pdf

[15] https://www.gov.scot/publications/neurological-care-support-scotland-framework-action-2020-2025/

About MND Scotland

MND Scotland is the leading charity in Scotland providing care and support to people affected by Motor Neurone Disease (MND), as well as funding vital research into finding a cure. We campaign on behalf of people affected by MND, and raise awareness of the disease, to ensure their voice is heard. People with MND are at the heart of everything we do, and we are committed to improving the lives of those affected now and determined to find a cure for those affected in the future.

Mobility and Access for Scotland (MACS)

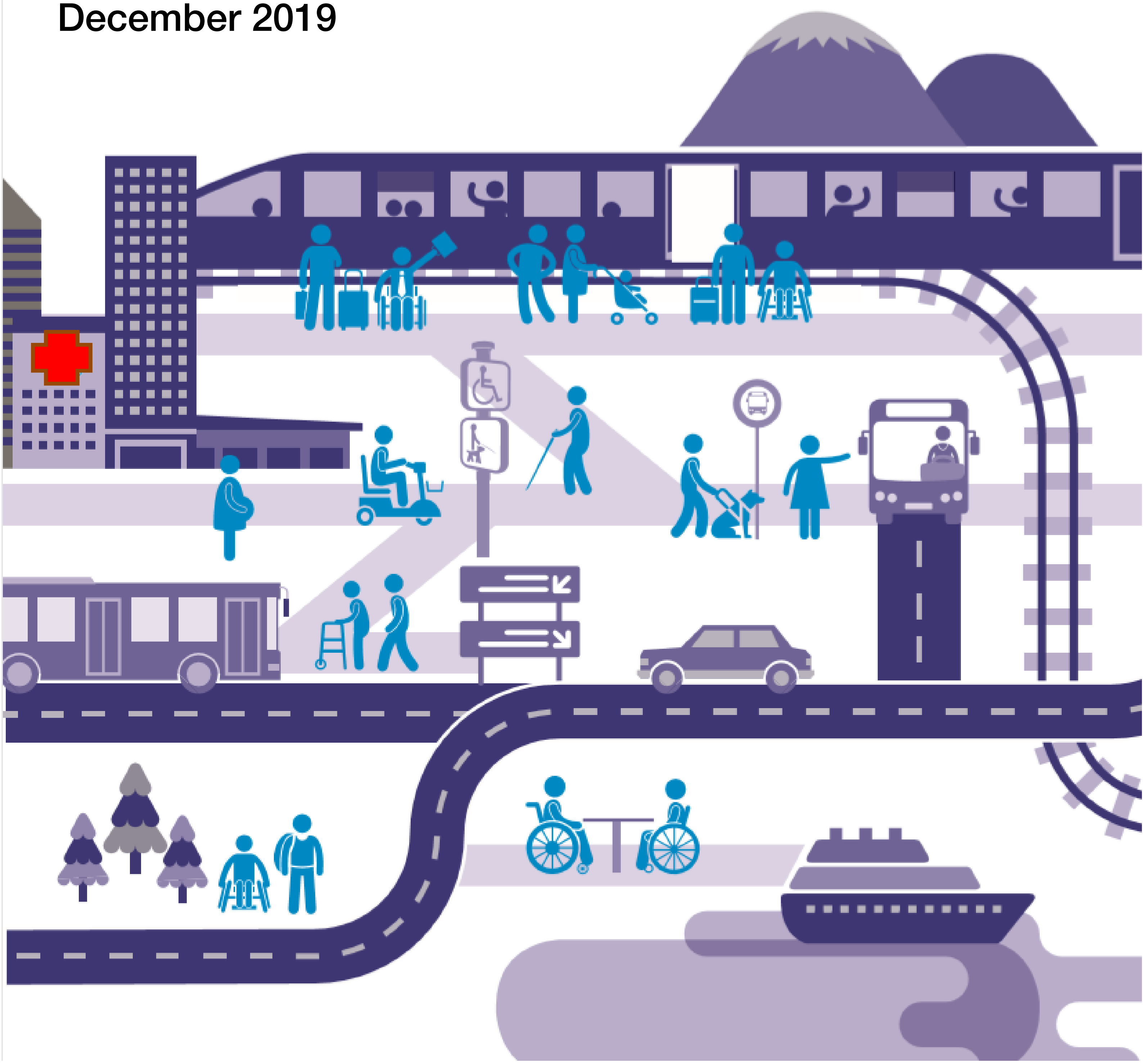


MACS
Advising Scottish Ministers
on Accessible Travel

Mobility and Access Committee for Scotland

Report: Transport to Health and Social Care

December 2019



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1. MACS National Convener's Introduction

I would like to take this opportunity to formally thank everyone who has been involved in our work over the past nine months to help us gain a better understanding of what works and what poses barriers for individuals accessing health and social care services.

This is the start of MACS' journey in this area and our findings stand us in good stead to have further dialogue, give advice to Scottish Ministers and to ensure the voices of disabled people and older people in Scotland are heard. It is our intention to use these findings to advocate for the changes needed to remove some of the barriers disabled people and older people face when accessing health and social care facilities. These are long standing issues.

MACS has reached out to several organisations and many individuals and asked them to share their experiences about the challenges they face when booking and getting to and from medical appointments.

In particular, we would like to thank Emma Scott, Disability Equality Scotland; Emer Murphy and Rachael Murphy; Community Transport Association in Scotland; the members of Badenoch and Strathspey Access Panel; Lochaber Access Panel and Voluntary Action Lochaber.

I would also like to thank my MACS Transport to Health and Social Care working sub-group, who have worked tirelessly over the last nine months, committing a great deal of their personal time to progress an agenda that they are passionate about and committed to advocating the need for change, the need to do things differently, and to allow the voices of those who use the services to be at the centre of designing these services around their needs.

Only when we take this approach will we have a chance of getting service design right and fit for purpose. This co-production approach fits with the ethos of "nothing about us without us".

Our "phase one" work has made recommendations based on all our work over the last nine months. Some of these recommendations are proposals to revisit past initiatives that had to stop due to sustainability of funding and some may be seen as ambitious and transformational.

We feel that this level of change is needed to start to make 'in roads' on this long-standing issue.

This change is needed to assist with delivering on the priorities of the imminent revised National Transport Strategy, the Fairer Scotland for Disabled People ambitions, and to ensure that those who need assistance to get to their health and social care appointments are not left to struggle and navigate what can be complex and stressful arrangements, before even reaching the medical facility for their treatment.

During our work we reflected on the 2011 Audit Scotland Report “Transport for Health and Social Care”[1] and we were disappointed to find that not much has changed since this report and that many of our recommendations replicated those made eight years ago by Audit Scotland.

In producing this report, of our phase one work, we ask that those who can, take away these messages, and we have no doubt that the personal testaments around the impact the current practices and barriers have on people’s lives will energise the agenda in the knowledge that we need to make things better.

For those who can, please consider these recommendations and work towards doing your bit, even if it’s just **one thing** that you focus on.

If everyone who reads this report, and those who have been involved to date, take away **one thing** to advocate and progress, we can start the change process and re-energise conversations.

Yours sincerely,

Linda Bamford
National Convener
Mobility and Access Committee for Scotland (MACS)

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[1] Audit Scotland Report

2. Executive Summary

During 2019 the Mobility and Access Committee for Scotland (MACS) undertook research to explore the transport barriers faced by disabled people and older people when accessing health and social care appointment and facilities. This work was undertaken to gather insights, find out about initiatives that worked well, and gain a better understanding of the issues and barriers facing disabled people and older people when accessing these essential services.

This research and evidence gathering involved a Transport to Health and Social Care roundtable discussion, hosted by MACS with assistance from Transport Scotland, and independently facilitated by the Scottish Government. This event brought together around 40 stakeholders, including individual disabled people, Disabled People's Organisations (DPOs), Community Transport Association (CTA), Transport Scotland (TS), Regional Transport Partnerships (RTPs), representatives from NHS Boards, Access Panels and Local Authorities (LAs) (detailed within **Section 5** and **Annex A**).

We also undertook an extensive evidence gathering exercise capturing the voices of over 1000 disabled people (**Section 4**).

This **MACS Report: Transport to Health and Social Care** is a summary of the findings of this work, including **9 key issues** clustered around five themes (**Section 6**), and **27 recommendations** to Scottish Ministers and others (**Section 8**).

Some of these key findings are:

- From MACS findings during research and evidence gathering, it is apparent that little or no progress has been made on Transport to Health and Social Care since the Audit Scotland Report in 2011. Indeed, many of MACS recommendations from this phase one work reflect those previously made by Audit Scotland.
- There is growing concerns amongst disabled people and older people in relation to the transport barriers accessing Health and Social Care appointments and facilities (this is evidenced in the second Disability Equality Scotland (DES) Poll run in August 2019, which attracted a much higher return rate than the initial poll, 849 people responded with 98 per cent of those responding stating that they faced transport barriers accessing health and social care appointments.
- There needs to be better joined up planning and working between the NHS, Local Authorities and Scottish Ambulance Service, Regional Transport Partnerships and Community Transport providers should also be central to these discussions.
- There is an absence of, or very limited/poor methods of, signposting to alternative transport organisations, with the onus left with patients to navigate complex arrangements.
- The Scottish Ambulance Service (SAS) doesn't have the capacity to meet demand and is filling the gap caused by poor public transport options.
- There is a gap in public transport, due to a lack of options (including accessible and affordable options) for some, especially in rural areas, and the SAS does not have the capacity to meet this demand.
- SAS' changes to the Patient Needs Assessment (PNA) application, changes to the escort eligibility criteria, daily demand capping and the loss of the SAS voluntary car service, have significantly reduced the number of journeys/bookings the SAS can accept. People are struggling to find suitable and affordable alternatives.

- Bus timetabling and routes don’t meet people’s needs and fail to connect communities to health and social care facilities.
- There are issues with the first and last part of the public transport journey, i.e. from the house to the bus stop and from the bus stop to hospital/medical facility, as well as the distance between departments within some hospital campuses/sites (i.e. the Queen Elizabeth University Hospital, Royal Infirmary Edinburgh, Glasgow Royal Infirmary).
- NHS websites tended to signpost to Traveline Scotland or Google maps, neither of which are particularly good for identifying accessible transport options needed for planning a journey. The accessibility of these websites is poor for people with visual impairments and those using screen readers.
- The planning and design of buses, bus routes, bus stops, information points, and public toilets are not geared towards disabled people and older people using public transport to get to hospital and other essential services.
- Disabled people and older people are not given enough influence over how transport to health and social care facilities works to tackle any difficulties they experience.
- The CTA's assistance with transport to health and social care appointments is not acknowledged and recognised and they are having to refuse some requests for transport to health and social care appointments from people within their communities, who have little or no alternatives.
- The reimbursement rate for CTA volunteer drivers is unaffordable to many, particularly for people in rural areas where distances are longer, as costs are based per mile.
- Many disabled people and older people cannot travel independently by bus (due to mobility, confidence, or medical condition).
- Coaches on registered bus routes have affected people’s choices and eliminated bus travel as an option to get to medical appointments due to accessibility issues/barriers linked to the design of the coach.
- Wheelchair spaces can’t be booked on buses. Therefore wheelchair users have no guarantee of being able to use bus services.
- For many people on low income the “Help with Health Costs Scheme” and NHS reimbursement schemes don’t work because the schemes do not meet their needs or take account of their individual circumstances.
- NHS Reimbursement schemes are complicated and over bureaucratic.
- The National Entitlement Card (NEC) Scheme is not flexible enough and the ‘plus a companion’ facility could be widened.
- The group agreed that many people who have a National Entitlement Card (bus pass) cannot use it, as there are poor bus services (or no accessible buses) in their areas as many of these routes are not commercially viable and services have been withdrawn.
- Hospital parking costs (even for Blue Badge holders) is unaffordable.

3. Background: MACS

MACS is an advisory non-departmental public body. The Committee has 14 members appointed by the Cabinet Secretary for Transport, Infrastructure and Connectivity in the Scottish Government. The overarching remit of the Committee is:

- To give Scottish Ministers advice on aspects of policy, legislation and practice affecting the travel needs of disabled people.
- To take account of the broad views and lived experiences of disabled people when giving advice.
- To encourage awareness amongst disabled people in Scotland of developments which affects their mobility, choices and opportunities.
- To work closely with the Scottish Government and ensure our work programme complements the work being undertaken by the Disabled Persons Transport Advisory Committee (DPTAC), the Equality and Human Rights Commission and other organisations, voluntary and statutory.
- To promote the travel needs of disabled people with designers including transport planners and operators so that these are fully taken into account in the development of vehicles and infrastructure and delivery of services.
- To monitor and evaluate the effectiveness of our work against the above aims and objectives in improving travel opportunities for disabled people in Scotland.

To deliver on this remit MACS works across Ministerial portfolios and has recently been more engaged with, not only the Transport portfolio, but also the Health and Older People and Equalities portfolios.

During MACS external engagements, as part of our remit to seek the views and lived experiences of disabled people, we are frequently being made aware of issues and barriers faced by disabled people and older people when accessing health and social care, using either transport provided by SAS, Hospitals, Local Authorities and/or public transport in general.

These experiences cited problems not only with the **A**vailability, **A**ccessibility and Affordability of transport (the triple **A** check) but also with the availability and accessibility of the information provided about services, the eligibility criteria for transport (particularly with SAS) and/or the booking processes.

Due to the above issues, MACS agreed to engage further on Transport to Health and Social Care.

4. Evidence Gathering

To complement and prepare for the roundtable discussion, MACS provided a briefing paper to all participants. This summarised the findings of the engagement and research work undertaken by them in advance. This included extensive survey work, desk based research, and attending external meetings and workshops, as discussed below.

In November 2018 Disability Equality Scotland (DES) undertook a weekly poll of their membership on behalf of MACS, themed around Transport to Health and Social Care. 28 returns were received. Some respondents were extremely emotive in the description of the impact the issues accessing transport to health were having on them and on many disabled and older people in Scotland. This survey work formed a prelude to a far bigger exercise to gather the views of disabled people carried out by DES, which is also discussed below.

In January 2019 MACS raised some of these issues with the Minister for Public Health, Sport and Wellbeing, Mr Joe Fitzpatrick, who acknowledged them, agreed to give them focus, and asked MACS to gain further insights to update him.

MACS asked DES to re-run this poll in August 2019 and found a similar position with no change in terms of the barriers.

However, this follow up poll attracted a very much higher return rate of **849** responses with **98 per cent** of respondents confirming they had encountered problems with either booking or getting transport to healthcare facilities. This poll again captured many emotive case studies describing the impact of not being able to book or access transport to attend medical and social care appointments.

In response to the above issues MACS convened a working sub-group to take a deeper dive into Transport to Health and Social Care, and agreed to collate some evidence prior to hosting a roundtable event with key stakeholders to discuss their findings.

CTA, which is the national charity that represents and supports providers of community transport, also carried out survey for MACS to gather evidence.

The CTA represents over 130 charitable organisations that offer transport in Scotland.

For those who cannot access public or private transport, community transport may be the only way they are able to attend health appointments. The research investigated barriers and challenges associated with transport to health journeys administered by community transport operators in Scotland. Some of the key research findings are shown below.

Evidence Gathering Box 1: **CTA research findings**

The survey found that:

- 79% of community transport organisations responding undertook transport to health
- 26% of community transport organisations responding received funding specifically to undertake transport to health
- 74% of community transport organisations responding, who receive funding to undertake transport to health, do not consider the funding to be adequate
- 61% of community transport organisations responding said they had received requests for transport to health appointments that they have had to refuse
- 18% of community transport organisations responding had received a request from their local authority to administer transport to health journeys
- 32% of community transport organisations responding had received a request from NHS Boards to administer transport to health journeys
- 68% of community transport organisations responding had received a request from patients themselves to administer transport to health journeys
- 61% of community transport organisations responding had transport to health schemes run by volunteer drivers

Resource barriers mentioned by community transport operators included administration, volunteers, lack of existing data and research and marketing approach. Systematic inconsistencies identified included accountability, management and administration, and funding.

The researcher made the following policy recommendations:

- Notable discrepancies exist in the way community transport operators are funded and commissioned to administer transport to health journeys. This tends to be a very grey area often disadvantaging community transport operators. The researcher recommends a standardised system/framework that employs a level of flexibility, thus can be applied on a regional or case by case basis. Purposefully, this will offer a level of protection to community transport operators.
- The researcher recommends a synergised approach to management and administration of transport to health journeys. The findings suggest that community transport operators are under resourced, which is evident by the refusal rate of transport to health requests received by organisations. A level of support is required from NHS/SAS to effectively and efficiently administer this service.
- Many community transport operators do not specifically label their transport to health activity, despite the fact they are executing multiple journeys every day, week and year. This results in inadequate recognition from Health Boards, thus impending their ability to be funded appropriately. The researcher recommends that community transport operators adapt a ‘marketing strategy’ that highlights the amazing work that they do. Effectively, this is a marketing ploy to gain the recognition they deserve.

MACS also undertook a review of available information about transport to health on NHS websites.

Evidence Gathering Box 2: **Findings of NHS website checks**

Key findings:

1. Overall the NHS websites tended to signpost to Traveline Scotland or Google maps, neither of which are particularly good for identifying accessible transport options needed for planning a journey. This includes failing to respond to the needs of people using screen readers to understand what the public transport options are. Where signposting to alternative transport providers was included, this gave no information other than the name of the organisation. For those needing to plan their journey around their accessibility needs, Traveline cannot currently accommodate this request in the journey planning function.

2. The overall accessibility of the maps provided or links to Google maps was poor and would not make planning a journey easy. The lack of phone numbers makes it even harder for those not digitally connected to attempt to use this information to plan a journey.

3. The information on travel reimbursement was inconsistent and excluded the reimbursement towards the costs for private taxis, even though in some areas (rural) this was the only option available. Many NHS Board and hospital websites gave no information at all on travel options or reimbursement of costs for those on low incomes. Note: The lack of information on reimbursement for taxi journeys may be because currently the NHS doesn’t appear to reimburse taxi fares, even though this may be the only way some people can reach their appointments.

4. Individual NHS Boards have websites for each of their hospitals but the information they publish on these websites for their facilities is not consistent.

5. Most sites don’t provide information on the bus stop location, its distance from the main entrance or the road/pavement gradient to make it easier for patients to prepare and plan the journey.

6. MACS welcomes the NHS Greater Glasgow and Clyde (Stobhill Hospital's) initiative, which states that concessionary cardholders can show their hospital appointment cards to get concessionary travel before 9 am.

7. MACS found every site to be different and that it was not always apparent where information on travel to hospital or reimbursement of costs could be found. MACS suggests that it would be better if headings and information could be standardised on NHS websites and the information on travel cost reimbursement made more prominent.

This systematic review work also identified issues around **a**vailability, **a**ccessibility and **a**ffordability. Some examples are provided below:

Availability:

- There needs to be better joined up planning and working between the NHS, Local Authorities and SAS.
- There is an absence of, or very limited/poor methods of, signposting to alternative transport organisations, with the onus left to patients to navigate complex arrangements.
- NHS websites tended to signpost to Traveline Scotland or Google maps, neither of which are particularly good for identifying accessible transport options needed for planning a journey. These websites also have poor accessibility features for people with visual impairments.
- The SAS doesn't have the capacity to meet demand and is filling the gap caused by poor public transport options.
- There is a gap in public transport due to a lack of options (including accessible and affordable options) for some, mainly due to rurality, and the SAS does not have the capacity to meet this demand.
- The SAS changes resulting in stricter application of the Patient Needs Assessment (PNA), changes to the escort eligibility criteria, daily demand capping and the loss of the SAS voluntary car service, has significantly reduced the number of journeys/bookings the SAS accept. People are struggling to find suitable and affordable alternatives.
- Bus timetabling and routes don't meet people's needs and fail to connect communities to health and social care facilities.
- The CTA's assistance with transport to health and social care appointments is unrecognised and they are having to refuse some requests for transport to health and social care appointments from people within their communities, who have little or no alternatives.

Accessibility:

- Many disabled people and older people cannot travel independently by bus (due to mobility, confidence, or medical condition).
- The planning and design of buses, bus routes, stops, information points, and public toilets are not geared towards disabled people and older people getting to hospital and other essential services.
- Coaches on registered bus routes have affected people's choices and eliminated bus travel as an option to get to medical appointments due to the inaccessible design of the coach.
- Wheelchair spaces can't be booked on buses therefore wheelchair users have no guarantee of being able to use bus services.

Affordability:

- For many people on low incomes the Help with Health Costs scheme and NHS reimbursement schemes are complicated and forms difficult to complete.
- The National Entitlement Card Scheme is not flexible enough and the ‘plus a companion’ facility could be widened.
- Many people who have a National Entitlement Card (bus pass) cannot use their bus pass, as there are poor bus services (or no accessible buses) in their areas as many of these routes are not commercially viable and services have been withdrawn.
- Hospital parking costs (even for Blue Badge holders) are unaffordable.
- The reimbursement rate for CTA Volunteer drivers is unaffordable, particularly in rural areas where distances are longer and costs are based per mile.
- Special permission has to be sought for use of taxis or for payment of a companion's travel costs.
- Where a hospital appointment requires an overnight stay (more prevalent for patients from rural areas and the Islands) the cost to the individual for accommodation is often unaffordable.
- For Islanders who require frequent trips to the mainland for medical appointments, the ferry travel is often unaffordable and current discount and voucher schemes don’t eliminate the financial burden of these costs.

On top of regular engagement with disabled people, MACS undertook a variety of other engagement work on this topic in advance of the roundtable discussion, including the following:

Engagement with Audit Scotland (AS):

In 2011 AS published a report on Transport to Health and Social Care[2] with recommendations on how to improve the whole health and social care system and make it work efficiently. Unfortunately the progress from these recommendations are either minimal or non-existent.

The key messages from the 2011 report being:

Transport services for health and social care were fragmented and there was a lack of leadership, ownership and monitoring of the services provided. The Scottish Government, Regional Transport Partnerships, councils, NHS boards and the ambulance service were not working together effectively to deliver transport for health and social care or making best use of available resources.

From the limited information available at the time it was identified that over £93 million was spent in 2009/10 on providing transport to health and social care services. This was a considerable underestimate as data on costs, activity and quality was poor. As such, the public sector would find it difficult to make efficient and effective use of available resources without this basic information.

Joint working across the public sector and with voluntary and private providers was crucial for the successful and sustainable development of transport for health and social care. Improved joint planning could lead to more efficient services. There was scope to save money by better planning and management of transport for health and social care without affecting quality. Pilot projects showed scope for efficiencies but these lessons have not been applied across Scotland.

Reducing or removing funding from transport services had a significant impact on people on low incomes, older people and people with ongoing health and social care needs. But the potential effect of changes to services was not often assessed or monitored and alternative provision was not put in place.

The public sector needed better information on individual needs and on the quality of the transport services they provide.

In 2011 Audit Scotland made key recommendations, including that the Scottish Government and partners should:

- Work together to clarify responsibilities for planning and delivering transport for health and social care and how these link together.
- Partners (councils, NHS boards, Regional Transport Partnerships and the ambulance service) should: collect routine and accurate data on the activity, cost (including unit costs) and quality of services they provide and routinely benchmark performance and costs to ensure resources are used efficiently.
- Assess the impact of proposed service changes on users and other providers of transport.

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[2] AS report on Transport to Health and Social Care

- Ensure that staff have up-to-date information about all transport options in their area and provide better information to the public about available transport options, eligibility criteria and charges.
- Integrate or share services where this represents more efficient use of resources and better services for users, including considering an integrated scheduling system.
- Ensure that transport for health and social care services is based on an assessment of need and that it is regularly monitored and evaluated to ensure value for money.
- Use the AS checklist detailed in **Appendix 3** of the full report to help improve planning, delivery and impact of transport for health and social care through a joined-up, consistent approach.

Engagement with Grampian Health and Transport Action Plan:

To network and discuss issues concerning travelling with confidence. This included attending workshops with service providers and service users to openly discuss the transport barriers people faced getting to and from hospital appointments, including their lack of confidence using a public transport system that was not fully accessible and unreliable.

Meetings with Access Panels:

This including the Convener meeting with Badenoch and Strathspey Access Panel (BaSAP), Lochaber Access Panel (LAP) and Voluntary Action Lochaber (VAL) to discuss local work undertaken around Transport to Health and Social Care. The Access Panels and voluntary Action Lochaber shared their experiences in both running a community transport scheme that was taking people for medical appointments and local social care facilities (BaSAP), and assisting people to get transport to their appointments by signposting to other organisations of being the conduit between the individual and the SAS to secure transport on medical grounds (LAP and VAL).

Engagement with the Scottish Ambulance Service:

MACS attended the SAS consultation event on patient transport service vehicle design. They also invited the SAS, Head of Patient Transport Service to a MACS Main Committee meeting.

The Convener attended the Disability Equality Scotland (DES) and SAS workshop in November 2019 to obtain an update from the SAS on their operating model for scheduled care services and also to listen to the voices of those in attendance (disabled people) and hear first hand of their experiences trying to book and use transport provided by the SAS.

Engagement with the Equality and Human Rights Commission (EHRC):

Engagement and liaison with the EHRC falls within MACS overarching remit. As part of their work on Transport to Health and Social Care, MACS continues to link with the EHRC around Strategic Goal 1 - Priority Aim 2 of their strategy for 2019-22[3].

Engagement with the Scottish Poverty and Inequality Commission:

MACS continued to link with the Poverty and Inequality Commission's work around Transport and Poverty in Scotland[4]. This links with MACS' triple **A** check for transport i.e. that it is **A**ccessible, **A**vailable and **A**ffordable.

Engagement with the draft National Transport Strategy (NTS2)[5] and the Strategic Transport Projects Review (STPT2)[6]:

MACS remained connected to the above emerging strategies and policies at a strategic level, messaging on the need for a transport system that reduced inequality and provided fair, affordable and easy access for all, regardless of ability, where people lived (urban, rural, Islands) or their level of income.

This messaging took opportunities to identify the current transport barriers accessing health and social care and asked for this to be an integral part of transport strategies and policies moving forward.

Engagement with Transport Scotland's Accessibility Team

Through the Accessible Travel Framework Steering Group meetings and through regular update meetings, MACS advocated for Transport to Health and Social Care to be considered as a priority area for Transport Scotland's Accessibility Team moving forward and for this to be planned for and incorporated within the Annual Delivery Plans from 2020 onwards.

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[3] EHRC Strategic Plan
[4] Poverty and Inequality Commission report on Transport and Poverty in Scotland
[5] The National Transport Strategy
[6] The Strategic Transport Projects Review

MACS has also undertaken a significant amount of desk-based research such as collating comments on transport to health submitted via the "Care Opinion" website[7] and examining relevant reports such as that produced by the Department for Transport on its Total Transport pilot initiatives[8].

***Evidence Gathering Box 3:* Total Transport**

Total Transport is about finding ways of commissioning public sector funded transport so that passengers get a better service with less duplication of resources. This can include services like non-emergency patient transport, adult social care transport and home to school transport.

These are all similar, provided in the same geographical area and often carrying the same passengers at different times. Department for Transport (DfT) allocated £7.6m to 37 separate schemes run by 36 local authorities in England to pilot Total Transport solutions in their areas. These pilots were focussed on rural areas. A number of key themes emerged from the pilots:

- Tackling integration involves a degree of local knowledge;
- While some approaches may be transferable, there is no easy 'one size fits all' solution;
- Constructive local engagement is important and it can take time to find the right person to engage with in each organisation;
- There is more to do to unlock the opportunities for integration between transport provision in the health sector and local authorities;
- Financial savings are difficult to assess as many participants did not have access to reliable 'before' data, although some savings do appear to have been achieved;
- While the actual savings achieved so far may be considered relatively low, the process has led to improved services in some areas at similar cost, and uncovered potential savings and benefits for the longer term;
- The benefits of Total Transport are a mix of short, medium and long term. Some of the bigger savings will take time to be delivered and benefits from larger scale changes can take time to bed down;
- Some of the delivery models proposed do not easily fit the existing legal framework of bus services, taxis and private hire vehicles and have required careful development to allow them to operate;
- The process of bidding for funding acted as a stimulus to think about provision in a different way and gave the successful local authorities the resource to look at new ways of working that they would not have had the space to do under 'business as usual'.

All of this work, taken together with the record of the Roundtable at **Annex A**, informs the recommendations of MACS to Ministers and other organisations on this topic (**Section 8**).

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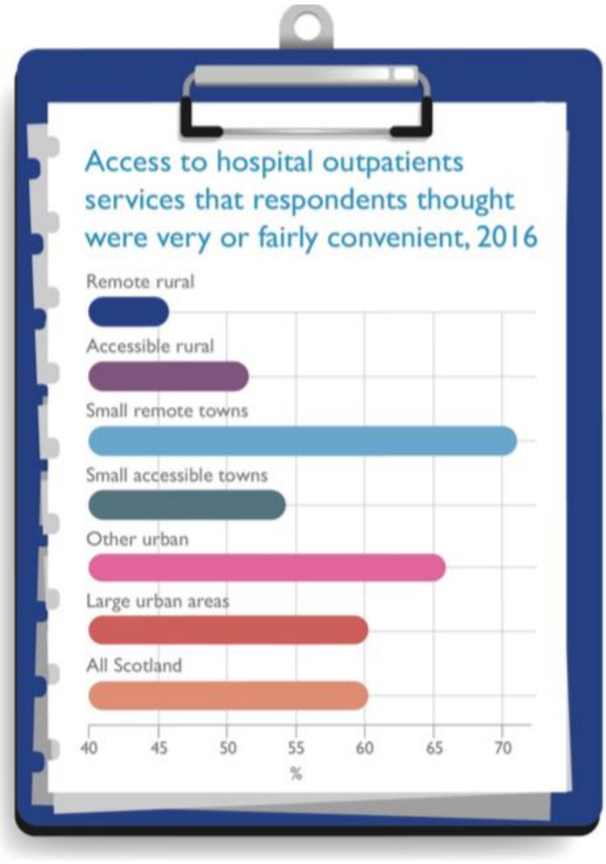
[7] The Care Opinion website

[8] UK Department for Transport's Total Transport Feasibility Report and Pilot Review

5. Roundtable Discussion

Through direct lived experience and engagement with disabled people and DPOs, MACS is frequently made aware of issues and barriers faced by disabled people when accessing healthcare using either specialist patient transport, public transport, or other means.

This is borne out by statistical evidence. In Scotland there is evidence from Transport and Travel in Scotland 2016 to show that only 60 per cent of people (disabled and non-disabled) consider access to hospital outpatient services to be very or fairly convenient. This drops to 46 per cent in remote rural areas.



These percentages do not fully reflect the problems faced by disabled people and older people. It is likely that for these groups the percentages would be significantly higher given:

- The examples and case studies reflected within the Disability Equality Scotland poll with 849 respondents (**Aug 2019 Poll Summary Report**);
- The fact that these groups are more reliant on assistance getting to hospital because of the known barriers with specialist patient transport and limited public transport options (current service provision failing the triple **A** check: **A**vailable, **A**ccessible and **A**ffordable);
- That disabled people and older people are more likely to need to attend medical appointments more frequently due to their underlying medical conditions as well as the needs of an ageing population;

- The prediction within the Programme for Government (PfG) 2019/20[9] relating to reducing waiting times is “this year’s investment will support more procedures such as cataract removal and hip and knee replacements, **as well as increasing the number of outpatient and diagnostic appointments”.** It’s likely that to achieve this it will, in-turn, increase the need for accessible transport options, and;

- That people on low incomes are more likely to suffer ill health.

As a result of these findings, combined with what people were telling us, a Transport to Health and Social Care Roundtable was convened in November 2019 by MACS to discuss the issues further.

This roundtable discussion had the following purpose:

- To discuss the research and evidence gathering key findings, acknowledging the impact of these issues on disabled people, older people and people on low or restricted incomes;

- To identify and recommend potential solutions, including potential opportunities for collaborative working and coproduction to improve booking and securing transport to healthcare facilities;

- To ensure the broad views and lived experiences of disabled people were heard in relation to the barriers they face booking, accessing and affording transport to medical appointments;

- To allow for discussions that will identify and share good and best practice;

- To identify improvements required in the information provided by territorial NHS Boards and National Boards (SAS and the National Waiting Time Centre) to assist with public transport journey planning and signposting to alternative transport providers;

- To discuss issues raised around the SAS booking process and share suggestions (made by disabled people) aimed at making the booking process easier and more consistent;

- To identify where links to transport providers and journey planning information (including to the Accessible Travel Hub hosted by Disability Equality Scotland) could be improved to assist with the booking process;

- To set the scene for the development day (hosted by MACS) in March 2020, themed around improving transport to health care facilities;

- To agree further actions required moving forward including recommendations and advice MACS can offer to Scottish Ministers, transport and service providers and key stakeholders, and;

- To be clear that stakeholders understand that MACS is not an implementing authority and our remit is to understand the current position, including barriers, ensure the broad views and lived experiences of disabled people are heard, give advice and make recommendations that could deliver improvements if followed.

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[9] Scottish Government's Programme for Government 2019-20

Participants at the event included individual disabled people bringing their direct lived experience of the issues, and representatives of a number of the organisations listed below. MACS identified these attendees as being key stakeholders in any work to improve Transport to Health and Social Care. From those invited, over 40 participants took part.

MACS November 2019 Roundtable: Participants and key stakeholders

- Mobility and Access Committee for Scotland
- Disabled people
- Disabled people's organisations
- Access Panels
- NHS Boards
- NHS Boards Equality and Diversity Leads
- Integration Authorities
- Local Authorities
- Regional Transport Partnerships
- Transport Scotland
- Scottish Government Health and Social Care Directorates
- Scottish Ambulance Service
- Transport Service and Infrastructure providers
- Regulators including Equality and Human Rights Commission
- University of Edinburgh

Note: A full record of the Transport to Health Roundtable, including the list of attendees, can be found within **Annex A** of this report.

MACS sought to get as wide a section of organisations involved in Health and Social Care transport planning and service provision and those responsible for leading on Equality and Inclusion within the NHS to the roundtable.

As well as bringing a wealth of knowledge and experience to the table it was thought that those invited had the capacity to influence change.

MACS' pre-roundtable briefing paper gave information on their findings during the research and evidence gathering stage, and signposted to other useful research and documents that MACS had drawn on and that would be useful background reading for attendees. The most recent survey results and reports from DES and the CTA were also distributed to all attendees prior to the event.

The agenda for the roundtable was constructed to ensure the day allowed time to confirm the current barriers, with the majority of the time being allocated to open discussion on the key findings.

The afternoon session was utilised to work in groups to seek solutions to the current transport barriers to accessing Health and Social Care appointments and facilities.

6. Key Issues

Through the discussion and evidence gathering exercises, the following key issues were identified:

Theme 1 - Accessibility - Public transport barriers:

- There is a lack of knowledge and awareness of what is available and by which organisation/transport provider i.e. hospital transport, local authority, community transport, ambulance service, voluntary drivers and charities/community initiatives.

- There is growing concern amongst disabled and older people in relation to the transport barriers accessing Health and Social Care facilities and how these are planned without meaningful engagement with service users.

- Disabled and older people are not given enough influence over how transport to hospitals and medical facilities works. This misses out on using their direct lived experience to design services that meet their needs and shows a lack of meaningful engagement in line with “nothing about us without us”.

- The replacement of buses with coaches has presented an additional barrier accessing Health and Social Care appointments and facilities for people with reduced mobility, due to the inaccessible design of some coaches.

- The planning and design of buses, bus routes, bus stops, information points, and public toilets are not geared towards disabled people and older people getting to hospital and other essential services.

- The first and last mile of the journeys is the most problematic (i.e. from door to bus stop and bus stop to medical facility).

- Many disabled and older people cannot travel independently by bus (due to mobility, confidence, medical condition). This links to limited affordable options to travel with a carer or companion.

- Bus timetabling and routes don’t meet people’s needs and fail to connect communities to health and social care facilities. This includes frequency of bus services, operating hours and network coverage (more problematic in rural areas)

Theme 2 - Booking information - Formats and signposting to alternative transport providers (what’s currently out there):

- Individual NHS Boards have websites for each of their hospitals but the information they publish on these websites for their facilities is not consistent and in most cases not in accessible formats.

- NHS websites tended to sign post to Traveline Scotland or Google maps, neither of which are particularly good for identifying accessible transport options needed for planning a journey. Accessibility of these websites is also poor.

- Most sites don't provide information on the bus stop location, its distance from the main entrance or the road/pavement gradient to make it easier for patients to prepare and plan the journey. This adds to the problem with the first and last mile.

- Booking processes are complicated and time consuming. They are heavily reliant on phone calling and queuing with no options for on-line booking.

- There is an absence of or very limited/poor methods of signposting to alternative transport organisations, with the onus left with patients to navigate complex arrangements.

Theme 3 - Availability - Scottish Ambulance Service booking procedures and impact of limited resources:

- The SAS doesn't have the capacity to meet demand for transport and is filling the gap caused by inadequate, inaccessible and unaffordable public transport.

- Changes made by the SAS to the Patient Needs Assessments, escort eligibility criteria, daily quotas/capping for journey numbers and the loss of the volunteer car service has significantly reduced the number of journeys the ambulance service undertakes and individuals and other services are being hit with the knock on effects (i.e. the CTA).

- There was little evidence of the SAS meaningfully engaging with users of the service during transformation and redesign and an absence of evidence in relation to conducting Equality Impact Assessments for any redesign or service changes on line with the Public Sector Equality Duty.

Theme 4 - Community Transport - Assistance and voluntary transport groups:

- There is an absence of, or very limited/poor methods of, signposting to alternative organisations with the onus left with patients. This links with there being no apparent resource sharing. For example, most people booking community transport are doing so themselves, normally through local knowledge, which could be addressed by involving Community Transport Operators in the Transport Planning (i.e. Health Board, Local Authority and SASall around the table).

- The local Community Transport Schemes are filling the gap in transport to health and social care. This demand is outstripping resources (financial and assets) resulting in many requests for transport being refused.

- The CTA's assistance with transport to health and social care appointments is unrecognised and they are having to refuse some requests for transport to health and social care appointments from people within their communities, who have little or no alternatives.

- The reimbursement rate for CTA Volunteer drivers is unaffordable to many, particularly in people in rural areas where distances are longer and costs based per mile.

Theme 5 - Affordability - NHS Reimbursement Schemes and costs of public transport and private taxis:

- During our research of NHS websites we found every site to be different and that it was not always apparent where information on travel to hospital or reimbursement of costs could be found.

- There appears to be no mention of reimbursement for taxi fares on any of the NHS websites. This may be because currently the NHS doesn’t appear to reimburse taxi fares even though this may be the only way some people can reach their appointments.

- For many people on low incomes the “Help with Health Costs Scheme” and NHS reimbursement schemes don’t work because they have to claim in arrears and as such these schemes do not meet their needs or take account of their individual circumstances.

- The National Entitlement Card Scheme is not flexible enough and the ‘plus a companion’ facility could be widened.

- Many people who have a National Entitlement Card (bus pass) cannot use it, as there are poor bus services (or no accessible buses) in their areas as many of these routes are not commercially viable and services have been withdrawn.

- Hospital parking costs (even for Blue Badge holders) is unaffordable.

- The variation in fares between bus operators made some journeys unaffordable, and not an option, as are rail fares.

- The cost of travel by local community transport schemes can be unaffordable, especially in rural areas where return journeys are long and reimbursement is charged per mile.

7. Conclusions

As a society we need to make sure that every disabled person can plan and get to their hospital or medical appointment. This includes being able to undertake the door-to-door journeys via a transport system that is easy to access and affordable to use. This also incorporates travelling with safely and straightforwardly, without being made to endure anxiety, distress, increased pain or additional costs.

There has already been some productive thinking about how transport could be improved to better support the health system, but it is at a relatively early stage and much more needs to be done.

AS undertook a review of Transport for Health and Social Care in 2011. There is little or no evidenced progress from the recommendations of this review. The ethos of the review being **"good transport services can help the whole health and social care system to work efficiently"**.

MACS phase one research and evidence gathering on Transport to Health and Social Care found many similar issues as reported by AS in 2011, which suggests that the AS recommendations have not been progressed in over 8 years since the audit was undertaken.

This begs the question of leadership and who needs to drive this agenda to gain traction and deliver the improvements required to address the transport barriers for disabled people and older people when accessing health and social care facilities and appointments.

MACS recommendations below are aimed at identifying solutions to some of the obstacles for disabled and older people accessing heath care. This includes recognising areas that are worthy of exploration.

Our recommendations are made to address some of the current barriers and many are based on feedback from disabled people using services and hence formed from their lived and direct experience of the current barriers.

This approach fits with the Scottish Governments commitment to "Democracy Matters" and the recent commitments around the Local Government Review, Developing and Testing Proposals, which confirms that Scottish Ministers and COSLA have a clear expectation that all public sector partners engage constructively in local level discussions to further develop ideas with the most transformative potential.

From MACS work it is clear that people want to be involved in designing the services they use and for their experiences to be used to identify solutions that would reduce inequalities and allow them fair and equal access to health and social care services. As stated, this aligns with the Scottish Government and COSLA's work on "Democracy Matters"[10] and in particular:

- For individuals and communities input to lead to practical action that improves their access to services and experiences.

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[10] Scottish Government's Democracy Matters web pages

- To be able to have more influence – having a voice in, and an impact on, decision-making and designing services.
- The need for transparency and accountability – public authorities being transparent about their decisions and communities being able to hold them to account for those decisions.
- Authority – having the authority and resources to take decisions.

People stated that they wanted an end to tokenistic engagement, poor communication, unwelcoming structures, inability to effect change/inaction and the current lack of meaningful representation.

Our approach is also intended to align with the imminent National Transport Strategy 2 and link to the progress required under the 5 ambitions of A Fairer Scotland[11]. Each of these, working towards achieving the outcomes of Scotland's' National Performance Framework[12].

Our approach also involved thinking about and discussing how existing transport resources could be deployed more efficiently, how we could raise awareness of their existence and to recommend how organisations can and should plan and work better (and better together) to improve transport to healthcare facilities.

There are far too many disabled and older people who find it difficult, stressful, often unaffordable, and often physically painful, to get to hospital and medical appointments. There are a number of practical steps that could be taken to reduce these problems across different forms of transport and planning functions.

Transport must be regarded as a key component of an integrated health and social care system and patient care pathway.

If disabled and older people cannot actually get to the services they need then the system will fail, impacting on the individuals health and wellbeing and placing further costs and pressure on our NHS.

Overall we need a more consistent approach to the provision of patient transport services so that the range and quality of services do not differ depending on level of mobility, disability, where you live or what you can afford.

Over the past decade or so, there has been a real shift across Scotland in the way communities are involved in decision-making. There is a recognition that empowering communities to make things happen and influence decisions can lead to more effective and responsive services, again aligning with "Democracy Matters" and the ethos of "nothing about us without us".

However, it has been noted that the views of people with direct lived experience are often used to illustrate a point, rather than to shape agendas, explain or increase understanding of the key issues relating to public transport and service provision failures. It is not always clear what impact involving people with direct lived experience has on policy and practice.

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[11] Scottish Government's Fairer Scotland web pages

[12] Scottish Government's National Performance Framework

Therefore, in looking through our evidence gathering and statements/comments from people with direct lived experience, we are not just interested in whether they are and will be heard, but we are interested in what impact this will have and how their views will be used by Scottish Minister, the Scottish Government, Public Bodies and other organisations in the development of their action plans.

8. Recommendations

This MACS Report: Transport to Health and Social Care makes **27 key recommendations** for the Scottish Government, NHS Scotland, the SAS, Local Authorities, Regional Transport Partnerships and the CTA. In comparison it should be noted that many of these recommendation reflect those made within Audit Scotland's report on Transport to Health and Social Care, in 2011 and as such would further evidence the lack of progress with this agenda:

Health transport (provided by NHS hospitals and the SAS) and public transport should cover provision for both disabled people and older people who do and do not qualify for NHS patient transport services but need to get to a medical appointment.

> **Recommendation 1:** The Scottish Government should review the operation of patient transport services to promote consistency, quality, and affordability, while ensuring that disabled and older people are not being unfairly excluded from accessing healthcare. This should align with the 4 priorities of the National Transport Strategy and in particular priority areas 1 and 4 (Promotes Equality/Reduces Inequality and Improves Our Health and Wellbeing).
>
> **Recommendation 2:** Transport should be built in as an integral part of the care pathway. There needs to be better joined up planning and working between the NHS, Local Authorities and SAS. The CTA should be recognised as key partners in these discussions (supported within the Transport (Scotland) Bill legislation).
>
> **Recommendation 3:** Transport should be designed around access to hospitals and other essential services. Organisations must engage in relation to getting disabled people and older people to their services, including with those who use their services.
>
> **Recommendation 4:** One organisation needs to take accountability for the lead strategic planning role (suggested to be Integrated Joint Boards) to ensure ambulance, hospital, community and public transport provision meets demand and is accessible, available and affordable to all (again this aligns with the 4 priorities of Scotland's National Transport Strategy and the recommendations of Transport Scotland's Accessible Transport Framework). Regional Transport Partnerships are also central to these discussions.

Transport resources and budgets could be shared between the NHS, Local Authorities, SAS and Community Transport Operators (budgets should be ring- fenced for transport).

> **Recommendation 5:** This should be explored further.
>
> There is a clear call for integrating resources and call centres to make it easier to identify and book transport, with one overall coordinator for transport to health. **A one-stop shop**. This call goes on to suggest budgets should be shared and ring-fenced and booking transport on-line should be an option. This is supported by a clear call for leadership, joined up working and sharing of resources. This should be explored further.

Recommendation 6: This should be explored further looking at previous successful pilot initiatives (example: the Grampian Health and Transport Action Plan – Hospital Discharge Hub and Travel to Health and Social Care Information Centre – THInC).

Recommendation 7: The SAS should consider introducing the option of on-line booking. Initially this could be done once the person has been through their Patient Needs Assessment and allocated a reference number that would be valid for 3 months. This number could be their gateway number to an on-line booking facility for ambulance transport.

Recommendation 8: Online booking of patient transport services should be explored by the SAS, bearing in mind comparator services disabled people use, to allow them to book online. There could be potential to make the booking system for patient transport services similar to Passenger Assist services on public transport where questions are asked less about one's medical condition and more about one's needs.

There is a call to reinvest in previous pilots and current initiatives that work to sustain funding and maximise opportunities to roll these out as best practice initiatives to drive improvements in transport to health and social care.

- **Recommendation 9:** This should be explored further looking at previous successful pilot initiatives (example: the Grampian Health and Transport Action Plan – Hospital Discharge Hub and Travel to Health and Social Care Information Centre – THInC).

There is a call for free travel passes to be sent out with appointment letters to "tackle" the unaffordable element of travel for people of low incomes.

Recommendation 10: This is worthy of further exploration by Transport Scotland and NHS Boards. This should include exploring the possibility of widening concessionary travel timeframes, including concessionary travel for medical appointments within the scheme (for those on low or restricted incomes and to those who rely on door to door transport services). This would also assist with reducing inequalities in areas where many people cannot use their NEC, as there are poor bus services (or no accessible buses) as many of these routes are not commercially viable and services have been withdrawn.

Recommendation 11: Transport Scotland should explore the possibility of a "plus one" on bus passes (beyond for those in receipt of high level Personal Independence Payments (PIP) or Attendance Allowance.

Recommendation 12: Local Community Transport providers should be involved in the planning of transport to medical appointments, particularly in rural areas – this recommendation may be part addressed in the technical amendment of the Transport (Scotland) Bill.

Not taking escorts is a false economy as patients are having to pay for their escorts separately (to meet them at the hospital) and where this is unaffordable hospital staff are getting diverted from their core duties to provide support that a carer or escort would normally have provided for the patient - There are suggestions that many appointments are being cancelled or missed due to the patients not wanting to attend without an escort. There are also statements on the added stress and anxiety for patients when they are not permitted their carer or escort to travel with them.

Recommendation 13: The SAS should review its escort/companion policies and practices (to ensure a consistent application nationally). A meaningful Equality Impact Assessment, involving disabled people and/or their representatives needs to be embedded within these reviews.

Recommendation 14: SAS refining the Patient Needs Assessment (PNA) – The upcoming review of the PNA must include disabled peoples' opinions and experiences of the service, so that it is more reflective of difficulties around mobility.

There are concerns over the cost to the NHS of missed appointments, which have resulted from transport barriers. This also cause additional stress to patients who have to cancel or miss their appointments, often at short notice (transport cancelled by the SAS) and return to a lengthy waiting list (which will also impact on the referral to treatment time targets). Tackling the transport issues would also address these and wider issues such as the financial implication, the impact on people's health and wellbeing and the potential for the patient's condition to deteriorate while waiting longer for treatment.

Recommendation 15: The full impact and cost of inadequate transport needs to be evaluated and measured to understand the scale and wider impact of the problem. This evaluation should look at the impact on an individual's health and wellbeing as well as the financial implications and bearing on missed referral to treatment times and waiting lists. The scale and impact of the above needs to be known and identified to understand the issues and measure the impacts to influence future financial investments and to enable ambitions 1 and 3 of A Fairer Scotland.

There is a call for data collection and analysis to better understand the wider impacts on inadequate transport to healthcare facilities. This should include but is not limited to:

- Cost of missed appointments;
- Administration costs of rebooking appointments;
- Impact on increased waiting lists and referral to treatment time targets as a result of transport failures (missed and re booking appointments);
- Impact on patient care and patient experience;
- Potential cost of deferred treatment (health and wellbeing and financial);
- Hidden costs of staff stepping into a "carer" role in the absence of the patient being able to travel with an escort or companion to provide this level of support;
- Unclaimed travel budgets/reimbursement funds.

Recommendation 16: The scale and impact of the above needs to be known and identified to understand the issues and measure the impacts to influence future financial investments and to enable ambitions 1 and 3 of A Fairer Scotland (as above).

Recommendation 17: All local authorities should have an accessible transport strategy and targets, which encourages and facilitates more disabled people and older people being able to use public transport to attend medical appointments.

Discharge areas could be made into "discharge or waiting hubs" designed around a more social and shared place and space setting to improve the patients experience and also assist with reducing loneliness and social isolation.

Recommendation 18: NHS Health Boards should engage with patient groups in the design of discharge lounges and transport waiting hubs.

Some people may know about ambulance transport and local bus services but be unaware of possible community transport and other options i.e. British Red Cross.

Recommendation 19: The SAS, Hospitals and GPs need to proactively communicate information on what is locally available to patients who may not be aware of this information. This should include online information and distributing offline information, particularly too hard to reach groups.

Recommendation 20: There should be clearer obligations on hospitals and GPs to offer information about alternative forms of transport where people do not qualify for ambulance service patient transport.

Recommendation 21: All local authorities should consider a well-publicised central information point giving details of all local transport options (including community transport) for getting to medical appointments.

Recommendation 22: Health Boards and hospitals facilities should automatically **consider the patient’s transport needs within the care pathway**, to ensure they can get to appointments and receive assistance if required. They should review all the options if a disabled or older person does not qualify for patient transport.

Many disabled people often tell us about the difficulties with insufficient hospital parking spaces for Blue Badge holders. We have been told of some patients having to cancel their appointments because hospital car parks were full and disabled drivers or passengers could not walk from the car to their appointments.

We have heard of people booking ambulance transport only because they have previously been unable to park at the hospital. This misuse of ambulance service resources could be avoided. Feedback suggest that parking arrangements for disabled people at hospitals are unrealistic as they provide only a limited number of accessible/ Blue Badge parking bays, and patients are not allowed to use their Blue Badges in other sections of the car park without a financial penalty (which for many is unaffordable).

Recommendation 23: Hospitals need to review the number of Blue Badge parking spaces and the distance from the clinics/main outpatients. The Blue Badge spaces should be more closely monitored with enforcement to eliminate misuse.

Recommendation 24: There should be a review of any charges for Blue Badge parking with a drive to eliminate costs for disabled people.

Recommendation 25: The facility to pre-book car parking spaces at hospitals and other healthcare premises should be explored.

Recommendation 26: The planning and design of buses, bus routes, bus stops, information points, and public toilets need to be geared towards disabled people and older people getting to hospital and other essential services. Disabled and older people should be given more influence over how transport to hospital works to tackle any difficulties they experience.

Recommendation 27: from SAS/DES Workshop Nov 2019: The Accessible Travel Framework (linked to the National Transport Strategy) should prioritise improving transport access to health and social care in line with their ambition of "more disabled people successfully completing more door to door journeys".

ANNEX A - Record of the Transport to Health Roundtable

The Transport to Health Roundtable held in Glasgow on 21 November 2019 began with introductory remarks from the MACS National Convener, who thanked attendees for participating.

The Convener explained that she understood this was a long-standing issue and she was aware that the areas being discussed were not new and indeed these are issues that many in the room had been trying to resolve for many years.

The Convener expressed her understanding of the frustration given people's efforts and that, when we listen to what people are telling us, not much has changed and potentially the availability of suitable transport to get to medical appointments had got worse as budgets had been cut, resources stripped back or redeployed and some bus services withdrawn.

The Convener also explained that she recognised the frustration and the fatigue with this agenda given these efforts and the lack of **or** slow progress. **But** - from today's turnout it was evident that there was still an appetite to work together and seek improvements. She acknowledged and welcomed this and thanked everyone for coming along to join in the discussion.

The Convener explained the opportunities to re-energise this agenda with:

- The imminent launch of the National Transport Strategy (NTS2)
- The consultation work of the Strategic Transport Project Review (STPR2) to support NTS2
- The review of the Scottish Governments progress on the Fairer Scotland due in Dec 2019 (transport being key in 2 of the 5 ambitions and an enabler for more)
- The new Annual Delivery Plan model for the Accessible Travel Framework, and
- More organisations focusing their work and strategies around the need for a fit for purpose transport system (such as the Equality and Human Rights Commission, The Poverty and Inequality Commission in Scotland and Disabled People's Organisations).

With these opportunities in the offing, she wanted to gather people's thoughts and talk about some of these issues to allow MACS to discuss them with Ministers in Jan 2020 and make some recommendations that **could/would** deliver improvements. This would include highlighting some areas worthy of further exploration - to enable disabled people and older people to be supported by a transport system that gives fair and easy access to healthcare and is available and affordable for all.

The Convener thanked Transport Scotland officials for helping to organise the event, and representatives from Disability Equality Scotland and the Community Transport Association for reaching out to their members and networks to gather information. She also thanked Badenoch and Strathspey Access Panel, Lochaber Access Panel and Voluntary Action Lochaber for giving up their time and making themselves available to discuss their previous work and the current issues.

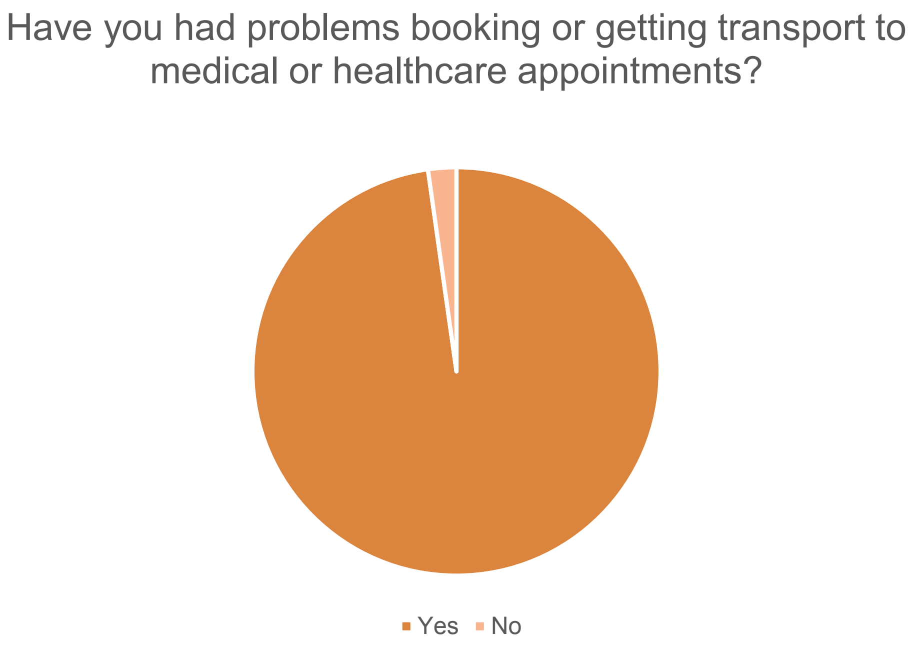
The independent facilitator for the day introduced herself, a member of staff in the Scottish Government. She explained the purpose and structure of the day and touched on some of the background, and explained it was timely to undertake this event.

Disability Equality Scotland (DES) presentation

The next item on the agenda was a presentation from the Operations Manager of Disability Equality Scotland (DES).

DES is a national Disabled Person's Organisation, working across Scotland to improve access and inclusion for disabled people. In August 2019 they ran a weekly poll of its members on the topic, access to transport for healthcare and medical appointments. They also arranged a roadshow in November 2019 where the SAS agreed to meet with DES members and discuss some of these issues in more detail. These findings were discussed in the presentation.

For the week commencing Monday 5 August 2019, DES asked their membership if they had problems booking or getting transport to medical and healthcare appointments. 849 people responded and 98% said yes, while 2% said no:



The poll also asked respondents to provide more information about key issues. These included the following:

- **Concern at carers not being transported on SAS patient transport.** DES members had experiences where disabled people supported by a carer, would not be able to travel using patient transport with their carer, but instead the carer would have to make their way separately to hospital. This caused many people stress and extra expense. Although this policy has changed it still causes concern.

- **Eligibility criteria for SAS patient transport being unclear.** For some patients, there is no clear indication of how eligibility is determined because on different occasions when booking they have answered the same questions, with the same responses but with a different outcome. Sometimes they are eligible and other times not. The Ambulance Service has clarified that the assessment takes place based on the situation at the time of booking. But this still left questions for DES members about what the eligibility criteria actually are, because these are not widely available.

- **Failure to respond to identified need.** There were incidences of patients making their own way to hospital, and then being unable to return home un-assisted after their treatment. These patients were told they were not eligible to use the SAS patient transport service because they had made their own way into the appointment. In response, many patients had relied on friends or family taking time off work to transport them to appointments, but felt that their needs meant they should be eligible for patient transport.

- **A perception that the eligibility criteria for SAS patient transport were biased against hidden disabilities.** For example, a respondent mentioned that anxiety and a lack of confidence meant that using public transport was not an option, then it isn’t assessed or recognised as a medical condition. At the roadshow event the SAS explained that the PNA (which is used to determine eligibility for patient transport) would be reviewed in January 2020.

- **Concerns were raised about the reliability of SAS patient transport and public transport.** This is problematic as it can result in missing an important medical appointment. Delays and cancellations were reported for many reasons. Similarly, the frequency of public transport meant that disabled people felt they could not rely on public transport to make early healthcare appointment times. A particular problem was that the Ambulance Service patient transport service might not be operating at times of the day when disabled people need to travel.

- **Particular issues were raised by disabled people in rural areas.** Distance and geography posed special challenges in these cases. The nature of the public transport offering in these areas was flagged up by disabled people. For example, one disabled person’s bus service used coaches. These were not accessible and ultimately resulted in cancelled appointments.

- **The accessibility and cost of public transport was problematic for disabled people travelling to appointments, and sometimes not a feasible option at all.** For example, issues were raised about the limited spaces on buses for wheelchairs, which means there is no guarantee that a wheelchair user can travel to an appointment. Also, many of the bus routes did not go close enough to hospitals or medical centres – particularly direct routes, so could result in a number of changes. Public transport can also be expensive, with many patients having to use taxis, which they couldn't afford. The frequency of journeys also made the cost untenable.

Quotes from DES survey

> "I really need my carer to attend the hospital with me but the ambulance service no longer allows this so I can't use ambulance transport and have to pay for taxis that I can't afford. I wouldn't manage by bus."
>
> "I've had an experience where I was found to be eligible for patient transport, only to be rejected on a subsequent follow up appointment. Where is the consistency?"
>
> "Lengthy delays to return home by ambulance often means I am really unwell by the time I get home."
>
> "I live north of Inverness and have regular appointments at Raigmore. Around a year ago our bus was replaced by a coach (Stagecoach) and the steps on the coach are too high for people with mobility impairments…this is the only bus on the route. Being rural we have no train service, many medical appointments are going unattended and cancelled which I am sure is wasteful to the NHS."
>
> "On the days I have to travel to hospital I have to skip a meal to afford the travel. I don't mind doing this because I need to see the nurses and doctors, but should this really be the choice?"

Taking stock of these findings, the question was raised: What needs to change? Based on the findings of the work DES had undertaken, they proposed the following:

- **Refining the Patient Needs Assessment (PNA)** – The upcoming review of the PNA must include disabled peoples' opinions and experiences of the service, so that it is more reflective of difficulties around mobility.

- **Integration** – A joined up approach between the SAS and hospitals to ensure those who are eligible for patient transport are given appointments during SAS operating hours.

- **Information –**Information about patient transport must be available in a variety of accessible formats, with an understanding that not all people can access information online.

- **Public Transport –** Build stronger relationships with transport providers to ensure alternative means of travel are available to patients not eligible for patient transport services.

- **Funding** - Funding is required to achieve meaningful change, to both restructure the system, improve communication between service providers as well as increase the capacity of the service.

The facilitator opened the discussion to the floor for reflections and comments about the DES findings. During this session the following points were made:

- The ambulance service does not have the resources to meet all the potential demand for patient transport. But if we could get elements like the public transport system and parking at hospitals right, so that it was accessible and affordable, then pressure could be taken off the ambulance service.

- A participant asked the room if others had examples of cases where transport to health was added to and an integral part of someone's care pathway, rather than just being something the patient has to organise themselves because it's seen as distinct from the care provided. She asked if the participants at the meeting felt that was a good idea.

- Noting the issues raised in the DES presentation, a participant said that rural transport was an important issue. But decisions about such transport were being made without full facts, like the number of missed appointments. There is ambivalence about whose responsibility it is to get people to appointments.

- A participant said that a lot of people associated the ambulance service with emergency transport. This was not correct, given the significance of the patient transport service. Moreover, it was important to separate outpatient transport from other public transport services.

- A participant reflected on her experience about parking at hospital where people who didn't have Blue Badges were using Blue Badge spaces. She commented that stress about finding a parking space drove the demand for other services. Separately, she felt there are opportunities for the third sector to work alongside partners to develop services to support people getting to healthcare appointments, not least to raise their profile. A key issue was who takes responsibility for transport to healthcare. At the moment that rests with the individual, to find a needle in a haystack. We need to make accessibility matter and it doesn't feel like that's happening.

- A participant reflected on hidden disabilities and anxiety, she distinguished between chronic anxiety and a lack of confidence when travelling. She felt more work ought to be done in making information available for travellers. This would help improve people's confidence to travel.

- A participant said that parking is a significant issue, with very limited monitoring of parking use in the hospitals. For example individuals park their cars very close to others, and make it difficult for people to access bays. She noted that Glasgow Disability Alliance members felt there was a lack of basic customer service when booking patient transport on the phone. Turning to the idea of introducing transport as a feature of care pathways, she mentioned that given the pressures on basic social care it seemed unlikely to happen in the near term.

- A participant said their needs to be a high-level, joined-up approach to **make accessibility matter**. At the high level of a number of transport organisations, people didn't understand the full range of accessibility needs. So there was a need for this joined-up approach to be undertaken. Also, she noted that traditional public transport often isn't the right answer for some areas and imagination was needed to design appropriate solutions.

- A participant said that he managed an integration project in Strathclyde where the ambulance service was unhelpful and obstructive. On the patient transport eligibility criteria, he felt a lot of questions needed to be answered. He didn't feel that just getting public transport right by itself was the answer because of people who couldn't use public transport.

- One participant agreed that there was a significant lack of transparency in how the patient transport service works from the Ambulance Service. It was also important to bear in mind that the subject of transport for disabled people went beyond disabled people and shouldn't just be seen as a transport issue. It was as much a public health issue. It was disappointing that this was not fully recognised by the public health community.

- A participant said that people with dual sensory impairments couldn't phone to make appointments. Issues have arisen where carers or guides/communicators have been refused admission to a patient transport ambulance. A system that reflects the full range of accessibility requirements is therefore needed.

- One participant asked if there was further information about the review of the Patient Needs Assessment? The convener reported that the Ambulance Service said that they couldn't disclose the assessment because of the complexity of the algorithms. At the DES roundtable the ambulance service confirmed they were reviewing the assessment and DES explained that, the review needs to be person-centred and have meaningful engagement with disabled people.

- A participant backed a point previously made, and gave an example from her experience with Shetland Islands Council where there were no commercial (non-subsidised) bus services, and it was difficult to provide more accessible services. She also noted that there were resource pressures on local authorities, so the idea that more than the legal minimum would be provided for is unrealistic. Another participant agreed with this point and said that until the legislation is changed, it is difficult to foresee progress. **So we need the politicians to come to the table, and stay at the table.**

- NHS Lanarkshire provided an example of work they are doing in this area. They are developing a transport hub. They're at the very early stages of development but it would be useful in providing a single point of contact. NHS Lanarkshire recognise that they have to be part of the solution rather than just transferring responsibility. It was important not to demonise the Ambulance Service as they too had a responsibility.

Concluding the morning session, the facilitator thanked everyone for their contributions. She noted themes about hospitals – not just lack of Blue Badge spaces, but concerning their design.

Issues around public transport featured and bus stop locations in relation to out-patient departments as did issues about the capacity of the third sector.

Issues around hidden disabilities were mentioned alongside a theme that there is a general lack of information and booking processes are complicated and inconsistent.

Table discussions

Each table (comprising a mix of participants with different experiences and perspectives) was given a particular topic to look at. The results were discussed after a presentation from MACS.

Presentation on Local Outcome Improvement Plans (LOIPs)

A MACS member spoke about Local Outcomes Improvement Plans stating that there are two main drivers for locality planning: the first is the law that brought about integrated health and social care services and the second is community empowerment legislation. The MACS member then went on to explain the background to Community Planning Partnerships and their requirement to produce a LOIP.

MACS analysed all LOIPs published in all 32 Local Authority areas in Scotland and noted that there was very limited information related to transport, and even less concerning transport to health. One local authority excluded a number of potential outcomes on the basis that a significant number of people didn't mention transport and acknowledged that the issues would be dealt with via another medium; for example within the Locality Plan for that area.

Local Outcomes Improvement Plans research results

On reviewing Local Outcomes Improvement Plans (LOIPs) the main finding was that there is no national outcome around transport provision to health. During research MACS found areas of good intention/good practice as below:

- **Inverclyde** focus most on transport to health and used the Place Standard Tool when engaging with communities. Their LOIP acknowledges that supporting older people and that attention should be focused on addressing issues such as transport and healthcare provision.

- The **City of Glasgow** refers to Health as a priority (page 10 of their plan) and transport was a recurring theme in terms of being a barrier. They focused on connected transport that links people to healthcare.

- **Engagement with communities within Falkirk** highlighted issues around transport and its affordability.

Generally, within the LOIPs, there was a lot of focus on modal shift from cars to sustainable transport solutions and improving transport connectivity within Scotland's towns and cities including the Islands.

Roundup of Group Discussions

The following sections provide an illustrative sketch of the group discussions, which took place during the roundtable:

Group 1 – Topic: Accessible public transport

The first group felt it was important to remember that good accessibility supports a wide range of other positive outcomes in areas like social isolation, recovery, poverty and inclusion. The group considered barriers to accessibility; issuing travel passes with appointment letters was suggested, organisations needed to look at accessibility in a holistic way. For example, benefit could be gained from looking at NHS travel staff patterns and using that to look at the potential for provision of new public transport services.

The group proposed a number of practical ideas for change, recognised the importance of enforcing the Blue Badge scheme in healthcare premises and punishing misuse. It also suggested making the National Concessionary Travel Scheme available so that people could get free travel on all types of community transport. This would assist in areas where there was limited or no bus services.

The group considered that collaboration is key to ensure end users are appropriately supported. For this reason having national accessible travel outcomes is important, but collaborative delivery of these at local level is key.

These reflections and suggestions are cited within the recommendations of this report.

Group 2 – Topic: Booking and Information

This group rapidly recognised that the map of existing services is complicated. For example, the ambulance service had one set of criteria while some community transport organisations disabled people may go to for transport to hospital might only help older people. This was a confusing and difficult environment for disabled people to navigate, especially with so much local variation. Therefore the group felt it was a good idea to have a single point of contact disabled people could rely upon to help navigate this.

One model that the group felt could work is improving the existing ambulance service patient transport call centre. In cases where someone is ineligible for ambulance transport, instead of being provided with a list of phone numbers of relevant organisations, it could refer to appropriate intermediaries to directly book onto relevant services such as community transport.

Suitable software could be used and joint working with other bodies like NHS 24 would also be helpful. Indeed, the group felt that other bodies might be better placed then the ambulance service to undertake this kind of work in supporting disabled people to access healthcare appointments.

There were a number of other points the group raised as relevant to tackling the issues.
The group felt the review the ambulance service will undertake of PNA ought to be undertaken in close collaboration with patients. There was also an idea that accessibility should be included in the Charter of Patient Rights and Responsibilities.

These reflections and suggestions are cited within the recommendations of this report.

Open discussion:

At this stage, there was significant open discussion among participants. In discussion the following points were made:

- A number of participants expressed agreement with the idea of a one-stop shop along the lines proposed. One participant said the technology was already there to deliver such a service. Another mentioned an example of how such services worked well in other contexts.

- A participant gave an example of how services can work well together to reduce the burden on disabled people of finding information about, and booking, suitable services to get to healthcare appointments. In Aviemore the local community transport organisation helps local people reach podiatry appointments on a street-by-street basis. Being with one’s neighbours when travelling also helps to make the experience of attending the appointment more pleasant.

- Some participants expressed caution about the implications of some of the ideas. One mentioned that it was important to bear in mind the budget for the concessionary travel scheme was limited. Another participant indicated that the NHS faces considerable resource pressures.

Group 3 – Topic: Availability

The third group focused on patient transport services run by the ambulance service. The group looked at existing pain points and suggested the following solutions:

- On-line booking of patient transport services, bearing in mind comparator services disabled people use allow people to book on-line.

- Making the booking system for patient transport services similar to Passenger Assist services on public transport where questions are asked less about one’s medical condition and more about one’s needs.

This group raised other ideas ranging more widely. So it suggested there should be a facility to pre-book car parking spaces at hospitals and other healthcare premises. And they strongly supported the idea of a one-stop-shop, bearing in mind that no ambulance transport service could pick up all demand for transport to healthcare services.

These reflections and suggestions are cited within the recommendations of this report.

Group 4 – Topic: Community Transport

The fourth group looked at how community transport can help to bridge gaps in transport services. It began by noting that there was a right to healthcare, but no corresponding right to transport. Given this gap, the group felt that transport providers are generally missing from conversations about healthcare. There was a connected point in this respect about whether disabled people's statutory rights should be bolstered.

A live question was what the role of a community transport operator should be. Much of the work community transport operators undertake in this area is filling gaps left from reductions in statutory or commercial public and patient transport services. Whether "more community transport" was the correct answer to the problems identified in this roundtable was not clear but there was a general consensus that they should be around the table for the transport planning meetings.

Bearing in mind that many community transport services are volunteer-led and particularly with respect to long journeys, it was important to be both fair about the expectations being placed on volunteers. A particular challenge was – where only those with full driving licences issued before 1997 could drive a minibus without undertaking another driving test – this loomed large. This could have an impact on the sustainability of community transport services being used now as less people had the D1 and D2 categories on the licence.

The group felt this all required some long-term thinking about the design of services. The group suggested some centralised hubs to deal with administration and booking could help free up resources within community transport organisations.

Joint procurement of services was also suggested. Introducing some form of National Voluntary Service was a bolder suggestion, but reflective of the challenge this group identified of maintaining levels of personnel.

These reflections and suggestions are cited within the recommendations of this report.

Group 5 – Topic: Affordability

This group developed a series of principles. These reflected how an ideal system would look:

- Transport to healthcare services is free to those that need it.
- People are to be referred or self-refer for such support.
- When the system does fail, and as such people are having to make their own arrangements, reimbursement will be undertaken by NHS.
- Phone calls to patient transport should remain free.
- Any carer travels for free.
- Any overnight accommodation is easy, quick and reflects the costs.

The group reflected at this stage that living cost is a particular challenge for rural areas, in particular. Things like work cost, childcare cost, and so on, all have to be borne in mind. In an ideal situation innovative solutions would be developed. **For example it might be possible and more cost effective for a hospital consultant to move to see patients, rather than vice versa**. Or IT solutions could be developed to reduce the number of times people have to travel.

The group itself acknowledged that many of its principles were very ambitious and deliberately reflected an idealistic look at what the situation could be like. It therefore made a number of other suggestions.

- It felt the application and assessment process for ambulance service patient transport could be made simpler.
- A key consideration in decision-making about healthcare services (where they are placed, how integration with social care takes place, and so on) is that the “purple pound” of disabled people’s spending power is not affected.
- They also felt that a continued focus on the accessibility of public transport needed to take place. For example, the group agreed with an earlier point about going beyond existing legislative standards of bus design. By giving people greater assurance their journey could easily and successfully be undertaken by public transport, this would reduce the need to undertake the journey using more expensive modes like taxi.

These reflections and suggestions are cited within the recommendations of this report.

Group 6 – Topic: Roles and Responsibilities

This group felt overall responsibility for transport to healthcare services should rest with the Cabinet Secretary for Health in the Scottish Government.

At operational level, they wanted a 24/7 call centre to exist, which they felt could be run by the Scottish Ambulance Service although other organisations could do this.

The group worked out a schematic for how an optimised service could work, similar to the proposed **one-stop-shop** discussed above. But they proposed some changes from the proposal made earlier. For non-urgent patient transport they felt that the **one-stop-shop** should directly book individuals onto services, including new services that could be set up to meet the demand.

They made a number of suggestions that ranged more widely. Trip sharing services, like those offered by Regional Transport Partnerships, could be used in this area. Reducing the number of times in-person attendance at healthcare premises should also be considered.

Parking at hospitals needed to be tackled rigorously.

This group came up with an idea about a statement of ambition. **They felt developing a Patient Assist service should be the aim**. This would take some of the lessons from Passenger Assist services when someone wants to travel by air, ferry or rail would be a good goal. This would provide a wraparound service of assistance based on need and meeting consistent standards, helping people make their journeys to healthcare settings.

These reflections and suggestions are cited within the recommendations of this report.

Group 7 – Topic: Accessibility, Affordability and Availability

The group agreed with a lot of the points made by other groups. On accessibility, the group felt the range and coverage of public transport services, good infrastructure like paths, pavements, tactiles, crossing points, bus stops, accessible vehicles, and fares (including the scope of the National Concessionary Travel Scheme) all needed to be examined.

The group agreed that many people who have a National Entitlement Card (bus pass) cannot use their bus pass, as there are poor bus services (or no accessible buses) in their areas as many of these routes are not commercially viable and services have been withdrawn.

This group also supported the idea of a **one-stop-shop** but came up with further ideas for how to make it work. In particular, they proposed a better relationship between the booking centre and the hospital. The **one-stop-shop** should facilitate better dialogue between the healthcare provider (such as the hospital) and transport providers, in the interests of the patients.

The group provided an example of how a one-stop-shop might be innovatively designed.

NHS 24 and the SAS decided to co-locate to handle calls and route them to the right clinician be in GP, community nurse or paramedic. From working together physically the inefficiencies have been pulled out from the system.

The group also explored other issues. They felt that it was important to move the thinking of local health and social care systems away from looking at costs and benefits and isolated targets, but towards holistic user outcomes. If this were done then transport to healthcare would be considered more of a priority and part of the care pathway.

They also felt that there should be a presumption that it is best to build new healthcare facilities with strong links to public transport.

For some of the newer builds of such facilities consideration needed to be given to how disabled people move from site to site within a campus, not just how they get to the campus.

The group spoke about the current variations of bus designs and stated that a basic principle should be that all vehicles are accessible to everyone and designed in partnership with users. They gave an example of the “Glider Buses” in Belfast where this approach had been taken from the very outset of thinking about new buses, routes and timetabling. They confirmed that any bus operating on a local bus route should be accessible to all.

The group discussed bus stop design and agreed that all bus stops should comply with a minimal standard of design based on guidelines for accessibility.

The group spoke about the value of and valuable service provided by local community transport schemes, the users satisfaction, confidence in the schemes and the bespoke door-to-door service these schemes provided. They felt that there should a push to invest and sustain the community transport schemes given these factors and benefits.

The group noted that their thinking on this subject had been constrained by costs verses benefits and what would be deemed affordable or where money would come from. There was an agreement that the overriding principle should be person centred and focussed on what access to suitable transport enables and the wider societal benefits investments would bring.

A general discussion took place on the possibility of electric shuttle vehicles (i.e. golf type buggies, MPVs) to connect patients getting off at the nearest bus stop with the hospital cite and also within the hospital or campus, as many had difficulties with these distances and the last stretch of the journey.

These reflections and suggestions are cited within the recommendations of this report.

Closing reflections

At this stage there was a final open discussion among all participants, to ensure any closing reflections were recorded. During this discussion:

- A participant raised the point that privacy had not been raised in the discussions. Data sharing could be an issue in this context. Ensuring any **one-stop-shop** solution complied with GDPR was important. Another mentioned that solutions for this have been found previously.
- A participant underlined the importance of healthcare appointments in the round, not just hospital appointments, which aren't the majority of interactions. GP and dental appointments posed just the same challenges.
- A participant agreed with a lot of the discussion on community transport. The feedback she had received about such services was that when disabled people used them, they felt more confident in travelling because of the nature of the service being provided i.e. tailored to their need, door to door and friendlier volunteers.
- A representative from Highland & Islands Transport Partnership (HITRANS) mentioned their recent successful funding application to make a single booking system for organisations like car clubs. This would be region-wide using a few of our existing platforms already. This spoke to how the technological challenges of some of the ideas mentioned, like a **one-stop-shop**, could be addressed.
- A participant gave example of when two villages lost their GP. She felt it was positive that the CTA represents a community transport organisation that has stepped up with a bus services. But it begs the question about the extent to which we would like local services to exist.

The convener thanked everybody for attending, and also the facilitator for their work. She confirmed that, in January 2020 MACS would meet with Scottish Ministers to discuss the issues raised.

Participants were informed that a report would be drafted comprising a record of discussion and advice from MACS to Ministers based on the day's contributions and the wider research work undertaken.

The report would identify recommendation based on the suggestion and proposals from the 1,000 plus engagement/voices in the run up to the roundtable and those put forward and discussed at the roundtable.

Appendix 1 – List of organisations attending the Roundtable Discussion

ORGANISATION
Aberdeen City Council
Aberdeenshire Council - Passenger Transport Unit
Badenoch and Strathspey Access Panel
Community Transport Association
Community Transport Association Scotland
Confederation of Passenger Transport (CPT) UK
DeafBlind Scotland
Directorate of Health Finance
Disability Equality Scotland
Dumfries and Galloway PSP (Annandale CT)
Dumfries PSP and SPT PSP
Equality and Human Rights Commission
Equality Unit
Facilitator
Glasgow Disability Alliance
Go Upstream
Guide Dogs
Highland & Islands Transport Partnership (Hitrans)
Local Authority Transport Coordinators (ATCO)
Lochaber Access Panel
MACS
NHS 24
NHS Ayrshire & Arran
NHS Ayrshire & Arran - East Ayrshire
NHS Equality & Diversity Lead Network (NHS Ayrshire & Arran)
NHS Equality & Diversity Lead Network (NHS National Services Scotland)
NHS Equality& Diversity Lead Network (NHS Greater Glasgow & Clyde)
NHS Lanarkshire
NHS Scotland Transport & Logistics Services Expert Group
Out of Hours Urgent Care and Optometry Team
Shetland Transport Partnership (ZetTrans)
South-East of Scotland Transport Partnership (Sestran)
Strathclyde Partnership for Transport (SPT)
Tayside and Central Scotland Transport Partnership (TACTRAN)
The Bridge - Third Sector Interface (TSI) for the Scottish Borders
Transport Scotland

Mydex CIC

Independent Review of Adult Social Care - Mydex CIC Response - September 2020

Contents

From: Mydex Data Services Community Interest Company, registered in Scotland running a live digital trust platform across health, social care and public services

The principal aim of the review is to recommend improvements to adult social care in Scotland, primarily in terms of the outcomes achieved by and with people who use services, their carers and families, and the experience of people who work in adult social care. The review will take a human-rights based approach

Current adult social care system

The Independent Review is an opportunity. Our Mydex CIC response shows **the safe, easy, inclusive, human rights based approach to secure the personal data logistics infrastructure** (collection, delivery, storage, sharing) that is needed. This change underpins the efficient provision of inclusive, personalised health and care to individuals by multiple agencies working together. **It is genuinely citizen centred and sustainable.** Our Response in particular addresses these areas of the Review :

- *Opportunities to redesign the overall system of social care to improve people's experience of care.*
- *How equitable and non-discriminatory enjoyment of rights can be achieved;*
- *How decision-making, participation, independent living and control can be maximised by people using adult social care services*
- *Arrangements for meaningfully involving users in the assessment of need and in co-design and co-production (including self-directed support);*
- *Social care and health care service models and their interaction with other services,*

such as housing, education and employment;

At the heart of adult social care today is a multi-agency model involving organisations across many sectors and citizens providing a diverse range of formal and informal care to individuals. Many of these individuals seeking and receiving Adult Social Care have complex issues and needs that require coordination in approach if sustainable positive outcomes are to be delivered.

The individuals being cared for do not see (or want to see) demarcation lines between sectors, organisations, policy or departmental functions. **They want a truly holistic approach, that is equitable, trustworthy** and that fully understands their particular needs and circumstances and responds to their particular situation sensitively and appropriately.

Provision of such holistic, integrated and coordinated care requires large amounts of personal data: data about the history of needs and circumstances of the individual and data about particular services being provided, including mundane operational details about what service is being provided by which agency, when. This data is often highly sensitive and detailed. It is always changing. And, if services are to be configured to meet the needs of the individual it needs to be shared.

Missing from today's adult social care is the safe, easy, human rights based approach to secure personal data logistics infrastructure (collection, delivery, storage, sharing) that is needed for the efficient provision of holistic, personalised care to individuals by multiple agencies working together.

Such an infrastructure cannot logically, legally or operationally be provided by any one, particular agency or system. It is not possible or desirable for a GP surgery to hold or share data collected by a care home or social services, or vice versa. What is needed is an extra level of data sharing - an additional 'layer' of data sharing infrastructure - that helps each separate agency join the dots, sharing what information needs to be shared safely, seamlessly and efficiently when needed.

However, long and bitter experience shows that attempts to build large centralised databases do not work. They invariably prove cumbersome and expensive, potentially invasive of an individual's privacy, and end up causing more harm than good (see below).

But an alternative approach is possible - indeed, has been tried and tested and is up and running. That is, providing every individual with their own personal data store that places that individual at the very heart of the process.

Such an approach is fully in line with the Scottish Government's consistently expressed policy in favour of a human rights based, person centred, citizen centric, self directed and self-driven approach to accessing and using the full spectrum of public services.

This citizen centred digital approach helps address many of the systemic level challenges around integrating and joining up services and removing the friction, risk, cost and effort that lies at the heart of the adult social care dilemma.

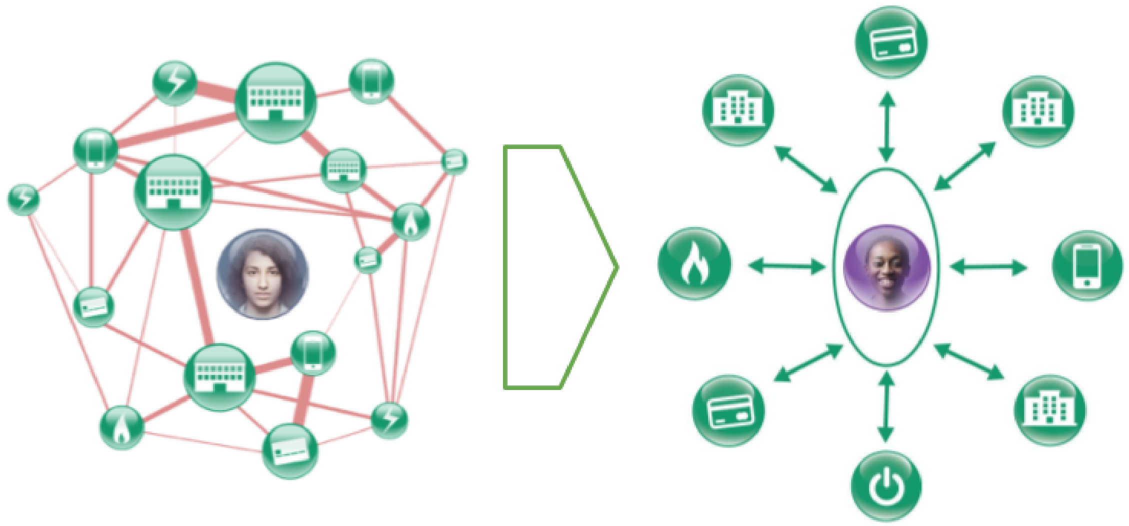
This approach is already being used in a range of innovative projects across Scotland working in local clusters. It provides the missing elements of what is needed to enable the delivery of the next generation of adult social care. It is a low cost, secure, easy to use approach that is, live and certified, that equips and enables citizens to be an active participant in the process and critically the point of integration. It is highly efficient, enabling data to be captured once and shared many times. And it has compliance to GDPR built-in to how it works, with the highest levels of information governance, flexibility and adaptability to support truly personalised, self-driven services

Crucially, this approach can also involve carers as well as those being cared for. There are currently 745,000 identified adult carers and 44,000 young carers under the age of 18 in Scotland. These carers care for relatives, friends and neighbours with longstanding illness or disability. They are all too often devoid of the data and information they need to be effective, operating outside of the organisations at the core of the formal adult care system. But they still need to be able to access data and contribute to the overall picture. The approach proposed allows them to have visibility of and contribute to the care process that helps them feel involved and engaged.

Redesign the overall system - trust and relationships

The Independent Review is an opportunity to recommend plans to implement a human rights based approach that empowers the individual to be an active participant in digital services and the point of integration, whether the individual is the one being cared for, or those providing the care. The individual as the point of integration between the organisations large and small who provide services to them is not only logical, it is inclusive, efficient, secure, safe and flexible.

Current thinking sadly remains limited to organisation to organisation data sharing which is complex in terms of information governance, integration and the issues around the basis of data sharing and whether and in what way informed consent is required. This model is sometimes described as a crown of thorns because it creates significant issues for citizens and organisations alike.



Crown of thorns
organisation centric today

Person centred approach
emerging model available now

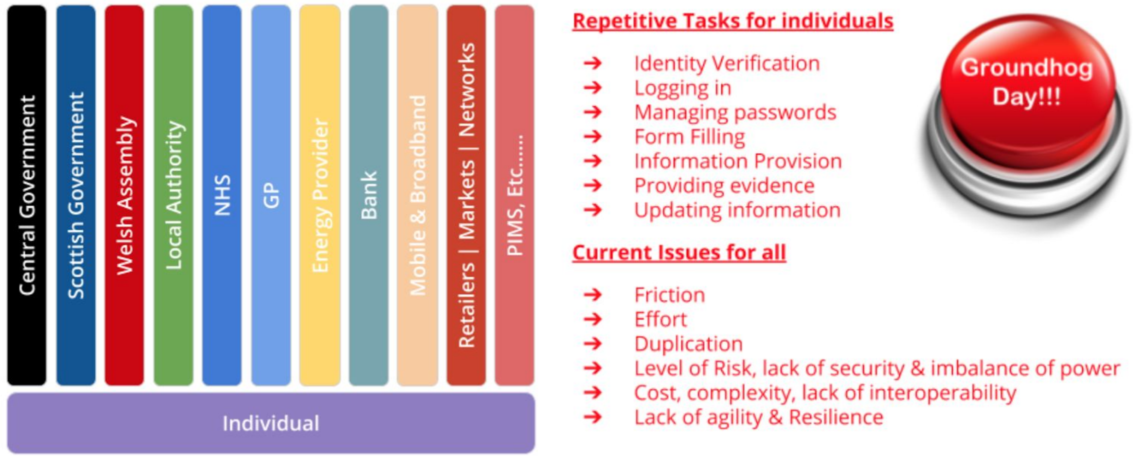
Research and analysis to date makes clear that, even with the best of intentions, a generation of investment in software systems run by organisations at a horizontal and departmental level have failed to deliver the efficiency and outcomes desired, they are too complex, too late and out of date. For the citizens who these organisations serve it has not delivered an efficient joined up service that is safe and easy to use or drives the outcomes and impact needed.

The typical response to this situation has been an endless series of attempts to integrate the systems or build bigger more complex ones. There has been no practical consideration or investigation of alternative approaches: distributed ones which deliver the policy objective of empowered citizens or active involvement of the individual. This has left us with a fragmented, expensive, time consuming and complicated environment for all stakeholders.

Under the current approach citizens in receipt of care are largely described as "data subjects" of transactions or services. They have little or no active role and have nothing in terms of retained data or proof points that can be shared with relatives, friends and neighbours or those formally providing care in different organisations. Furthermore, without capture and retention of this important data they have no opportunity to reuse any of it in other transactions. Citizens have to start all over again filling in more forms simply because the data is locked up in silos run by organisations, silos not easily accessed and only there for the use as intended by the organisation not the individual the data is about.

The result of this approach and environment is that citizens are left with complex journeys, duplication of effort, huge friction, time and cost in getting things done. The same is true for many front line service delivery people who only see part of the picture they need because of these silos and lack of access to the data needed. Almost all service providers, who have a stated strategy of providing integrated joined up services, working within local clusters of organisations, are still operating in an isolated and disjointed manner particularly in relation to how personal data flows between them.

Organisation centric model



Repetitive Tasks for individuals

- → Identity Verification
- → Logging in
- → Managing passwords
- → Form Filling
- → Information Provision
- → Providing evidence
- → Updating information

Current Issues for all

- → Friction
- → Effort
- → Duplication
- → Level of Risk, lack of security & imbalance of power
- → Cost, complexity, lack of interoperability
- → Lack of agility & Resilience

Data sharing between silos inside and across organisation complex, with risk and compliance issues

The current assumption that large scale 'organisation centric' systems is the only way to do things simply maintains these stove pipes of data collection and keeps individuals locked into complex, chaotic, inconsistent processes that hinder their ability to interact with services designed to support them.

This is even more pronounced in Adult social care because it interacts with other domains where these issue are endemic in such health, social care, advice services (e.g. relating to fuel poverty or debt advice) and the broader spectrum of public services including social security, education, employment and benefits.

There is clear evidence of these challenges in a broad spectrum of reports focusing on Scotland and more broadly. These are not issues the market will resolve as they are counter to their interests, this is a civil society challenge one measured by how much friction, risk, cost and effort can be removed from delivering services and how this can improve access, inclusion, outcomes and capacity from existing resources.

Current programmes of work exploring and proving that there is a better way, one that is a more distributed, resilient, and scalable way of working that places the individual at centre as an active participant equipped with the tools needed to be the point of integration across this distributed range of service providers.

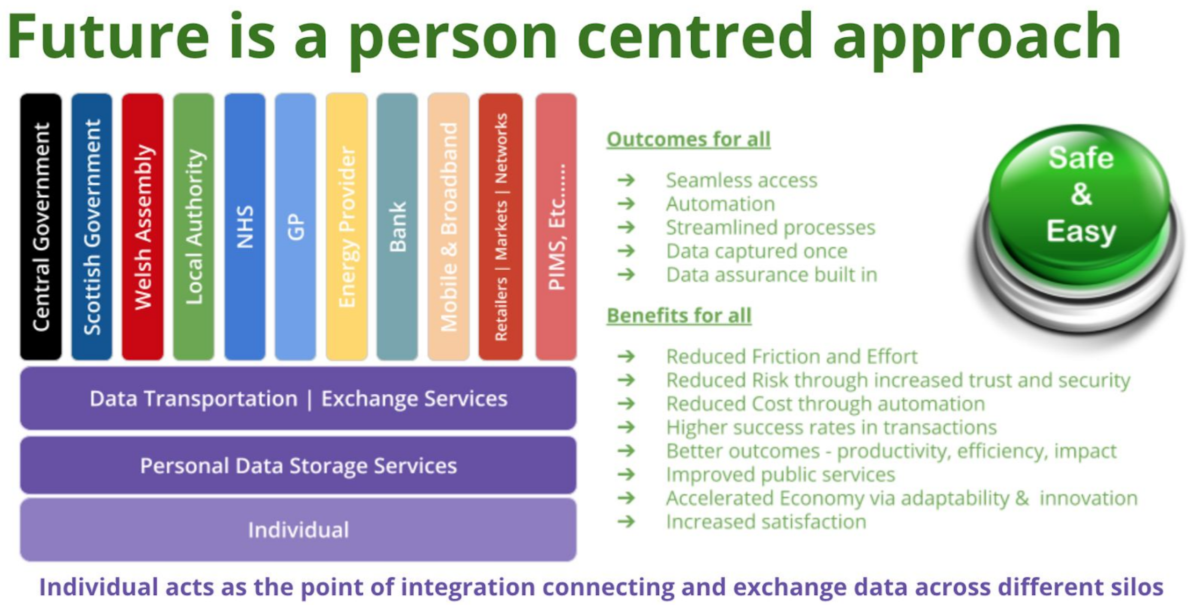
Independent living, choice and control and the overall system

These lifelong needs are powered by a personal data store (PDS) under the control of the individual, independent of service providers. A PDS can be thought of as a personal health and care record, a passport of portable evidence and proof, working in the background, able to accumulate, store and serve up what is needed to access, configure and secure support services, easily and dynamically based on the context of a person's life.

The key lessons learned in these projects and programmes are that while legacy and current back office systems used by service providers are essential to internal administration, process and record management, they are not the right way to engage with citizens. Citizens need a familiar way of working that is intuitive regardless of the service they are using, it needs to be independent from the service they use because so much of what they need to do touches multiple services. This independent experience supported by their own independent ability to store their own personal data and to exchange information across the full spectrum of services they engage with will deliver the flexibility needed for truly self-directed and self-driven care.

The need for and creation of seamless journeys for people receiving, providing and supporting adult social care is self evident. To achieve this requires safe, secure and easy data sharing to remove friction, risk, effort and cost.

By making the individual the point of integration using a personal data store that receives, collects, stores and distributes personal data where and when needed means that **Scotland will have a flexible, dynamic, resilient and scalable personal data ecosystem** working as part the independent shared infrastructure layer of Scotland. This will allow local clusters of organisations to connect in and work together serving common cohorts of individuals and be able to deliver personalised and seamless services across organisational and regulatory boundaries with full compliance. The individual is the logical point of integration as it enables connectivity across all sectors and between UK wide and Scottish services.



Future is a person centred approach

Outcomes for all

- Seamless access
- Automation
- Streamlined processes
- Data captured once
- Data assurance built in

Benefits for all

- Reduced Friction and Effort
- Reduced Risk through increased trust and security
- Reduced Cost through automation
- Higher success rates in transactions
- Better outcomes - productivity, efficiency, impact
- Improved public services
- Accelerated Economy via adaptability & innovation
- Increased satisfaction

Individual acts as the point of integration connecting and exchange data across different silos

Social care service models - the shared vision/common outcomes for adult social care

Empowered, equipped citizens able to personalise and undertake self-directed and self-driven adult social care, or have it done for them by a delegate such as a family member with a lasting power of attorney or advocate. A rich and diverse range of cross sector service providers with a seamless experience and secure data sharing via the individual. **An approach to drive down friction,effort, risk and cost (FERC)** whilst improving agency, quality of outcomes and sustainable improvement in the wellbeing of those receiving and delivering care. An approach that is secure, resilient, distributed, easy to access and focused on the needs of the individual.

Developing the vision/outcomes

By leveraging the innovations available today, educating the existing front line domain experts in the art of the possible in terms of service co-design to enable the citizen to be both an active participant and point of integration.

Use co-design to transform specific transactions to be seamless for the citizens and front line teams and informal carers first. Prioritise those transactions that are currently paper based and on the edge outside of the constraints of large scale systems and commercial contracts

Drive existing systems to expose secure API services that enable data to be collected or delivered to the citizen for onward use and distribution. Stop the development of vertically (non) integrated systems with their own identity services and front end user experience, and focus on the API services layer.

Build a directory, using an open source meta data meta protocol, of all the critical data held across Scottish Government, Third Sector that relates to Adult Social Care regardless of location in order to better map this into personal data stores and front end seamless journeys.

Realising the vision/outcomes

- Equip every man woman and child in Scotland with a personal data store and ensure they can receive, collect and deliver verified personal data about themselves, their life and their entitlements where and when they need to, with any organisation that is delivering adult social care or any other form of support services
- Ensure that all public sector organisations have a clearly defined catalogue (directory) of the personal data they hold which explains how it is collected, generated and can be accessed by the citizen totally free of charge using API's. The range and scope of data should include proof of entitlements, status, engagements, interactions and any form of evidence about them.
- Promote through policy and funding to the third sector to undertake the same approach to the data they hold and consume. Third sector organisations must be committed to data portability and interoperability to support those they serve.
- Adopt an approach to co-design an independent experience layer leveraging open source web applications that require little technical intervention that can be produced by practitioners and citizens. Integrates these into personal data stores and separate from the traditional organisation systems.

Measuring quality and success

- The number of verified attributes available to be collected or delivered to citizens personal data stores via secure API's for onward use via.
- The number of organisations delivering adult social care able to provide secure APIs to deliver and collect personal data from the citizens personal data store.
- The number of transactions that deliver seamless experiences, using web apps that work on any device, for citizens, front line staff and those acting as informal carers.

- Baseline the current cost, risks, effort and friction in current transactions and measure improvement against these over time and report publicly.
- Baseline the current outcomes from current approaches for citizens, front line staff and those informal carers and track the improvement in outcomes over time.

Priorities for a citizen centred programme

Start to drive adoption of a personal data store infrastructure and ensure they can be connected safely and securely to organisations' systems from which they can collect or choose to have delivered the data needed to underpin Adult Social Care.

Start to implement co-design using front line staff and citizens focusing on seamless integrated journeys in support of the end to-end services they need. Keep these independent of back end systems and ensure they use a personal data store as the point of integration.

Change the emphasis of the current programme away from research and revalidation of the known facts and support implementation of specific measures that actually drive transformation and improvement.

Create a team whose focus is on data cataloging and mapping, data portability and interoperability.

Risks and potential pitfalls in the development and implementation of the programme

Perpetuation of organisation centric, large scale systems procurement and implementation models that concentrate data about citizens into large databases and systems, that keep citizens disempowered and ill equipped to work independently and take control of their own care.

A failure to see that anything that relates to Adult Social Care will necessarily cover a very broad spectrum of a citizen's life. Issues from health, social care, deprivation, fuel poverty, debt management, mental health, social isolation, transport, benefits, employability and education. **This means the spectrum of data required is extensive. There is no practical way this can be managed centrally by ever increasingly large systems. We need to face up to the need for a person centred approach and distributed way of working that allows for flexibility and adaptability.**

A refreshed Implementation Plan for self-directed support 2019-2021

A strong focus on the creation of a secure and independent personal data infrastructure layer in Scotland; one in which citizens are equipped with a personal data store and able to collect, receive, store, share and distribute the information needed to secure and drive the adult care they need.

A clear commitment to measuring the real progress of organisations becoming verified attributes providers to citizens personal data stores and equally being able to consume them from personal data stores

A focus on measuring progress in terms of impact and progress on the steps needed.

A reduction in the amount of research and reaffirmation of the status quo and facts and stronger emphasis on implementation of real steps towards transformation and implementation of policy

Direct funding provided to support adoption of personal data stores and independent seamless journeys using web applications that work across all devices.

Stronger focus on support for front line staff and those adults and minors providing informal care. Whilst there is a separate Carers Act, implementation needs to be integrated.

Specific work we are doing in Scotland

Yes. Please see our work in Glasgow, Renfrewshire, West Dunbartonshire and with the Digital Health and Care institute and Third Sector. We have also been CivTech winners and now work on the *Inclued* platform in Glasgow with Glasgow City Council and other organisations. We have contributed to Scottish Online Identity Assurance Programme, (Digital Identity Scotland Programme), Smart Entitlements and we provided input to the tackling fuel poverty bill, the new Social Security Systems, the Health and Sport Committee around innovation. We have seen first hand the strong correlations between Adult Social Care, Fuel Poverty, Debt, Mental Health and the impact of social isolation through the work we are doing with front line teams.

We have an ongoing education programme seeking to help the public and third sector understand and embrace person centred design principles as part their service design endeavours and help demonstrate the strong return on investment through reduction in friction, risk, cost and effort this approach takes as well as the significant social value and impact it creates and the overall improvement in capacity and capability it delivers.

Live today

Yes. The Mydex Platform is live, independently certified and working in Scotland today.

It is available via a range of existing procurement frameworks and low cost along with a range of accelerator services designed to educate, equip and enable organisations to make connections today from their existing systems

Mydex also led the design and development of a web application generator (WAG) available on an open government licence that enables front line practitioners to map journeys and undertake co-design activities for the creation of seamless journeys for key stakeholders in any service that are fully compliant with the Digital First Standard. It does NOT require any programming to design, develop and deploy.

The WAG was developed to address the long tail of services that have not been moved to a secure digital channel and remain largely paper based. It is integrated into the Mydex platform already so the data logistics capability is in place. This, coupled with simple connections from existing organisation back end systems, means independent seamless end-to-end journeys can be created easily.

The focus has to be on ensuring there is a secure independent personal data infrastructure that enables individuals to be the point of integration and an active participant in creating and configuring personalised services they need using their own personal data.

Organisations have to become verified attribute providers and consumers delivered seamlessly and securely via the individual. This will increase capacity at the same time as reducing risk, friction, effort and cost.

Additional comments

Scotland has led the world on setting a person / citizen centric approach to delivering public services and empowering individuals to self-drive, self-direct their own lives. This policy is in our view correct but **the Independent Review and policy recommendations need to be implemented** as Scotland is fighting the inertia of the market, the status quo and generations of organisation centric thinking. Policy will only realise its potential if an ongoing proactive and positive endorsement and education of that value and clarity of what person / citizen centric means and how it can be implemented. In the same way the discrimination and bias requires positive steps to overcome the inertia, so does the redesign of Adult Social Care.

Great people are seeking to deliver great services but with little understanding of the emerging potential of personal data stores and the tools designed to help citizens be independent, empowered and equipped to be an active participant and take responsibility for their access to and use of services.

As Scottish Parliament said, *“the draft vision sets out its intentions to:*

- *Move from organisational-centred developments and architecture to placing the citizen at the centre;*
- *Make better use of data –both health & social care and citizen-generated –for decision support, service delivery, planning and research;*
- *Start to develop digital ecosystems around the individual, home & place;*
- *Create a permissive culture through improved leadership, workforce development and rebalancing our approach to risk;*
- *Foster a fertile environment for innovation and economic growth;*
- *Contribute to social care reform and supporting delivery of health & social care integration;*
- *Build on what we have, and spreading what works;*
- *Use guiding principles such as Citizen-centred; Data-Driven; Flexible; Familiar; Facilitative; Innovative; Safe & Efficient; Open."*

We believe in this vision. We are implementing it today. Our recommendations are based on this vision. We think the Independent Review of Adult Social Care needs to align itself to this vision. Currently it feels like more research and discussion and Scotland can move to action and implementation.

We have to move the needle and improve outcomes. We have to improve the quality of what is being delivered today. We have to remove friction, risk, cost and effort (FERC) now.

Mydex CIC was founded to empower individuals and the Mydex platform is designed to enable all the positive outcomes and improvements we outlined in this paper to become a reality safely, easily and securely. Our goal is to be a utility for social impact and value reducing the friction, effort, risk and cost in delivery of public services and improving outcomes for all.

Contacts:
David Alexander - Chief Executive david@mydex.org
Alex Stobart - Director for Scotland alex@mydex.org

National Autistic Society Scotland

National
Autistic
Society
Scotland

The National Autistic Society Scotland: Response to Independent Review of Adult Social Care in Scotland

About autism

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while there are certain difficulties that everyone with autism shares, the condition affects them in different ways. Some autistic people are able to live relatively independent lives, while others will need a lifetime of specialist support. It affects more than one in 100 people in the UK[1].

About us

The National Autistic Society Scotland is a leading charity for autistic people in Scotland and their families. There are around 56,000 autistic people in Scotland, both children and adults, plus an estimated 225,000 family members and carers. We provide local specialist help, information and care across Scotland to children, adults and families affected by autism. We offer a wide range of personalised quality support at home and in the community, both in groups and one-to-one. Our branches in Scotland offer families and autistic people help and mutual support, and our employment team support autistic people in work and their employers.

Introduction

The National Autistic Society Scotland welcomes the opportunity to respond to the Independent Review of Adult Social Care in Scotland. We particularly welcome the review's principle aim of recommending improvements to adult social care and its focus on human rights, and we are pleased to play an active, productive role in the first phase of the review. Our work has consistently highlighted numerous issues within social care services in Scotland, with a number of repeated concerns regularly raised by autistic people and their families and carers. Far too often, the difficulties and barriers faced in social care lead to crises, not just for the service user, but also for those around them. It is, therefore, vitally important that the conclusions reached and recommendations made by the review have been produced after consideration of the views of autistic people, their families and carers, professionals, and organisations such as National Autistic Society Scotland.

Access to Social Care

As a spectrum condition, autism results in autistic people across Scotland facing a wide range of varied needs in order to live their daily lives comfortably and productively. For some, just an hour or two per week in order to support day-to-day activities can suffice. For others, being autistic can mean needing round-the-clock care and assistance. No matter what level of support an autistic person requires, the most important thing is that they are able to access it. However, we hear from many autistic people, and their families, throughout the country who tell us that they are simply unable to access required services and support in their local

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[1] Baird, G. et al. (2006) *Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)*. The Lancet, 368 (9531), pp. 210-215, and Brugha, T. et al (2009) *Autism spectrum disorders in adults living in households throughout England: report from the Adult Psychiatric Morbidity Survey, 2007*. Leeds: NHS Information Centre for Health and Social Care. Available to download at http://www.hscic.gov.uk/catalogue/PUB01131

communities. Without this necessary access to social care, reaching a crisis point further down the line becomes a greater possibility, if not a probability, as things escalate due to a void in the support available.

We have also received concerns regarding the withdrawal of social care for autistic adults specifically, often abruptly, affecting the individual's standard of living, health and family life, as well as funding cuts also negatively affecting the support available to autistic people. More generally, autistic people constantly tell our charity that they feel the vast majority of support available, regardless of quality and accessibility, grinds to a halt when they reach adulthood, with support becoming inaccessible or non-existent after leaving children's services. This not only leaves autistic adults without the support required to live active, autonomous lives, but can also leave them feeling isolated and abandoned, with the phrase "cliff edge" often used to describe the situation that arises. Scotland requires an approach to autistic people, and disabled people in general, that encompasses and values the entire life journey, not just that of childhood. It is clear that the social care sector is no different in this regard.

The recent report *The Accountability Gap*[2], published in October 2020 and written by National Autistic Society Scotland and Scottish Autism on behalf of the Cross Party Group on Autism, following the CPG's extensive review of the Scottish Strategy on Autism[3], has effectively laid bare these issues, while amplifying the voices of autistic people and their families. The review itself included surveying the views of around 900 autistic people and their families in Scotland, with damning results. An alarming 78% of those who responded to the review told us that it was not easy accessing support locally, with 72% telling us that they do not have enough support to meet their needs. In addition, many of those respondents reported lengthy battles with local authorities to receive support they should be entitled to, telling us that where services exist, they are often inflexible and require the service user to comply with requirements and priorities without question, finding themselves, if unable to do so, refused support on the basis of being uncooperative.

We know that this stark difficulty in accessing services has a profound effect on autistic people in Scotland. Without access to support, autistic people are at great risk of negative impacts on their mental and physical health, and both their ability and confidence in undertaking everyday activities, such as gaining and keeping employment. Through the CPG's review, we know that autistic people in Scotland recognise not just the difficulty in accessing services, but the positive impacts that would come from readily available local social care services. 49% of review respondents told the Cross Party Group that their physical health would improve with more support, with 52% telling us that better support would also allow them to be more independent. Almost a third of autistic people involved in our review also told us that, with more accessible support, they would be able to enter the workforce – something that could result in not only a beneficial development in their own lives, but could also lead to them becoming more active, productive members in their communities and our society as a whole.

Social isolation, in particular, continues to be a critical issue for autistic people in Scotland. Research by the National Autistic Society has shown that autistic people are among the

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[2] Cross-Party Group on Autism (2020), *The Accountability Gap.* Available at: https://www.autism.org.uk/what-we-do/news/scotland-cross-party-group-on-autism-report

[3] The Scottish Government & COSLA (2018), *The Scottish Strategy for Autism: Outcomes and Priorities 2018-2021.* Available at: https://www.gov.scot/binaries/content/documents/govscot/publications/corporate-report/2018/03/scottish-strategy-autism-outcomes-priorities-2018-2021/documents/00533392-pdf/00533392-pdf/govscot%3Adocument/00533392.pdf

most isolated and lonely in the UK, with autistic people four times as likely to be lonely as the general public[4]. We also know that 66% of autistic people in Scotland say that they feel socially isolated[5]. The reasons for this are varied but such shocking statistics do suggest that autistic people are not being supported to build relationships and be active in their local communities, with devastating results. This is supported by 69% of respondents to the Cross Party Group on Autism's review of the Scottish Strategy for Autism telling us that, with more accessible support, they would feel less isolated.

In addition, we know that this lack of support can have other incredibly negative knock-on effects. The Mental Welfare Commission for Scotland's *No through road: People with learning disabilities in hospital* report[6] highlights that almost a third of current inpatients across Scotland are experiencing delayed discharge, with the figure reaching 46% in one particular health board area. The Mental Welfare Commission have concluded that the main reasons for this lie in a lack of funding, a lack of accommodation or appropriate care provider, or a combination of these issues, emphasising the seriously detrimental implications delayed discharge can have on an individual.

This is further explored in the Scottish Government's own *Coming home: complex care needs and out of area placements 2018* report[7], which focusses on both delayed discharge and out of area placements, finding that more than 22% of those spoken to have been in hospital for more than a decade, with a further 9% in hospital for five to ten years. This crisis of delayed discharge, that is currently impacting the lives of autistic people in Scotland, could, therefore, be alleviated by a far more efficient, accessible social care service, paving the way for inpatients to be discharged in a more acceptable timeframe. We believe that autistic people should be living within the community with the appropriate support – hospitals are not homes. To do this, there needs to be investment at a local level to tackle unmet need and ensure the appropriate level of social care and suitable housing is available.

There is, without question, major issues in terms of the accessibility of adult social care services for autistic people, which is having adverse, and even traumatic, effects on those who require support, and their families, and we recognise that local authority budgets have been tightened considerably in recent years. This, along with strategic decision-making in different local authority areas, can often lead to a postcode lottery of care from area to area. In many of these areas, this has led to eligibility for care often being reserved for those already in crisis. However, relatively inexpensive yet valuable preventative care can effectively provide autistic people with the support they require, avoiding reaching a crisis point further down the line which ultimately leads to the need for more expensive forms of support. It would be most effective for local authorities to balance their financial constraints with the needs of autistic people by providing such inexpensive preventative care in the first place, rather than having to fund the support they ultimately require as a result of the lack of preventative care.

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[4] National Autistic Society (2018), *Hidden crisis: Autistic people four times more likely to be lonely than general public.* Available at: https://www.autism.org.uk/get-involved/media-centre/news/2018-04-25-hidden-crisis-autism-and-loneliness.aspx

[5] National Autistic Society, *Too Much Information.* Available at: https://www.autism.org.uk/get-involved/campaign/tmi.aspx

[6] Mental Welfare Commission for Scotland (2016), *No through road: People with learning disabilities in hospital.* Available at: https://www.mwcscot.org.uk/sites/default/files/2019-06/no_through_road.pdf

[7] Scottish Government (2018), *Coming home: complex care needs and out of area placements 2018.* Available at: https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018

Recommendation: The Scottish Government and local authorities should address the chronic underfunding of adult social care. The evidence shows that preventative care is less expensive than the care required when a crisis point has already been reached. Funding should be made available to develop quality person-centred care at a local level to meet the needs of the population, Doing so will help people reaching crisis point and people entering institutional care – something that is inappropriate for many individuals and ultimately more costly for local authorities. The costs of something as vital as social care services should be met by our society as a whole, not by an individual.

Accountability and Training

In addition to the lack of accessible services, there continues to be a lack of accountability in this area. As autistic people, and their families, reach out for the support they require, they often find themselves passed from pillar to post with no recourse and no route of redress. Not only does this lead to a fundamental lack of support in the first place, and the associated stresses and anxieties caused by this, but it also results in confusion over where support is available and a complete loss of confidence in the system. It is, therefore, no surprise that 54% of autistic people who participated in the CPG's review told us that they do not even know where to go to ask for the support they need in the first place, due in part to the culture of simply being signposted elsewhere.

In terms of service provision for autistic people in Scotland, including social care services, there remains a void concerning what is committed to and planned for at a national level, and what is subsequently put into practice by local authorities. The Scottish Strategy for Autism provides a strong example of this - the Strategy contains many potentially life-changing commitments, which, if all implemented, would make Scotland the best place to be autistic in the world. Yet these aspirations and aims are still to be achieved because the commitments made by the Scottish Government have simply not been implemented by local authorities, Health and Social Care Partnerships, NHS Boards, and others. There are a number of reasons for this – such as lack of resources and geographical challenges – but we believe that the primary cause of this disconnect is the clear accountability gap both between national and local levels, and within service providers themselves.

It is also evident to us that autistic people and their families and carers have concerns over the standard of training provided to health professionals and other service-providers in particular, including in the social care sector. It seems to be the overwhelming view, in our experience, that autistic people are consistently seeking support from professionals who do not possess adequate understanding of autism, and social care has been directly referenced during these discussions. It is, therefore, no surprise that so many autistic people continue to feel let down in areas such as social care, where they experience an unsatisfactory and inappropriate level of support from professionals and other staff members who do not seem to possess a sufficient grasp of the knowledge required to identify and support their particular needs. This, in turn, can lead to autistic people subsequently being redirected or rebuffed because no one is entirely sure how to deal with the situation.

In addition, other concerns have been expressed to us. For example, an issue of "judgemental scrutiny" has recently been raised, concerning what some believe to be the intrusive, detrimental way that some autistic families are approached by social care workers. As well as having a negative impact on the support received and the ability of the family to feel confident and secure in the service, this also hints at the deeper underlying issues around the level of training provided to those involved, where staff are unable to ascertain what is and is not autism-related, and why a more understanding, knowledgeable approach should be considered.

Without accountability at local and national level, this lack of appropriate training continues to go unchecked, leading to both inadequate service provision and the passing from pillar to post of autistic people by professionals, care workers, and other staff members who are unable to provide necessary support or advice due to a lack of knowledge and understanding. In order to ensure that training is not only consistent across services and local authorities, but also meets the required standard, accountability must be ensured in some way. We fully agree with *the Independent Review of Learning Disability and Autism in the Mental Health Act's Final Report*[8] which recommends that the standards of information from professionals to support decision-making should be set and enforced by a Commission or Commissioner, and would like to see this proposal extended to covering all aspects of service-provision and support for autistic people. The Cross Party Group on Autism, following the recent review, has subsequently proposed a similar recommendation of a Commissioner that can oversee and regulate this area, included in its *The Accountability Gap* report.

Recommendation: Our charity, along with Scottish Autism, ENABLE Scotland, and a number of other organisations and individuals, are in the process of working on proposals for a Commissioner, which we fully believe would give the opportunity to seriously, successfully tackle the issues around accountability. The Commissioner's role would be to strive for better outcomes, introducing accountability in public services, and promoting the rights of autistic people, people with a learning disability, and their families to have the choice and control to live a good life, free from discrimination. They would close the current accountability gap – between what the law prescribes and what actually happens in reality – so that autistic people, people with a learning disability, and their families would actually have recourse when the system falls short and fails to deliver for them. The Commissioner would ensure that autistic people and people with a learning disability receive the services and support to which they are entitled, ensuring that they have an equal stake in Scotland's future.

Carers and Families

There is no question that it is the autistic people who require social care services who bear the brunt of these negative issues and their consequences. However, thought must also be given to the families and carers of autistic people, who have to live with the effects of inaccessible, inadequate or simply non-existent service provision. As detailed above, with so many autistic people failing to access the support they require, the burden to provide this often falls on parents or other family members who are thrown into a position with little or no training, experience, or additional support.

With a network of 15 branches across Scotland, and 116 UK-wide, we regularly hear from families struggling to support their autistic children, not just in younger years but in adulthood too. Some are able to track down resources and information, or fight for the services that are required, but too often families are simply left feeling abandoned and alone, unable to tackle

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[8] The independent review of Learning Disability and Autism in the Mental Health Act (2019), *Final report*. Available at: https://www.irmha.scot/

both the lack of service provision and accountability. The impact of this cannot be overstated, as having to plug the gaps in support is often to the detriment of a whole host of aspects of life, such as employment opportunities and relationships, as well as their own mental and physical health. In some of these situations, serious mental health issues, feelings of isolation, or impending crises can be faced by not only the autistic person, but also their parent or guardian.

With so many parents and family members forced to act as unpaid carers for their autistic loved ones, it is paramount that adequate support is provided to unpaid carers so that they too can fulfil their potential and live their lives fully and with as little anxiety as possible. If society is unable to provide the services that are required for autistic people, as is so often the case at present, it is unacceptable and unfair to expect unpaid carers to carry on providing what support they can, often at the expense of their own wellbeing, careers, and relationships, without additional assistance from the Scottish Government and local authorities.

Recommendation: The Scottish Government must provide increased support for unpaid carers. This could include increased breaks and core support, including helping carers to juggle work and care, and increased carers' benefits.

Person-Centred Care and Joined-Up Budgets

The identified lack of accessible services, allied to a perceived deficiency in adequate levels of training for service providers, professionals, and staff, means that vast improvements are required in order to achieve the aspiration of person-centred care. As discussed above, when services are accessed by autistic people or their families, they often find themselves provided with inadequate support, unrealistic requirements, or a poor standard of knowledge, understanding, and awareness.

Our charity's work is shaped by the autistic people we support - autistic people are more than capable of providing their own input into the services that they require and the lives they wish to lead. Because of this, we believe it is vitally important that such input is sought throughout the process of acquiring service provision. The views and experiences of service-users and the wider public, a snapshot of which we have attempted to convey in this response, should be given a far greater value than is currently the norm. Decisions taken about care should be based on and shaped by that input from the start of the support, rather than being used to simply fine tune or slightly alter decisions that have already been made previously.

Autistic diagnosis information across all local authority areas should also be collated and published centrally. This would provide incredibly valuable information, giving Integration Joint Boards a hugely beneficial starting point of being able to understand the make-up of the local population in terms of autistic people. Boards could also draw on the Scottish Government's *The microsegmentation of the autism spectrum: research project* report[9], which estimates numbers of autistic people with and without a learning disability across all local authority areas. This, as well as other important figures contained within, could be

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[9] Scottish Government (2018), *The microsegmentation of the autism spectrum: research project.* Available at: https://www.gov.scot/publications/microsegmentation-autism-spectrum/

utilised at local level to ensure that the commission and procurement of social care was well informed by concrete information and statistics related to the autistic population of any given area. It is only by involving the needs of those at the centre of social care services, can person-centred care truly be established.

In terms of finance, we presently have a system where local authorities are effectively issued core grants which they must triage to where they believe it will be most impactful. As a result, budgets differ markedly between local authority areas – some splitting learning disability, mental health, and autism budgets, while others combine them. This kind of approach will always be detrimental to less visible issues such as autism, and will inevitably lead to rationing, as we have already seen in many local authorities. In some cases, if you are autistic you also need another ‘condition’ in order to receive care – for example, some families have fed back to us that they are unable to access social care because their son or daughter doesn’t have a learning disability. Without a consistent approach in each local authority area, both financially and with regards to approach, the definition of and ability to achieve ‘person-centred care’ will automatically differ between local authority areas too.

Recommendation: Decision-making and the planning of services should be needs based and undertaken with the input of autistic people and after consideration of the number of autistic people in any given local authority area. Autistic people, and their families, should be involved in the conversations that are had about the support they require throughout their lives, something that they are more than capable of having an input in. Information that is readily available, such as diagnosis statistics, should also be utilised to outline the number of individuals who may need support in an area. The entire process for allocating social budgets should be revamped to produce a system where local authorities draw down resources centrally, on a case-by-case basis, removing any anxieties around the rationing of resources. This would ensure a system where the priority is putting in place the right package of support for an individual, rather than an incentive for local authorities to ration their support.

Pressure on Third Sector Providers

Not only is the resourcing pressure on third sector providers, particularly during the ongoing pandemic, well documented, but as a provider ourselves, we have first-hand experience of this. It is an issue that is also compounded by providers not being in attendance when strategic planning is taking place. Collaborative working between third sector organisations, social care service providers, and local authorities should be considered crucial both in terms of providing efficient and accessible support to those who need it, and alleviating the strain on third sector providers. Instead, third sector providers are often seen as an after-thought, with services planned, designed, and built by local authorities, before being contracted out for tender at the last minute. This is both an inefficient and unsustainable practice.

When collaborative working is encouraged and third sector providers are considered equal partners in planning for future care, the results are successful. For example, in Dundee, the Strategic Housing Investment Plan (SHIP)[10] allowed for collective forward planning in terms

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[10] Dundee City Council (2019), *Strategic Housing Investment Plan 2019-2024.* Available at: https://www.dundeecity.gov.uk/sites/default/files/publications/ship_2019_-_24.pdf

of developing suitable accommodation and provision for vulnerable people, including autistic people and people with a learning disability.

In addition to involvement as equal partners, third sector providers should be free to be innovative and creative, designing and implementing trailblazing models of support that meet the needs of service users. However, due to a risk averse culture created by very detailed regulation, this is often stifled or prevented. Regulation is, of course, extremely important in these areas but providers must be given the opportunity to innovate and try new things.

Recommendation: The Scottish Government and local authorities should no longer view third sector providers as an after-thought when it comes to adult social care. Third sector providers must be involved at the outset, when it comes to the planning, development, and implementation of services, with the freedom to be innovative and creative in their approach. To this end, a complete overhaul of the tendering process is required to prevent a race to the bottom and halt competition between providers as a way to lower costs. The result should be a true co-production model where local authorities and providers can plan and implement care packages together.

Establishing a National Care Service

The structure of social care is highly devolved, often down to individuals, and so nationalising care entirely would require seismic upheaval. We would have concerns that, given the very diverse nature of care, the choice that people have would be curtailed with such a move. However, a new agency could bring helpful benefits in terms of raising the profile of care, promoting good practice, setting standards, working with regulators, and championing individual people’s rights.

Any National Care Service would need to recognise that social care should be highly personalised to the individual and, therefore, a ‘one size fits all’ is unlikely to work. Only by delivering authentically person-centred care with people’s human rights at its core, rather than just aspiring to it, will a National Care Service be able to provide the adequate, accessible services that autistic people, and many others across Scotland, need and have a right to.

A National Care Service should also target consistency of quality across the whole of Scotland in all areas, including funding and accessibility, if it is to successfully replace the current setup, which has great inconsistencies across local authority areas. In addition, any National Care Service would also have to consider the perennial problem of retaining staff within social care. Great consideration would need to be given to appropriate salary levels, career pathways, and other aspects of employment to ensure that staff would be encouraged to not only remain in post, but progress and thrive. There is simply no point in establishing a National Care Service that continues to suffer the same issues around staff retention as the current setup, when well-planned measures could be designed to avoid this.

Recommendation: A National Care Service, with the rights of people central to its service provision, must achieve consistency across local authority areas, both financially and in terms of accessibility and service efficiency, while also avoiding a disastrous ‘one size fits all’ approach. Any new Service must see a consistent approach to budgeting and expected standards throughout Scotland if it is to achieve real progress for the adult social care sector. In addition, the care sector in Scotland requires further professionalisation, with the appropriate support provided. National pay and employment conditions must be fair and appropriate for the roles in question, ensuring parity between all providers, including local authorities and third sector organisations.

Recap of Recommendations

- The Scottish Government and local authorities should address the chronic underfunding of adult social care in a way that ensures effective preventative care.
- The Scottish Government should legislate for a, responsible for introducing accountability in public services and promoting the rights of autistic people, people with a learning disability, and their families.
- The Scottish Government must provide increased support for unpaid carers.
- Autistic people should be involved in decision-making and planning of the support they require.
- The current process for allocating social budgets should be replaced with a system that ensures the priority for local authorities is providing the right care package for an individual, rather than how best to ration service provision.
- The Scottish Government and local authorities should adopt a co-production model that ensures third sector providers are considered as partners.
- The introduction of a National Care Service must result in consistency across all local authority areas, while avoiding a ‘one size fits all’ approach.
- A National Care Service must ensure fair national pay and employment conditions, ensuring parity between all providers.

Conclusion

The National Autistic Society Scotland continues to fight every day to better the lives of autistic people in Scotland by working to create a society that works for them. There are fewer areas that generate as many difficulties for autistic people, and concerns amongst their families, as that in regards to social care services. In particular, these difficulties usually arise in terms of a lack of accessibility to services, a lack of accountability and training within services, and inconsistency in approaches from one local authority to another. In order to ensure that autistic people receive the support that they need and are entitled to, it is vital that the Scottish Government ensure improvements in all of these areas. For our charity, the experiences of autistic people who have reached crisis point due to not being able to access suitable support, and parents or other relatives acting as unpaid carers who are at breaking point due at the lack of accountability and assistance, are all too common. Only properly considered and implemented improvements that eradicate these negative experiences can see genuine progress towards a social care service that works for autistic adults in Scotland.

Oxfam Scotland

Derek Feeley,
Independent Review of Adult
Social Care in Scotland.
secretariat.adultsocialcarereview@gov.scot

Oxfam Scotland
4th Floor, 10 Bothwell Street,
Glasgow, G2 6LU
https://oxfamapps.org/scotland/

25 November 2020

Dear Mr Feeley,

Firstly, warm congratulations on your appointment as Chair of the Independent Review of Adult Social Care in Scotland. Given the timescales involved, I'm sure this is a significant and challenging task.

I am getting in touch with you to share Oxfam Scotland's new report: **Care, Climate and COVID-19: Building a Wellbeing Economy for Scotland**. The paper captures our priorities for the Scottish Parliament, both immediately and beyond the Scottish election in May 2021. While we recognise the scale of the public health crisis, our report highlights four linked priorities:

- **delivering a wellbeing economy built on care, while leaving no-one behind;**
- **the better valuing of – and investing in – all forms of care work and those who provide it;**
- **caring for our planet by delivering climate justice; and**
- **caring for people in poverty and humanitarian crisis globally.**

The report outlines 20 recommendations across these priorities, including those designed to build on the surge in public and political solidarity for those with caring responsibilities. We believe that care is systemically under-valued and that this is leaving too many people, particularly women, trapped in poverty. We are therefore calling for **a new National Outcome on valuing and investing in all forms of care** – including ensuring paid and unpaid carers are protected from poverty – to be placed at the heart of the National Performance Framework. We believe this National Outcome can help lock-in the lessons from COVID-19 and deliver meaningful, and measurable, change.

The COVID-19 crisis has highlighted the incredible dedication of paid social care workers and the urgent need for substantial new investment in the sector to protect them from poverty. Even before the coronavirus crisis, far too many paid care workers, were living in poverty due to poor quality work. Our report therefore makes two core recommendations for the Scottish Parliament on social care:

- Commit to significantly, quickly, and consistently boosting investment in social care in Scotland, while protecting other vital services, including consulting on a dedicated Scottish Social Care Tax on high incomes or wealth.
- Commit to reforming the approach used to commission and procure social care to ensure it consistently delivers fair work for those working in the sector, alongside high-quality care and self-directed support for all those who need it, with input from paid care workers, those who receive care, and unpaid carers.

Our new report follows the release in July of **Making Care Count in Scotland** (available here). This briefing explored the context for people with different types of caring responsibilities in Scotland – including paid care workers. It complements Oxfam's work on these issues at British and global levels.

I hope these papers are timely and helpful, and I would be delighted to speak directly with you.

Yours,

Jamie Livingstone
Head of Oxfam Scotland

Penumbra

Penumbra’s submission to the Review of Adult Social Care

About Penumbra (www.penumbra.org.uk)

Penumbra is one of Scotland’s largest and most innovative mental health charities. We support around 1800 adults and young people every week and employ around 500 full, part-time and relief staff across Scotland.

Founded in 1985, we work to promote mental health and wellbeing for all, prevent mental ill health for people who are ‘at risk’, and to support people with mental health problems.

We provide a wide range of community services across 18 Health and Social Care Partnerships which offer hope and practical steps towards mental health recovery,

These services work across the mental health spectrum from early intervention/prevention services to 24/7 services for people experiencing longer term mental ill health issues. Many of our services are innovative and/or leading creative responses; examples such as 5 services that support people who self harm, the Edinburgh 24/7 Crisis Centre (unique in Scotland), as leading partners in the Distress Brief Intervention programme, services for people experiencing Alcohol Related Brain Damage (ARBD) and our Nova services which have redesigned day/drop in services by closing the building based services and delivering meaningful support and connections for people to access community resources in their own localities. We have also developed and validated our HOPE/I,ROC approach which ensures we take a personal outcomes focused approach to delivering support. I.ROC (www.irocwellbeing.com) is our measure of personal wellbeing/recovery and is now used by 78 organisations worldwide. We have English, Dutch, Spanish, Czech and Chinese versions. Penumbra is the host for the Scottish Recovery Network (www.scottishrecovery,net) and we campaign to increase public knowledge about mental health and to influence national and local government policy.

Introduction

We welcome the review of Adult Social Care as we believe it is now time for radical transformation in the way we plan, commission and provide care and support for people who experience mental ill health.

We endorse the submission to the review by the Coalition of Care and Support Providers Scotland (CCPS) which takes account of our hopes for reform across social care.

Our submission will deal more specifically with mental health issues as this is the area we know best.

System issues

When we look across the field of mental health services it is interesting to reflect that many of our services operate across the spectrum/divide of Health and Social Care. Many of our services are registered with the Care Inspectorate, but not all. Often the determination of what is and isn't registered is uncertain. It tends to be judged on whether people are referred to the service following a social work assessment or if they can self refer/walk in.

At a national level mental health policy still depends on a 'medical model' of service delivery whilst we believe a more modern way of looking at mental ill health needs to consider a more holistic, social approach that recognises trauma, distress, life events, poverty of opportunity and finance and lack of wellbeing as social determinants of mental ill health and not a system based merely on the presence or absence of codified mental illness signs and symptoms.

The opportunity exists for mental health services to be truly integrated, multi agency and person centred but this will require a shift in the current practice and culture of many services.

We still have a fragmented system where secondary and primary care/community services are often managed separately and people can fall between the gaps.

People who experience mental ill health find that services are often not flexible. Our systems tend to be linear rather than flexible and elastic to meet the fluctuating needs of people's mental health. People will often talk of 'hanging onto' their support/service as they don't know if they will be able to get the same service again should their issues escalate. This means we are often supporting dependence on the system when they may not need that level of support at that time.

Mental health recovery (where people can achieve fulfilling and meaningful lives despite ongoing mental health challenges) has been reflected in Scottish Government policies for a number of years. However, we have yet to sustain any significant progress towards a culture of recovery focused approaches across the field.

A key issue in social care is **commissioning and procurement.** We experience this as a blunt device and often involves generic frameworks based on hourly rates which do not work well for people experiencing fluctuating needs associated with their poor mental health. We are on countless framework agreements across the country but if there is not sufficient volume to sustain our work it is difficult to provide a good quality service. Frameworks often involve one-off short term pieces of work which are very difficult to recruit staff for. We can't afford to have staff simply waiting in the wings for contracts to come along. There is often little focus on personal outcomes for the people supported as the system relies on counting outputs in hours of support delivered.

These frameworks are often specified to provide 'more of the same' and stifle creativity and autonomy to 'do the right thing'. An example of this was the recent Scotland Excel national framework for supported living services where the original aims of this work were commendable, but ultimately it ended up as a fairly generic time and task framework based on hourly rates. Many competitive tenders have been reduced to answering 4 or 5 technical questions in 2000 characters along with a pricing score based on rewarding the lowest price. This has turned the tendering process into an 'essay writing' competition where professional bid writers are often involved. No account is taken of other information on quality or local knowledge or the types and numbers of staff to be employed

Regulation and Legislation

We believe the original Regulation of Care (Scotland) Act 2001 needs to be revised to reflect a modern understanding of the support and care provided for people. Categories for services and staff are anachronistic. The Care Inspectorate registers individual services and not the organisation which is time consuming and costly. Instead, we should register the organisation (an approved provider register?) and then seek to inspect and monitor the approaches and practices delivered by the organisations which would enable more flexibility and creativity in designing and delivering services.

The Scottish Social Services Council has too many categories of registered care workers (some of our staff have to register on two or three different registers to do their routine work). We would suggest a register for managers of care and support services and a register for practitioners/workers in care and support services.

National Care Service

We don’t know what a national care service is. However, we can surmise that this might be seen as an adjunct to the NHS. We do not believe this is a suitable way forward. Social care supports people to live meaningful and fulfilling lives as far as possible. The emphasis is on the person not the ‘illness’. Supporting people to recognise their strengths and abilities is central rather than simply focusing on their dis-ability. The use of the term social care may in fact hinder the true aim and meaning of how we are trying to support people to flourish within their communities. In mental health we can see merit in having a shared vision, mission and values that underpin the approaches, culture, practice and delivery of recovery focused, person centred services across health and social care.

Workforce

Recruitment and retention of a skilled, valued and appropriately rewarded workforce is a real challenge. We cannot compete with the terms and conditions of the statutory services now. We used to be able to do this, but successive rounds of tendering and retendering of services has led to a significant gap between us as contracted providers and the NHS/HSCP workforce. We often recruit, train and develop staff only to see them move to similar roles in HSCP’s that are better paid.

Our staff are often the people who spend most time with the people we support and know and understand them well. At times they are not involved in reviews or plans for that person (mainly as they do not have the time to attend reviews as we are not funded for this). The current Covid 19 situation has meant that we are often the only support available to people as other services have been suspended or eligibility has been changed.

The current process of procurement often makes it difficult to sustain a valued workforce as short (3 year contracts) mean that there is uncertainty when services are retendered and staff will look for other opportunities. Framework agreements also mean that we need to deliver higher levels of productivity for our services than expected by NHS/HSCP staff. An example is when we compare the hourly rate we receive for a Care at Home Service with that of an inhouse HSCP service. We might get £18 per hour of delivery whereas the inhouse service cost is about £40 per hour.

We propose that there should be parity of pay for social care workers with the Agenda for Change NHS scales (previously we could benchmark our staff to Band 3 or 4, now we can only meet the first increment of Band 2.)

People receiving mental health support

The people we support value our focus on recovery. They feel involved in the decisions that affect their day to day lives. They like our wellbeing approach as this focuses on the aspects of day to day life that can be challenging or difficult whilst coping with mental health issues. Our approach is based on hope which we know is a significant part of people's recovery journeys.

hope

home
a safe and secure place to live

opportunity
to pursue meaningful leisure, recreation, education and work possibilities

people
as friends, confidantes and supporters

empowerment
fully involved in decisions affecting own life

People we support like our 'stickability', to be alongside them on their recovery journey. We work with and alongside people.

We are reminded of the phrase printed on a t-shirt during a very difficult tendering process which said, 'my life is not a three year contract'.

Conclusion

Thank you for considering this brief submission. We would be happy to provide more information if you require it, but we are mindful that you will be inundated with submissions. Therefore, we have highlighted some of the issues and tensions that challenge us.

Nigel Henderson, Chief Executive.

Penumbra November 2020

Police Scotland - Drugs Deaths Task Force

Date: 6th November 2020

Your Ref:

Our Ref: VA/DD

secretariat.adultsocialcarereview@gov.scot

POLICE
SCOTLAND
Keeping people safe

POILEAS ALBA

Dear Sir/Madam,

Review of Adult Social Care - DDTF response

I write in your response to your invitation for Police Scotland to provide feedback on the review of Social Care in Scotland. This response provides a general overview of our experience within the Social Care landscape rather than specifically from a Drugs Deaths Task Force perspective. Police Scotland has daily interactions with members of the public who access these services and, indeed make thousands of referrals into the Social Care system annually. It is for this reason Police Scotland would like to contribute to this review.

Consistency of Approach

As a national organisation, Police Scotland deal with all local authority Social Care Services. There has not been an opportunity to take a national view of the consistency of services provided however anecdotal evidence suggests that there are differences. Police Scotland would be happy to assist the Review by surveying our territorial divisions to establish a national assessment, which could then be used to direct further investigations within Phase 2.

The Interface Between Drug Services, Children & Family Services; Justice Services; Wider Health Services

The services provided through Health & Social Care Partnerships are extensive and in some areas, due to the scale of the services being delivered, clear delineation seems to exist between business areas. As with all large organisation this can result in silo working on occasion, which in turn could result in a disjointed service for the individual.

Furthermore, the Community Planning Partnerships across the country regularly make further distinctions between Alcohol and Drug Partnerships, Children's Services and Community Justice Partnerships which also contributes to this tendency to silo.

In addition, at the Community Planning level Regional Health Board services tend to have less involvement, instead attending/reporting to the Health and Social Care Partnership grouping. Police Scotland recognises the link between Public Health and criminality, victimisation, vulnerability and general wellbeing and therefore sees this additional separation as detrimental to the wider delivery of Community Planning objectives where it occurs.

The Involvement of People With Lived Experience in Planning, Designing & Delivering Services

Police Scotland acknowledge the benefits of utilising the skills and experience of people with lived experience in the planning, design and delivery of services however we are not aware of current processes within the statutory Social Care setting and therefore are unable to comment further.

Commissioning & Procurement of Services

Police Scotland are placing greater emphasis on prevention, not only of crime and victimisation, but also extending to vulnerability and wellbeing. Public Health principles directly link the various early stages of harm with a person's long term prognosis. Currently services are often concentrated around those who could be described as at immediate risk or in severe crisis at a point in time; often missing the various smaller events that have contributed to create that situation. It is only through early and rapid intervention at points further upstream that we can ever hope to divert these major times of crisis which can often end tragically or in a situation where the level of statutory service support becomes long term and expensive.

As a Police Service we feel we are not the appropriate organisation to commission services. To ensure the appropriate levels of safeguarding and monitoring of commissioned services are in place this role must sit within a structure where professionally trained staff can monitor, manage and judge the suitability of services being offered. It must also sit within an organisational structure where levels can be flexed to meet local demand.

Police Scotland have a great deal of respect for both the statutory services and 3rd Sector services working within this arena and would welcome an opportunity to be able to refer the vulnerable people we have contact with to a wider range of services to meet their varying levels of need.

Accountability for Ensuring Appropriate & High Quality Service Delivery

Police Scotland are committed to taking a Whole System Approach and accept the resulting responsibility of our role as part of the 'System' to ensure the benefits of all services are realised. Our organisation already works with others in multi-agency fora and we would hope to continue and expand this constructive and co-operative way of providing the best services to those in need.

Police Scotland is also a learning organisation where we monitor and review our service to the public. We would welcome the opportunity to provide feedback on local service provision to commissioning organisations on the effectiveness of services from a policing perspective.

Data Sharing

Police Scotland appreciate the benefits of data sharing to ensure public safety and to make effective and efficient use of available service provision. We are happy to share specific data with relevant partners through our Vulnerable Persons' Database however this can be restricted to all but essential information, particularly for those organisations working in prevention. The extension of commissioned services through statutory social care providers could allow more individuals, identified to be at low to medium risk, to be referred through our current data sharing processes, allowing for more meaningful information to be shared.

Another aspect is the benefit of sharing outcome data. The provision of data relating to the success of referrals made to social care providers and the meaningful improvements for individuals would be welcomed and could be met with reciprocal feedback that might indicate reductions in offending and/or requests for emergency response, possibly indicating a growing resilience. This would encourage sharing and promote positive interventions.

Outcomes Based Investment in Services

It is essential to monitor the effectiveness of services to ensure that they are making a difference to the individuals but also to guarantee value for money. However moving to a model where we focus more on prevention and the value of services to an individual means that the measurement of outcomes must be calculated differently. This again requires commissioning organisations to embrace the whole system approach, to look not only at their own measurement criteria but also at those of other participants within the system as well as the individual themselves.

It is also important to accept that some of those leading the most chaotic lives may require multiple attempts by service providers to engage and this should not be seen automatically as a failure. Flexibility in approach would benefit those with more entrenched difficulties.

Observations

Police Scotland understand the benefit of local services for local people and a focus on place is important to us. We would therefore support, where possible, commissioning local organisations, or those recognised as such by communities as local.

The facility to provide access to Community Prescribing could be extended to allow easier routes for more organisations to refer into. This would be particularly helpful for situations where our officers identified loneliness or isolation as an issue.

Police Scotland appreciate the demand on the current Social Care system however acknowledge that some of this is caused by a failure of the system to take appropriate action at the earliest opportunity. The adage of 'striking while the iron is hot' is often appropriate to people who reach out for help and any delay in responding to this request can limit the effectiveness of a later engagement.

Police Scotland acknowledges and supports the advancements in mental health service provision with the NHS24 Mental Health Pathway and the extension of the Distress Brief Intervention programme across the country. This however may not suit all situations and the addition of local face to face services would be of benefit to some.

Conclusion

Police Scotland's links to those working in Social Care have been part of our organisational structure for many years and could easily be described as our most important and largest partners when dealing with those most vulnerable within our communities. This relationship is hugely important to us and we are keen to help develop the future service of social care provision in Scotland.

Quarriers

Independent Review of Adult Social Care

Overview

1.1 Quarriers is a national charity that provides care and support to around 5,000 people across Scotland. We provide a wide range of services that fall within the scope of this review, including: supported living and short breaks for disabled people (learning disabilities, acquired brain injuries, autism and physical disabilities); the provision of support to people with epilepsy; support for people with addictions and mental health problems; support to unpaid carers; support for disadvantaged families; and youth homelessness services (including young adults). We work in 19 of Scotland's 32 local authorities, employ around 1,700 members of staff, and receive support from several hundred volunteers. Our portfolio of services illustrates well the breadth and diversity of the care sector and the work that happens within it.

1.2 Quarriers supports a human-rights based approach to the delivery of social care. We are committed to transforming lives by enabling the people we support to realise their true potential; to support people to be active citizens who are in control of their support; and to have greater independence and be included in their communities. Our job reaches far beyond the narrow concept of 'personal care' – rather, it is to create the conditions that allow people to contribute as citizens and to pursue a fulfilled and purposeful life.

The Social Contract

2.1 The social contract that exists between the citizen and state defines the support arrangements that citizens can expect from government – and what they must contribute as citizens in return. In respect of healthcare, most citizens tacitly understand that we each contribute through general taxation based on our ability to pay, and in return receive healthcare free at the point of use. By contrast, there is no clearly defined social contract in relation to care: it sits at the heart of a much more complex public service offer which draws partly from the welfare state, from the NHS, from local authority commissioned support, from charitable fundraising and from direct/private funding from the citizen. The independent review has an opportunity to change that - to define the social contract more clearly in respect of adult care and support.

2.2 We recognise that the Scottish Parliament has sought to bring some clarity to this matter by legislating in relation to Free Personal Care, even though this was restricted to personal care and to older people (the Scottish Government has since sought to remedy this by extending the policy to under 65s, but this is a contingent offer that it is not grounded in legislation). Nonetheless, the Free Personal Care legislation frames a social contract of sorts: we all contribute through taxation and in return receive personal care if needed in our older age for free. This foundation could be radically developed beyond the existing focus on personal care, to deliver a better-defined social contract for all adult citizens who need care and support, defining rights and obligations. A consolidated Bill of Rights would support this ambition.

2.3 It is also fair to say that the cost of the Free Personal Care policy was hugely underestimated and has grown significantly since being adopted by the Parliament. We make this point to underline that the Scottish Government's policy aspirations **must** be accompanied by commensurate resources – otherwise, growing demand will be managed locally by restricting eligibility or access.

2.4 Quarriers believes that social care (as distinct from personal care) should be a right, provided free at the point of use to those whose needs are assessed as requiring support. But we would rather that the Scottish Government does not commit to that aspiration without a similar commitment to resource it, recognising that it is politically challenging to increase income from the tax base or reallocate resources from other areas of public service. Meaningful investment and reform must be advanced together.

Voice, Choice and Control

3.1 The Social Care (Self-Directed Support) (Scotland) Act 2013 has not achieved its transformative potential, despite this being the intention of the legislation. This is partly because it is difficult to apply to all models of care (residential care is still a significant part of the social care sector), partly because of insufficient change capacity within local partnerships (who have also been focused on health and social care integration – another key priority), and partly because of inherent conservativism within the structures and processes of local commissioning and procurement arrangements.

3.2 Self-Directed Support (SDS) needs to be reinvigorated if it is to provide more people with the opportunity to exercise choice and control over their support arrangements. The approach has its roots in human rights: social care begins with a recognition of human agency, the desire to decide for ourselves how we want to live, with whom and in what community. It is potentially empowering and radical.

3.3 To enable the potential of SDS, we believe that the Independent Review should commit to overhauling policy and practice in relation to procurement.

Commissioning and Procurement

4.1 The strategic commissioning of care (the process by which support arrangements are brought into being) has been aided by health and social care integration, in that it allows for whole system planning and investment. Although further work in this area is undoubtedly required, the function and duty are appropriately situated with Health and Social Care Partnerships.

4.2 Health and Social Care Partnerships need time and space to develop, to focus on cultural change. However, new opportunities should be developed to embed collaborative leadership. For example, it is a peculiar reality of the health and social care system in Scotland that two key leadership positions (the Chief Officers of HSCPs and the Chief Executives of providers of national care providers) very rarely meet and talk – we are only now seeking to change that through collaborative engagement. The Scottish Government should place much more emphasis in supporting this type of leadership and strategic engagement. Relationships are better aligned within the public sector, but often strained by competing demands of governance and control.

4.3 Procurement practice has become an industry of its own, leaving the impression that when good social care arrangements *are* commissioned, it is *despite* rather than *because* of the procurement process. The competitive tendering process in particular reinforces unequal power dynamics between local authorities and providers: it implies the latter are there to price a job and compete, rather to be engaged as strategic partners.

4.4 All stakeholders within the care system are held captive within these arrangements, including those procuring care and those providing it. The procurement process at its worst drives providers to unsustainably low operating contract prices, erodes or restrains the terms and conditions of care staff, and often delivers poor quality outcomes.

4.5 As an organisation, Quarriers chooses not to compete for contracts below a certain price threshold because we are committed to quality, to being a progressive employer and a contributor of social value.

Workforce

5.1 The social care workforce has been historically undervalued. Quarriers seeks to be a model employer, to pay more than the Scottish Living Wage, to offer progressive terms and conditions, and a career structure. However, it scarcely needs mentioned that our terms and conditions compare unfavourably with public sector arrangements, as evidenced by the following table for entry level care:

Year	Quarriers (Support worker)	Local Government (Carer) (sample)	NHS (Healthcare Assistant)
2020/21	£18,860	£20,816-£22,726	£20,700-£22,594
2019/20	£18,252	£21,192-£22,045	£19,945-£21,947
2018/19	£17,745	£20,557-£21,384	£18,292-£21,349

5.2 Third sector providers will typically have a lower starting salary, alongside wider disparities around incremental progression (typically the preserve of the public sector) and pension benefits. What is more, while the living wage policy agenda has helped improve pay for entry level care workers across the sector, other more specialist roles have received relatively modest increases in pay, which can give rise to differentials of around £10k per annum between the third and public sectors. This downward pressure on terms and conditions is a result of an operating context where public agencies outsource significant efficiency savings.

5.3 Were the Independent Review to recommend reform in the direction of the Fair Work principles, then that would be positive, but it will be important to guard against perverse outcomes. If the cost of delivering care within the third sector converges with the public sector as terms and conditions improve, we could see more services brought into a public sector delivery arrangement. Were this to happen, it would reinforce the idea that third sector providers have a purely instrumental value whose existence can be justified only insofar as they deliver cheaper care. We would argue the value of the third sector ought therefore to be positioned to highlight its inherent value: as purveyors of quality; as fundraisers; as strategic partners with real insight into the issues that matter most to the people we support. Besides, the plurality of providers that currently exist in the third sector is a prerequisite of the choice and control imagined by Self Directed Support.

Community Coproduction

6.1 The future of commissioning needs to be articulated at individual (SDS) and community levels, not just at HSCP level. Most local authorities are administrative vehicles whose boundaries do not align with natural communities. Consequently, services can be designed and applied without regard to more fundamental principles around local buy-in and ownership.

6.2 Our most valued services were not simply procured by local authorities; they have been developed over time, with community/neighbourhood involvement, supported by an assembly of grant funding, commissioned care, and charitable funds. They deliver on the principles of the Christie commission: coproduced, asset-based, developed from the grass roots, where need is most clearly articulated and understood. And yet, these arrangements are the exception rather than the rule.

Improvement and Support

7.1 Quarriers has a positive relationship with the Care Inspectorate and Healthcare Improvement Scotland. In respect of the former, we meet regularly with our link inspector and have cultivated an open and honest relationship that supports improvement and compliance.

7.2 However, as indicated elsewhere, the regulatory regime in Scotland can invert the customer relationship, where those with responsibility for service delivery and quality improvement define their agenda by reference to the Care Inspectorate's requirements rather than in relation to the people we support.

7.3 We have strong internal systems to support quality improvement, but we would nonetheless benefit from a revised improvement offer nationally.

Appetite for Change

8.1 All stakeholders within the sector need to be committed to change, including third sector providers. That means more openness to partnership, sharing information, mutual improvement, strategic planning. Some of this is beginning to happen, but it is often piecemeal and disjointed. A coordinated national effort to support collaborative leadership and to reset strategic relationships is required.

8.2 Existing structures could be improved; most providers remain distant from the Integration Joint Boards, despite a third sector presence being required (the third sector interface has not worked well, though we acknowledge the challenge of collectively covering off the representation of the sector). Relationships with local authorities and Health Boards are more distant still.

Conclusion

9.1 Quarriers is pleased that a national conversation is beginning to develop around the future of adult social care. Based on the analysis above, we would commend the following reforms:

- Rearticulate the social contract for adult care and support, defining the obligations of the state and the citizen, providing investment which is commensurate with the ambition of the social contract.
- Break the connection between procurement, commissioned hourly rates and staff terms and conditions within the third sector by channelling support through core grant funding to providers or as a personal budget to an individual.
- Remove the bureaucracy around workforce policy and resource the Fair Work agenda. As a result of Covid-19, the uplift to pay for the Living Wage commitment was delivered nationally – this was far more efficient and allowed providers to commit earlier in the year to a staff wage increase.
- Strengthen our commitment to community benefit – less an add-on to a procurement process, more a central driver in the allocation of funds, focusing on the principles espoused in the Christie Commission report. Use this process to support partnerships between providers of care and support, and as a mechanism to recirculate resources within communities (jobs, social capital, etc.).
- Sponsor a coordinated national effort to support collaborative leadership and reset strategic relationships.

Queens Cross Housing Association

Queens Cross Housing Association

45 Firhill Road,
Glasgow G20 7BE
T: 0808 143 2002
E: Contactus@qcha.org.uk
www.qcha.org.uk

Independent Review of Adult Social Care
Submission from Queens Cross Housing Association (QCHA)

Queens Cross Housing Association are members of the Coalition of Care and Support Providers in Scotland (CCPS) and we are in agreement with their submission. We also participated in an Alliance focus group with housing colleagues on 3rd November 2020 to contribute to the discussion on the review of adult social care.

In addition to feedback CCPS have provided we would like to highlight the essential role that Housing Associations, like Queens Cross Housing Association, have in providing adult social care.

QCHA is a community based Housing Association in the North West of Glasgow. We provide nearly 4500 homes. Our vision is for excellent housing in vibrant communities. In addition to general tenancy sustainment support for people who are struggling to maintain their tenancy we operate three registered housing support services.

Through our Wellbeing services we provide adult social care to young people who have experienced homelessness, people aged 60+ and people experiencing or recovering from mental health related issues. We currently support over 500 people and employ over 50 social care staff. We use an outcome and strength based approach to support people with managing a tenancy and accommodation, enabling them to live independently in the community. We focus not only on housing but also on health and wellbeing, relationships, safety of self and others, managing money and personal development.

We feel it's important that the Panel of the Independent Review of Adult Social Care are aware of the impact that Housing Associations like QCHA have in delivering a community based approach to social care and supporting people to be independent and engaged in their local community.

Our starting point is providing people with a home, a place where they feel safe and secure and this provides the basis for people to engage with support and lead fulfilling lives. From here support is provided with an emphasis on engaging people in their community and accessing community resources, many of which are provided by QCHA. This model of support, where secure accommodation in independent tenancies combine with support provided by the same organisation allows for a joined up approach that delivers excellent outcomes.

It is worth noting that this model is flexible and support can also be provided to people out with our tenancies. A variety of successful permanent accommodation with support models are operated by Housing Associations across Scotland.

At QCHA we know our tenants needs. We regularly complete a household profiling survey with all our tenants called 'Getting to Know You'. The results of this survey give us a comprehensive understanding of the lives of our tenants and their needs, which we use to direct our services. Through this survey we are able to identify people that would benefit from preventative support and we know this support would make a significant difference to people's lives.

There would be considerable benefits if the adult care system was more flexible and reformed to facilitate the provision of preventative support via our registered, in-house Wellbeing services. However to access a support service you need to meet the criteria set by commissioning which focuses on medium to high needs. Social landlords are well placed to identify needs in their communities and if interventions were made earlier this would not only have a better outcome for the person but would also save money in terms of reduced hospital admissions, presentations at A&E, relieve pressure on the criminal justice system etc.

For example our staff routinely identify people who are struggling with their mental health, or their physical health or are at risk of losing their home, however they are generally not able to make a direct referral to our commissioned Wellbeing services.

An exception to this is our Wellbeing 60+ service which, following the decommissioning of sheltered accommodation in Glasgow was remodelled and is delivering a pilot ‘Intervention Service’ for older people. The Intervention service is open, taking referrals from owners, private renters as well as our own tenants and helps older people through a short period of crisis such as hospital discharge or following illness / a fall and providing intensive tailored support for up to 6 weeks until the individual recovers or long term arrangements are put in place.

QC Wellbeing Housing First for Young People Case Study

Amanda* is 19 years old has been supported by QC Wellbeing for young people service, initially in residential accommodation for 18 months and then in her own QC secure tenancy in the surrounding community.

Amanda is a care leaver and has been accommodated since the age of 14. Prior to being accommodated her name was placed on the Child Protection register on 4 separate occasions. Amanda was subject to physical abuse and neglect from her parents and has been at risk of significant harm for most of her lifetime.

Amanda’s time in care was difficult, with 5 different placements all of which broke down. Amanda has endured significant trauma and has a diagnosis of emotionally unstable personality disorder, while also suffering from low mood and social anxiety. During her placements Amanda would regularly display aggression towards those who were responsible for her care and would regularly engage in self-harm and risk taking behaviour. She was detained under the Mental Health Act on numerous occasions and was seen as being at high risk of accidental suicide.

Amanda moved into QC Wellbeing for young people’s residential service and immediately she put up barriers to the support provided. Amanda expected the placement to fail. However our support team persevered and Amanda gradually began to trust and build relationships with the support team (our young people describe this as our stickability .. we don’t give up).

When Amanda moved into the service was having several incidents a week of self-harm requiring the involvement of the ambulance, police and out of hours mental health services. However, since receiving our support these have reduced significantly to 1 or 2 incidents a month. Amanda now engages with the community mental health services and trauma team, while being supported to develop better coping strategies. Our support team have worked in partnership with the trauma team who have delivered bespoke training so we can provide the support, responses and boundaries that Amanda needs.

Amanda since receiving support from QC Wellbeing has gained many new skills including, managing her health and wellbeing, being responsible for her own medication, budgeting, household skills, cooking and engaging in positive activities with her peers. She has been empowered to build positive relationships with others and keep herself safe. In addition Amanda has recently completed a college course, despite having a disrupted education where as a child, she spent more time out of education rather than in.

In January Amanda will be moving into her own permanent tenancy with QCHA. She will continue to receive support from the service and will have the same keyworker – no need to share her story again. Her new home will be in the locality where she is settled and within walking distance of our 24/7 support team. In addition to this support she will benefit from the QCHA community focused approach with this move - from the Home Team who will help her build furniture for her new tenancy to the Financial Inclusion team who will ensure she is able to maximise her income to energy advice to set up affordable fuel tariffs to social regeneration who will engage her in activities in local community.

* Name has been changed to protect young person's identity.

Royal College of Nursing

Royal College
of Nursing
Scotland

RCN Scotland response to the Scottish Government's

Independent Review of Adult Social Care

Context

RCN Scotland is proud to represent members working in social care settings. As a Royal College, we believe it is the right of everyone to receive high quality, safe care in all settings, and to be treated with dignity and respect. In Scotland's integrated health and social care landscape, adult social care is providing an essential alternative to hospital care and complex health care needs are increasingly being met within a social care environment. Where nursing care is required, people who use social care services, including care home residents, deserve to have it provided by the right numbers of nursing staff with the appropriate skills, competencies and training.

The RCN Scotland paper, *Registered Nursing in Care Homes, March 2019*[1] makes the case for a greater acknowledgement of the clinical needs of care home residents and a person-centred approach to social care. Since the COVID-19 pandemic, we have consistently and loudly stood up for our members working in social care settings. Unfortunately, this sector, as has been the case before the pandemic, was all too often overlooked.

RCN Scotland recognises the breadth of the social care sector and that nursing is just one important element of the workforce. We represent nursing staff, both registered and unregistered, working for private, public and voluntary providers. There is no clear evidence suggesting that one specific model of delivery and funding is inherently better than another; the 'bottom line' is that whichever model is used requires sufficient resourcing. We therefore do not take a view on the merits of creating a National Care Service. We do however strongly believe that the current way of operating is not fit for purpose and needs radical overhaul.

Our focus is on ensuring that, whichever model is pursued by policy makers, the professional nursing perspective is understood and appreciated. There is still a tendency to view health and social care separately and it is important that policy makers hold the vital contribution of nursing central to their thinking when developing new approaches to social care. We believe that whatever model is adopted needs to move towards a commissioning process which is based on outcomes, not costs, with a greater acknowledgement of the role of nursing in social care.

RCN Scotland proposal:

Adult social care is in need of a radical overhaul, which better takes in to account the professional nursing perspective. While the RCN does not take a view on the merits of a National Care Service, whatever model is adopted needs to result in a shift away from commissioning based on costs towards a system focused on outcomes.

What our members are telling us

> “Workloads and working conditions have deteriorated because residents are frailer and have more needs than in the past and staffing levels do not reflect that. In addition, we spend so much time proving what we do through copious amounts of paperwork that we have far less time to deliver the care that is needed.”
>
> Agency nurse, care home, RCN Scotland Staff Survey, November 2019

RCN Scotland has around 3,200 members working in Care Homes and a significant number working in other parts of social care. These members work as Registered Nurses and in a range of non-registered nursing support roles (which we give the broad term ‘Nursing Support Worker’).

Even before the pandemic our members working in social care were telling us they felt over-worked and under-valued. Data from RCN Scotland’s 2019 Employment survey[2] showed 70% of respondents working in care homes felt under too much pressure at work (compared to 60% overall) and 79% of those working in care homes felt they were too busy to provide the level of care they needed. COVID-19 has made a bad situation worse and since the pandemic, 34% of respondents to a member survey carried out this summer told us that staffing levels have got worse[3].

Traditionally, there has been a perception amongst the profession that social care is a difficult area to work in, with worse terms and conditions compared to the NHS. Despite efforts in recent years to promote the huge value of working in social care, new nurses too often hear from colleagues that social care isn’t the place to begin your career nor a good setting for career progression. As such we have a sector which is not attracting the workforce it requires and in which the existing workforce feel overstretched and undervalued.

Recruitment and retention is a key challenge - Care Inspectorate data published this year suggests that 19% of all adult social care services report nurse vacancies, with 40% of care home services for older people recording vacancies[4]. These recruitment challenges are made all the more difficult with a nursing vacancies rate of 5.1% in the NHS and 3,200 nursing posts required to be filled in healthcare settings[5].

Care at home

Care at Home services have received less public, media and policy attention in recent months than residential care services. There was initially a significant withdrawal of services during the pandemic, with more than half of Care at Home recipients indicating their service had been partially or fully withdrawn[6]. And throughout the pandemic, significant concerns were raised around those providing Care at Home services in terms of PPE, financial protection for the workforce and testing. Indeed, on the latter point, despite care home staff being offered regular asymptomatic testing since May, Care at Home staff still do not have access to regular testing.

Care at Home services are a vital part of the adult social care system, impacting on both acute services on one hand as well as care home and community services on the other. Too often policy changes in this area have fallen fowl of 'silo thinking' and this must be avoided in this review. Just as with the future of care homes, Care at Home provision is reaching a crisis point and a longer-term plan is overdue.

RCN Scotland proposal:

Any consideration of Care at Home services needs to consider what is sustainable in the medium and long term and there is a need to consider the impact any withdrawal or change in Care at Home services has on community care, especially GP services and community nursing.

The impact of COVID -19

"The care home sector has been undervalued for too long and that its problems must not simply be allowed to fade into the background as the route to recovery is plotted. Care home staff hold the key to unlocking much needed solutions.

"We can no longer just promise to listen to and hear their voices. Their views must be represented more effectively so that their needs – improved working terms and conditions and pay, education and training, resources, support and advice, changes in policy, whatever it may that they say they need representation on – can be met."

Theresa Fyffe, RCN Scotland Director [7]

The impact of COVID -19 (continued)

The pandemic has brought adult social care, especially care homes, into sharp focus in the public's minds. There is an opportunity here to build on this new awareness and appreciation of the sector and the care it provides. The RCN reacted to this increased focus in every area of our activity over the last nine months. Across the UK, we have lobbied governments and politicians about personal protective equipment (PPE), testing for staff and residents, and on pay for COVID-19-related absence and death in service benefits. We've commented frequently in the media on problems and solutions, published regular blogs highlighting issues prevalent in the sector. Most importantly, we have responded directly to enquiries from many individual members working in care homes.

While COVID-19 has brought a seemingly new and unprecedented challenge to adult social care, the truth is that the pandemic has highlighted pre-existing issues, around workforce, around staffing levels and around the way in which care is delivered in Scotland. These issues have always been present and even if we hadn't had a pandemic this year, significant reform would be necessary in adult social care to avoid a crisis of services in 2021.

RCN Scotland proposal:

Huge challenges existed before COVID, which required long term, sustainable solutions. Nevertheless, adult social care is receiving greater attention from the public, media and policy makers due to the pandemic, which provides this review with an opportunity to push for change. If the increased public awareness around the contribution of adult social care to the wellbeing of so many Scots is harnessed, there has not been a better time to push for a long term, sustainable solution.

What should be considered for any review of adult social care?

Safe staffing

Delivery of adult social care is built on a highly skilled but low paid workforce, which is expected to go above and beyond in order to keep the system running. These are the people who should be setting the agenda for change and who need to be central to shaping the future of adult social care in Scotland.

At the very least, the workforce deserves staffing levels that are safe, and this is one of the most important considerations when reviewing social care. There is significant evidence[8] that in some parts of social care, workforce levels and skill mix are not producing the best outcomes for those in receipt of social care.

What should be considered for any review of adult social care? (continued)

We know that workforce shortages were having a major impact on staff morale, mental wellbeing and safety before the pandemic and this pressure has been heightened further by the crisis. As we continue through winter facing a second wave, urgent action is needed to tackle staffing shortages.

The Health and Care (Staffing) (Scotland) Act 2019 provides the tools to facilitate safe staffing levels in adult social care. This legislation sets out a legal requirement on all care providers to ensure suitably qualified staff in sufficient numbers as in place to ensure good outcomes for service users. It also requires the Scottish Government to report on the steps they are taking to support staffing levels in care services to meet this legal requirement.

The substantive part of the legislation provides the Care Inspectorate with the power to develop, in conjunction with the sector and stakeholders a “staffing method.” These workforce tools are well understood in health settings but will be a new concept to some care providers. In short, they are a methodology which can determine (based on the needs of residents and a variety of other factors) the number and skill mix of staff that are required to ensure the best outcomes for recipients. There is flexibility in the legislation in terms of how prescriptive this staffing method has to be, but as a bare minimum it must utilise a staffing level tool which provides quantitative information relating to workload based on service user needs and it must also provide quantitative or qualitative information relating to professional judgement, both in order to assist in determining the appropriate staffing levels. The staffing method can take in to account a whole range of other relevant factors which the NHS equivalent (the Common Staffing Method) takes into account in order to determine appropriate staffing levels and skill mix. It is the RCN’s strong view that the development of a staffing method which is close to the Common Staffing Method would go a long way to improve outcomes and tackle a number of challenges which social care is facing, regardless of whatever future model is adopted. This change needs to happen as soon as possible, and at the very least the Act needs to be fully implemented in 2021. This process should not be delayed by any reform of adult social care because it is needed regardless of what future model is adopted.

RCN Scotland proposal:

Implementing the Health and Care (Staffing) (Scotland) Act 2019 in 2021 will go a long way to addressing many of the issues highlighted above. It is hugely disappointing that the pandemic has delayed implementation of a set of measures which would have ensured the sector was better equipped to cope with the challenges COVID-19 has presented. Implementation of this legislation, in particular the creation of a workforce tool equivalent to the Common Staffing Method, should be seen as a matter of priority and must be factored in when considering the future model of social care.

The acuity of those receiving social care is on the rise

A combination of factors means that the acuity of those receiving social care is increasing in Scotland. With the integration of health and social care within Scotland the balance of care is Shifting the balance of care to the home or a community setting is a longstanding policy driver[9], which Health and Social Care Integration is designed to enable. Care homes are providing valuable alternatives to hospital care and are increasingly being used to reduce delayed discharge from the acute sector, making them essential to local health economies. Combined with the fact that as a population we are living longer as well as living longer with long-term conditions, care homes are increasingly caring for people with complex clinical needs.

Care home residents' increasingly complex clinical needs can include multiple long-term conditions and co-morbidities such as Frailty, COPD, Dementia, Multiple Sclerosis, or Parkinson's Disease, and palliative and end of life care needs. People in Scotland are living longer and by 2043 the number of people over 75 is projected to grow by 71% from the 2018 figure. Figures from the 2019 Care Home Census[10] show that 63% of long stay residents in care homes for older people homes now require nursing care.

Providing the care that is required to people receiving social care with increasingly complex conditions is therefore a highly skilled job. There is a professional complexity of ensuring that the appropriate care is provided to social care recipients and that potential clinical issues are identified early and escalated where appropriate. There is also the emotional complexity of caring for a person, often in their own home, in particular at the end of their lives. Even before COVID, just under half of all deaths were outside a hospital, with 23.4% of people dying in their homes and 18.8% dying in care homes[11]. Recent analysis indicates that if current trends continue by 2040, two thirds of people will die outside of hospital in a community setting (in a home, care home, or hospice)[12]. With more people dying in their homes or in care homes, the social care workforce will increasingly be providing and supporting palliative care outside of hospital.

The contribution of nursing to social care

The Scottish Government's policy ambition of supporting more people closer to home requires high quality nursing provision to be available throughout community settings, including in care homes. As residents' complexity of clinical need increases, the skills, competencies and availability of the registered nursing workforce employed within care homes will become ever more important.

The contribution of nursing to social care (continued)

Registered nurses lead, co-ordinate and deliver person-centred care within care homes and, when given the right support, are well placed to manage acute illness and emergencies, prevent health problems and promote mental health and wellbeing. During admission to a care home, registered nurses can play a pivotal role in supporting the transition process. This includes assessment of the new resident's needs and care planning as well as creating a sense of home and safety. Likewise, as care homes offer services including respite, intermediate and rehabilitative care, the role of the nurse in enabling self-care and arranging follow up assessment and interventions is key to the process of discharge.

A key component of supporting care home residents to age well, and to be independent and equal members of society, is managing clinical conditions effectively, at the same time as promptly responding to new symptoms. For many residents, their clinical needs will require the presence of a registered nurse 24/7. Registered nurses in care homes have a valuable role in being able to recognise and act when a person's condition is deteriorating. Their actions can enable greater and more timely clinical intervention within that homely setting and help to prevent avoidable hospital admissions for residents. It may also reduce the need for assessment by primary and community care teams.

Registered nurses have the clinical skills and knowledge to respond to residents' changing needs, managing medication, monitoring deterioration and overseeing infection control. Their leadership and oversight support the wider team of carers and care assistants. Studies of staffing levels in healthcare settings[13] have shown that for every patient added to a Registered Nurses' workload is associated with a 7% increase in mortality and substituting a Registered Nurse for a Healthcare Support Worker is associated with a 21% increase in mortality. Within Care Homes, there is a growing body of international evidence how access to stable, registered nurse staffing in care homes delivers positive care outcomes for residents as well as improved quality of life[14].

In 2020, COVID has highlighted the fact that nursing input into social care has been lacking. New oversight arrangements have been deemed necessary and arranged at haste. This includes the new role for Health Boards' Executive Nurse Directors with responsibilities around Infection prevention and control and staffing levels in care homes. While this has been in response to the challenges a global pandemic has presented to the sector, it highlights a gap in input which existed before the pandemic and something which any new system will have to consider.
Griffiths et al (2018), Nurse staffing, nursing assistants and hospital mortality: retrospective longitudinal cohort study.

The contribution of nursing to social care (continued)

RCN Scotland proposal:

Registered nurses have a significant role to play in social care, in particular in care homes. With the acuity of residents increasing, the best way to ensure nursing input is to have the required skill mix, including Registered Nurses, employed directly by the care home provider, rather than relying on overstretched community nursing services which may not be available at times that residents need them.

Nursing numbers

Despite the increase in acuity of residents in care homes and the increasing evidence of the importance of nursing care, the number of nurses working in adult social care appear to be falling.

SSSC workforce data, published annually, gives an estimated number of nurses who work in social care. Due to missing data and incomplete responses, SSSC have to gross up the figures, and there are often corrections issued, so they need to be interpreted with caution. However, these figures do seem to suggest that despite increasing clinical needs in care homes for adults, the number of nurses being employed by care homes is falling. Although analysis of this data should be treated with caution, the trend is clear: since 2012 (the first figures available), the number of registered nurses has fallen by 14%[15].

Training and career progression

RCN members tell us that a barrier to nurses working in adult social care is a lack of opportunity to undergo training at work, as well as a perception, rightly or wrongly, about career progression.

Action needs to be taken so that career and development opportunities in adult social care are promoted from the very start of the undergraduate nurse education curriculum with expanded placement opportunities. In recognition of their specific skills and expertise in older people's care – and the urgent need for more nurses to work in care homes – there should be more placements for students in the care home sector. A clear career pathway for nurses working in the care home sector is also required to make a career in the sector more attractive.

Training and career progression (continued)

Working in a care home provides nurses and HCSWs with an opportunity to develop expertise in older people's care and specific areas like frailty, dementia and palliative care. Funding of adult social care must include the time required, and costs, for all staff to access appropriate learning and CPD opportunities to enhance their practice. CPD and access to ongoing support and training are imperative as this is an area that is often missing in care homes. The Health and Care (Staffing) (Scotland) Act requires all staff working in care services to receive appropriate training for their work and assistance with CPD. Employers will be required to ensure all staff are appropriately trained and get the support (including time off) to develop their skills.

We would like to see more opportunities for nursing staff working in the sector to network, share good practice and learn from each other to improve resident outcomes. In order to promote transferable skills and help integration, there should also be greater opportunities for nursing staff in adult social care to work in healthcare environments and vice versa, whether that be on a secondment or collaborative basis.

RCN Scotland proposal:

Development of adult social care needs to promote "good work" (as well as "fair work") principles. For nursing, this means improved career pathways, funding for learning and CPD opportunities and increased opportunities for social care staff to gain experience in healthcare settings and vice versa.

"A Homely Setting"

"We are committed to supporting people to stay at home or in a homely setting"

(Scottish Government, 2020) [16]

"The reality is that they [care homes] are often akin to hospital environments in terms of the levels of need they are supporting, whether they are categorized as nursing or residential homes."

Scottish Care, Care Homes, Then, Now and the Uncertain Future, 2018 [17]

"A Homely Setting" (continued)

We feel that it is important to address explicitly the concern that, by acknowledging and addressing the clinical needs of people outside hospital, we are at risk of turning people's homes into clinical environments. No one wants to fluorescent lights put up in the corridors of care homes or wipe clean surfaces installed everywhere – but we are all now acutely aware of the need for good infection prevention and control measures. Equally, the reality is that the level of residents' needs means some care homes are having to provide support which are now more akin to what was traditionally seen in a hospital environment. The arguments against the medicalisation of social care are often embedded in principles of human rights, but those living in care homes or requiring care their own home deserve the same level of healthcare as everyone else. An unsafe nursing environment in a care home undermines human rights. Care homes are the subject of such concerns, as illustrated by the quote from Scottish Care, above. We would, however, argue that a rights-based approach means that access to the palliative care or complex clinical care people need should not depend on where they are, whether they are in their own private residence, or a residential or nursing home.

The deinstitutionalisation of care in Scotland has certainly been a positive development and it is important to ensure that residential care facilities are part of and rooted in their communities. However, on consequence of this is that the old distinction between nursing and residential homes has largely been abolished, at least in formal/legal terms. The result is that there is a lack of clarity around what nursing care is provided by a given home and what it is necessary for the NHS to plan to provide.

Any review of adult social care needs to consider where and by whom nursing care should be provided to properly meet the needs of people using social care services, including care home residents, and therefore how funding for this is allocated. There is a strong argument, given the increasing complexity of many older people using adult social care services, for nursing staff to be directly employed by the provider of care, to the level required for safe staffing, rather than relying on NHS community services. For this clinical model to be achievable, it needs to be sufficiently funded and there needs to be an ability to be able to clearly identify the level of nursing care required by the use of a staffing method.

Self-Directed Support

The RCN supported the principles behind the Social Care (Self-Directed Support) (Scotland) Act 2013, namely the desire to enable people to sustain or regain their independence. However, we had significant concerns around the detail of the legislation[18] and, in particular, any attempts to extend the principles of SDS into healthcare without further consultation and scrutiny by the Scottish Parliament.

Self-Directed Support (continued)

A relevant concern the RCN had over SDS was that whether SDS would improve outcomes for people. In our response to the Health & Sport Committee during the passage of the Bill, we said:

“The ultimate intention behind SDS…is to generate improved outcomes for people. The RCN questions whether the Bills provisions will realise this desired intention. According to the policy memorandum, local authorities will ‘need to be satisfied that the option chosen can meet the desired outcomes’ for an individual. They will have the right to deny people SDS, whether in the first instance or during a review of changed circumstance, ‘where it is clear that the option itself or the implementation of a particular option will fail to meet assessed needs and desired outcomes. However, the legislation does not mention outcomes. Given that SDS packages of care are funded from the public purse, the RCN considers the review and evaluation of the spending of tax payers’ money against an agreed set of outcomes to be an important point which is not, to our eyes, currently provided for clearly enough in the Bill.”

It is unclear whether what impact this lack of agreed outcomes has had on the roll out of SDS, because implementation of the legislation has been so patchy. Recipients of social care are largely unaware of this option to them and SDS packages are rarely utilised in practice[19]. However, the RCN is of the view that lessons needs to be learned from the implementation of SDS and that this should be considered closely by the independent review into adult social care. The system must become more person centred, but this change will not be achieved without a clear set of agreed outcomes, nor will change be meaningful if there is a lack of understanding or buy-in from recipients of social care themselves.

The funding model

As with the delivery model, the RCN does not take a position on a funding model for social care.

Given the financial challenges care providers are facing and the increasing complexity of the needs of social care recipients, it is clear that the current funding model for social care is unsustainable and needs radical change. The sector has been undervalued for far too long and many long-standing problems have been brought into sharp focus during the COVID-19 pandemic.

Funding for care home services must be determined on the basis of accurate information about both the dependency and clinical need of individual residents, and the staff required to meet those needs. Public funds provided need to ensure that staffing levels are safe, and this includes appropriate provision of nursing staff.

Fair Work principles

> “Staff working in private care homes and agency often work when sick because you don’t get any pay. Most people can’t afford to be off for any length of time in this case.”
>
> Senior nurse, independent sector care home,
> RCN Scotland, Employment Survey 2019

Nurses deserve a significant pay rise, no matter where they work. There is a unique value of the nursing profession in adult social care settings. All nursing staff share the same need for recognition of, and equal value, for their professional level of competence, education, skills and level of responsibilities, as their nursing colleagues in the NHS.

The impact of poor pay is on recruiting and retaining staff who know they can work in an NHS role for better pay and terms and conditions. In order to tackle this issue, it is vital that nurses (both Registered Nurses and nursing support staff) are paid at least the same level as their Agenda for Change (AfC) counterparts working for the NHS. The RCN advises its members that this is the position they should negotiate and to date, it has been the RCN’s position which we adopt through separate recognition agreements with employers or via individual negotiations. There is an opportunity with this review to come up with a better system to improve nursing pay.

The Royal College of Nursing has recently adopted a UK wide position on the best way to ensure that nursing staff are paid fairly. At present, it is left largely to providers to determine both nursing staffing levels and nursing pay, subject only to ‘market forces’ and a National Care Homes Contract which does not sufficiently provide for, nor prioritise nursing. Like other Trade Unions, RCN Scotland has only been able to negotiate individual recognition agreements with providers in order to push for better pay.

It is the RCN’s view that the best way to ensure that nursing staff should receive at least the same level of pay as their NHS colleagues, that pay going forward needs to be track any subsequent rises in NHS pay and that the best way to provide for this is for the Scottish Government to ensure sufficient funding is put in to the system at the point in which public funding is put in to adult social care.

Fair Work principles (continued)

The only way to ensure that nursing is an attractive career option in adult social care and tackle recruitment challenges is to ensure that nurses are paid properly, and the only way they will be paid properly is if providers are given the funding to implement that change. Crucially, it is not enough to simply adopt the current NHS pay in a single year, nursing pay in adult social care must then continue to track any rises in NHS pay, otherwise we are simply storing up the same issues further down the line.

RCN Scotland proposal:

Nursing staff working in adult social care should be paid at least the same rate as colleagues working in the NHS. Any subsequent Agenda for Change pay rises need to also be tracked by pay in adult social care. The RCN believes the best way to ensure this happens is at the source of funding and that funding settlements for adult social care, in whatever system is adopted, must include money to pay nurses in this way.

Data issues

Because care homes are no longer registered as nursing or residential care homes, there is a lack of basic information about the provision of nursing care in the sector. There is no central record of the proportion of care homes which provide nursing for example. There is currently no national picture of the number of care home residents (only the number of beds offered).

COVID-19 has also highlighted several additional data gaps, including difficulty with tracking patients as they move between their own homes, hospital and care homes and mortality and infection rate.

This lack of data has hampered recent academic research in IPC in care homes and response to COVID-19. While research has found[20] that the size of a care homes was significant to whether that care home experienced a case of COVID, a lack of data has meant it was difficult to draw conclusions as to why this was the case. We also do not have, to date, enough information to be able to determine the impact staffing levels have on the spread of COVID.

Problems identifying discharges from hospitals to care homes raise a wider point about the needs of residents in adult social care. Because acuity and clinical needs accompany discharge data, a lack of the latter means we have less of an understanding about who exactly is in a care home and what their clinical needs are. This makes planning for safe staffing in care homes difficult, but it also makes identifying the needs of the recipients of adult social care problematic. A lack of data is therefore an impediment to improving planning, commissioning and delivery of adult social care.

Data issues (continued)

The picture has been improved in care homes by the collection of the safety huddle tool data, but this needs to be further developed. It is important that the workforce methodology, as provided for by the Health and Care (Staffing) (Scotland) Act 2019 is implemented (as discussed above).

RCN Scotland proposal:

We support the Public Health Scotland Recommendation that "Priority should be given to the development of a national dataset collected by care homes themselves which records information on all people resident in a care home including temporary stays. This would allow a better understanding of the capacity and use of the sector, and allow linkage to other data sources to better understand resident needs and patterns of care." (Public Health Scotland, October 2020) [21]

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Royal College of Nursing Scotland

Published: December 2020

Royal College of Occupational Therapists

Occupational Therapy's contribution to Adult Social Care

The Royal College of Occupational Therapists (RCOT) is the professional body for occupational therapists and represents over 33,000 occupational therapists, support workers and students from across the United Kingdom. Occupational therapists have a unique skillset offering support to people with physical and mental illnesses, long term conditions, and / or those experiencing the effects of aging. As many people will have experienced through the current coronavirus crisis, a loss of occupation can come in many ways. Occupational therapy can support those most in need to adapt to a change in circumstances – whether it be related to change in social or healthcare need.

The Royal College believes that the future delivery of social care in Scotland must include a move to person centred care which is focused on what is important to the individual, with a shift to a focus on earlier intervention, rehabilitation, and reablement to help people live as independently as possible for as long as possible.

Key challenges in adult social care

- Individuals find their first interaction with adult social care services is through a period of crisis. This immediately places the priority on meeting an individual need rather than a long-term focus on rehabilitation or reablement.
- As a result of limited resources, social care services have begun to prioritise risk management. The Royal College believes the assessment process must take a longer-term view, focussing on attaining goals set by the service user and supporting positive risk management to consider which matters most to the individual.
- The quality and limited availability of accessible housing in Scotland contributes to pressures within social care. Housing adaptations are made which meet immediate needs, but aren't suitable in the long-term as individuals move through stages on the LifeCurve.[1] Housing Options conversations encourage people to think what their future housing needs may be and this model should be rolled out across Scotland and not be a conversation "owned " by occupational therapists – these should be opportunist to support people to plan ahead rather than manage crisis and should be part of a wider offer of universal rather than specialised support. In the Adaptations without Delay (AWD) model Occupational Therapists work at a universal level to upskill others to provide minor adaptations thus reducing wait for service users.
- Acute services are under pressure to discharge people as soon as possible due to intense demand. While this allows individuals to move into a more homely setting, it presents challenges in the transfer to adult social care as often people are medically stable but still will require timely reablement – rehabilitation to regain optimal function. This also affects those that are not in acute care who are awaiting social care support, as resources are often focused on hospital discharge.
- Services are limited by current edibility criteria. While occupational therapy is well embedded within social care, eligibility,and the occupational therapy role, differs

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[1] https://adlsmartcare.com/

across Scotland. This results in a postcode lottery where individuals may not receive the most appropriate care for them and decisions may be made based on diagnosis rather than needs led assessment. An excellent example of transformative work to consider needs and not diagnosis is the work in Fife to provide stair lifts for people with dementia.

- Individual needs change as people move through the Life Curve or adapt during their reablement journey. Care packages should adapt as individual needs change, requiring ongoing specialist, outcomes focused, care/support reviews.

Opportunities in adult social care

- Individuals are often referred for a “care package" which meets current needs. Adult social care services should begin with an assessment of functional ability, resulting in a longer-term support and reablement plan. Assessment should not be considered a one-off process but part of ongoing support and review process.
- The range of knowledge and skills of the occupational therapy workforce is often underutilised within adult social care, often focussing on referrals for equipment or adaptations or in generic care management roles. An earlier intervention from occupational therapy allows for a holistic approach which assesses independent living needs and can support individuals to “add good life to years”. Occupational therapists are dual trained in physical and metal health at point of graduation so offer a unique approach to supporting people.
- Introduce the three-conversation approach[2] being implemented in NHS Lothian, which aims to avoid using assessments for services as the individuals first interaction with social care, this provides immediate support rather than immediate referrals and waiting lists – allowing issues to compound and worsen.
- Further integration of occupational services in care home settings can provide ongoing support to individuals as needs change later in life. This could include occupational therapy led training of care home staff.
- It is important to consider how we measure progress is this outputs or outcomes for the individual? In Monmouthshire in Wales services have moved to simple measures such as ‘did we meet the individuals’ goals and how many service “hand-offs” did the individual experience?’

Recommendations .

- IT systems should be integrated to share patient data between services, providing a holistic approach to patient care planning.
- We need to consider the language we use. Do we accept referrals or do we accept requests for assistance. Do we provide care or support?
- A single point of access for individuals to request social care assistance before circumstances result in a personal health or social care crisis – make it easier to request assistance.
- The future of social care should be based around a clear framework of delivery that enables identification of associated knowledge skills and behaviours. To adequately

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[2] http://partners4change.co.uk/the-three-conversations/}

support people we must consider how they live within their home but also their access and ability to integrate and be part of with their wider communities and the positive risk taking required to support this.

- Elements of an ideal model of social care would include suitable housing, investment in training, technology enabled care, capacity building in communities, funding for community rehabilitation, and a shift away from crisis intervention to a much earlier more enabling, person centred, model of care.
- Ensure parity of recognition, esteem and funding between health and social care. Treating social care as equal to healthcare is essential to ensure individuals can manage their symptoms in the community, valuing their independence whilst also relieving pressure on acute services. Keeping people well in the widest sense – for longer
- There needs to be a shift from crisis response to early intervention. Occupational Therapy has already contributed to training and development of care staff to help identify a change in needs quickly and to support a wider group of people have the skills to address low level needs following a universal model of care, without the need to escalate to another team member. This should be further strengthened at a locality level, making responses to referral quicker and less bureaucratic and to focus on "what matters to you".
- A national campaign to get people thinking about their future housing needs earlier, preventing unnecessary delays and unsuitable short-term adaptations. Involvement of occupational therapy in the planning of future housing – if we had more suitable housing options more people could live at home for longer
- Reablement and rehabilitation support should focus on optimising people's function, enabling individuals to live as independently as possible.

Case Study from STARS Reablement Service in Dumfries and Galloway

Predicted Needs Based on Need Assessed for Hospital and Eligibility Criteria:	
2 Carers x 4 daily 7 days – Do Not Attempt CPR (DNACPR) - hoisted, provided with food/hydration and catheterised	= **56 visits weekly long term**

Service and resources once home and occupational therapy led reablement in partnership with Care at Home, AHP and Nursing Colleagues (16 weeks later)	
1 Carer x 3 and 2 carers x 1 7 days	= **35 visits weekly** *(with potential to further reduce)*
No longer DNACPR, now walking with zimmer, washing, sharing matrimonial bed and considering wider outdoor opportunities. Has also completed Anticipatory Care Plan (ACP) to ensure future needs are anticipated and choices understood.	

Royal College of Speech and Language Therapists

RCSLT Scotland

Response to the Independent Review of Adult Social Care

November 2020

The Royal College of Speech & Language Therapists is the professional body for Speech and Language Therapists (SLTs) in Scotland and we welcome the review of adult social care in Scotland.

We support a rights-based approach and believe that everyone should experience appropriate and safe care in the right place, at the right time and have easy and timely access to the right health and social care professionals to enable them to live life to its fullest potential.

Key Messages:

- Support for communication and swallowing difficulties is often neglected but is a key component of care for people who are, for example, frail and elderly, have had a stroke, have dementia, Parkinson's, learning difficulties, mental illness, ASD.
- Fundamental to implementation of a human rights approach there should be a requirement in law that health and care services mainstream inclusive communication approaches in everything they do.
- Delivering health and social care requires multi-agency and multi-disciplinary co-operation.
- Required skills and competences of health and care staff should be defined, developed and sustained.

Speech & Language Therapy in Social Care

Speech and language therapists

- support individuals, their families, carers and care home staff and other health and social care staff to identify communication and / or swallowing difficulties (prevention and early intervention; self management);
- provide direct therapy to enable individuals to eat, drink, swallow safely and / or communicate (intervention / rehabilitation)
- provide training, support and resources to those who live, work for and with individuals with eating, drinking or swallowing needs – so that they can support the individual to live as independently as possible.

The role and impact of SLT services are described in the following;

https://www.rcslt.org/-/media/Project/RCSLT/rcslt-dementia-factsheet.pdf

https://www.rcslt.org/-/media/Project/RCSLT/rcslt-learning-disabilities-factsheet.pdf

https://www.rcslt.org/-/media/Project/RCSLT/rcslt-stroke-factsheet.pdf

Current SLT provision:

The provision of SLT for adults in community settings is best described as patchy and inconsistent.

Service leads highlight significant levels of current unmet need and regularly find that when support is provided e.g. through training, that this leads to increased referrals they can struggle to meet.

Workforce and workload planning is absent, historical and doesn't reflect either demography or care home demand in local communities. Workforce and health service planning has not been done based on responding to growing needs in community settings. Services have instead been planned to focus on separate professional groups rather than a multi-disciplinary approach that identifies the right combination of skills required to meet needs. The Staffing Act (2019) should eventually improve this situation however no growth of investment in AHPs is anticipated.

The move to integrated workforce planning is welcomed but we remain concerned that the actual understanding of demand in community settings is not well developed and this will make it difficult to plan for a sustainable workforce. Clarity is needed on what models of care and support will look like, what needs are to be met, the skills required across a team of professionals to meet those needs and a plan for a workforce deployment that will fulfil those requirements.

Impact of Covid-19

Evidence shows many who are recovering from COVID-19 have ongoing rehabilitation and care needs. It is critical the same urgency and resource put in place for acute services and intensive care is now deployed to community services.

There is currently significant risk to people's health due to pauses in planned care, delayed diagnosis and treatment.

Supporting rehabilitation through an integrated primary and social care system is a priority. AHPs are looking to the Scottish Government's *'Framework for Supporting People through Recovery and Rehabilitation'* and the new National Advisory Board for Rehabilitation to guide policy quickly.

The delivery of effective rehabilitation services, particularly in the COVID and post-COVID environment, will be dependent on appropriate resourcing, including increased use of digital platforms.

As a member of the Allied Health Professions Federation Scotland (AHPFS) we have jointly identified five priority areas which will be necessary for the future rehabilitation needs of Scotland to be met:

- A right to rehabilitation: A rights-based approach to support people to receive the appropriate care in the right place at the right time by the right health and social care professionals to live a life to full potential.

- A Rehabilitation strategy: A national strategy for quality rehabilitation, making it an integral part of the health and social care system must be matched with resources and timescales.
- Multidisciplinary leadership: Expand and modernise rehabilitation services to meet the scale of need - both Covid and non-Covid related – with particular focus on delivering this in the community.
- Workforce planning: Grow the multi-disciplinary rehabilitation workforce, with the right skills and staff needed.
- Revitalise services: Learn from the impetus and changes in response to the pandemic, and use them to shape the future of rehabilitation.

Appendix

Appendix

Direct links to organisations' and representatives bodies' submissions to the Independent Review of Adult Social Care in Scotland as published on their own websites

IRISS - Transforming services for people using digital technology: Mapping activities and exploring experiences

IRISS - The cost of separation: the impact of visiting restrictions on families of care home residents during COVID-19

IRISS - The cost of separation: the impact of visiting restrictions on families of care home residents during COVID-19 (summary)

Law Society of Scotland - Submission to the Independent Review of Adult Social Care

Life Changes Trust - A Vision for a Whole Life approach to Social Care in Scotland

National Carer Organisations - Submission to the Independent Review of Adult Social Care

Oxfam Scotland - Care, climate and Covid-19: building a wellbeing economy for Scotland

People-led Policy Panel and Inclusion Scotland - Submission to the Independent Review of Adult Social Care