Independent Review of Adult Social Care in Scotland Evidence Submissions

Volume 4

Contents

Introduction

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 S to W and the Appendix links directly to organisations' and representatives bodies' submissions where they were published on their own websites.

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To whom it may concern

INDEPENDENT REVIEW OF ADULT SOCIAL CARE

SUBMISSION FROM

SACRO

Thank you for the invitation to submit views & evidence to the review. We are pleased to offer you this paper as a contribution to your work.

About Sacro

Sacro is an organisation with a long and rich history in the field of justice-based services, supports and interventions. Having reached our fiftieth year of supporting high risk, challenging and hard to reach individuals, ensuring the public is kept safe from some of the most high risk offenders released from prison, we find our reputation as an organisation who has the expertise to support individuals others often aren't willing or able to support, being drawn upon more regularly. We find these individuals often lie out with the justice landscape, with their needs being much more embedded in 'social care'. Until now Sacro's social care experience has been focused in two main areas: learning disabilities and housing. Our Regulated services support both adults and young people with a diverse range of support needs, spanning a large geographical area in the North of Scotland.

The third sector and "adult social care"

The not-for-profit sector provides just over a third of all registered social care services and employs just under a third of all social services employees. It is important for you to understand our interpretation of "adult social care". We believe that this is important because the review comes at a time when the public view of "social care" is principally perceived as the personal care of older people, and even more specifically, those who live in care homes.

For Sacro, this simply is not the case, in line with our vision mission and values, our social care services are underpinned by the following principles:

- Supporting people & communities
- Enabling everyone to live a valued life – the life they choose
- Enabling people to have a brighter future
- No barriers – for all of life
- Ensuring individuals to reach their full potential
- Care you can put your faith in
- To make transitions as positive as possible.

Fundamentally, we see "social care" as a supportive relationship, in which we work alongside people who have significant challenges in their lives (disability; impairment; long-term condition; addiction; experience of the justice system; homelessness). We support them to retain or regain control of their own lives so that they can make their own decisions, live the life they choose and look forward to a better future. Where our system and our society make it very difficult for them to do that, then we work to ensure that the people we support are comfortable, cared for, enjoy greater peace of mind and still retain the ability to make as many of their own decisions as possible.

In this context, "social care" is not a *service* (ie. someone stepping in to do something that you can't do for yourself); rather it is a *vehicle* through which people can live their lives in a way that those of us without such challenges take for granted. In this sense, "social care" is not a destination, end point or outcome in itself; it is the provision of support and assistance that allows people to achieve their own destination, end, or outcome.

We see care & support as an investment in Scotland's people. We see it as a public good in & of itself, and as a means of preventing more acute stress & distress, or a deterioration in quality of life. In the public arena, it doesn't have a high profile: but when it is not available, lives are much the poorer for it: witness the huge levels of stress and distress experienced by people who have had their social care support removed or disrupted during the pandemic.

Good care & support can lead to reduced use of other, much more intensive and expensive public services. But that is not to say it's just a pressure valve for the NHS, or for prisons. It's a key public service in its own right.

The emergence of "adult social care"

Over time, this concept of a supportive relationship has been overlaid by a significant architecture of policy, legislation and regulation that has conferred important rights on people who need support and placed commensurate duties on public bodies.

This architecture has also had the effect of codifying care & support into:

- category definitions ('settings' – care homes, day centres, care at home)
- practitioner tasks ('personal care', 'housing support')
- organisational and practice standards
- service specifications
- contract conditions.

Some of this codification has been developed, we believe, primarily for budgetary and monitoring purposes.

The third sector strives to maintain its basic proposition of a supportive relationship within the confines of this architecture. Some of it is helpful (the conferring of rights, a shared understanding of quality), some of it less so (rigid service categories, time & task specifications, transfer of financial risk through contractual conditions).

But we have, arguably, reached a point where the codification has in effect become the service, now described as "adult social care". People are assessed as "needing" 20 hours of home care a week; "needing" four 15-minute visits a day; or "needing" a permanent care home place. This is what is meant by social care having become 'service-led': the system responds to need by deciding the quantity or volume of service that it will allocate to each person, from a range of services that it has *a priori* decided to provide.

The development and introduction of self-directed support (SDS) was intended to change all this: assessment of need was to shift away from considerations of what people couldn't do (and therefore needed help with), towards a discussion about "outcomes", and the things that people would like to be supported to achieve. But self-directed support has not had the transformational impact that we had hoped for: that is partly the result of poor implementation, but we believe it is also because the system architecture described above has remained largely unchanged, rendering SDS the proverbial square peg in a round hole.

So our key interest, now, is in how we can **reset the system** so that it focuses on the following key dimensions of good care & support:

- "Care" as a supportive relationship and a vehicle to good lives, full citizenship and the exercise of human rights; <u>not</u> as a series of pre-determined tasks, or setting-based services
- Real choice & control for people in how their needs are met and how their support is delivered
- A rich diversity of support providers and approaches
- Robust & independent critical challenge applied to the whole system, not just to "services"
- Fair Work, and real professional autonomy, for people employed in care & support, whoever their employer
- Collaboration between agencies, not competition: partnerships of equals, sharing of risks, transparency of financial arrangements
- Investment in care & support as a public good.

This, in effect, represents our agenda for "adult social care". In this context, we note the **key areas being considered and explored by the review**, and we would comment briefly on each, as follows.

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

Assessment of "need", as noted above, is often service-led, locking providers into a cycle of commissioning (and re-commissioning) the same services again and again, because people "need" them. ***We would encourage the review to consider how to break this cycle.***

Service-led assessments, coupled with the application of eligibility criteria based on urgency or criticality of need, undermine the agenda for prevention & early intervention, since the focus is often purely on "personal care". Social care is, or should be, about whole lives, but other types of support can remain excluded (and unfunded). ***We would encourage the***

review to consider how to expand the scope of funded social care to include less "formal", currently non-commissioned support.

The rights conferred on people with care & support needs are scattered across various legislative instruments. ***We would encourage the review to consider bringing them together in a single "Bill of Rights", at a national level.***

Self-directed support (SDS), and its focus on people's needs, rights and preferences, should be the foundation of any changes to the social care system in Scotland. SDS remains largely misunderstood and poorly implemented; other parts of the system have not been adjusted in order to support it (especially procurement) and the shift of power required to make it work has not happened. ***We would encourage the review to consider how best to 'turbo-charge' the adoption and implementation of SDS.***

There is insufficient critical challenge applied to systems and decisions that (appear to) undermine the rights of individuals, and the principles of SDS, including many procurement decisions. ***We would encourage the review to consider how to strengthen our collective ability to challenge poor decision-making without recourse to the courts, particularly where people's rights are concerned.***

Linked to the above, independent advocacy is essential in ensuring that people's rights are respected. ***We would encourage the review to consider how best to support, expand and strengthen it.***

2. The experience of staff working in the social care sector

Evidence shows that most people working in third sector care & support enjoy their work and are committed to it. ***We would encourage the review to avoid being drawn into a narrative that characterises care & support workers as dissatisfied and unfulfilled; at the same time it should consider how best to support the good employers in our sector to continue nurturing and developing their staff.***

Third sector staff and employers are generally supportive of the aims of professional registration and regulation, but our collective aspirations for a competent, confident & qualified workforce are undermined both by the characterisation of care work as 'low-skilled', and the associated trend towards low pay. This is not unrelated, in our view, to the workforce being composed predominantly of women. We are also aware that in the context of health & social care integration, some NHS colleagues remain unaware that care &

support is regulated, with a qualifications-based registration process. ***We would encourage the review to consider how best to ensure that our professional aspirations are reflected in awareness, status, esteem and reward.***

The codification of social care into a set of tasks, categories and standards, combined with high levels of monitoring, compliance and regulation, has served to undermine the autonomy of care & support workers; this has contributed to the perception of social care as low-skilled. We support the conclusions of the Fair Work Convention's report into social care in this regard, and its recommendations. ***We would encourage the review to examine the report's findings in this area, and to consider ways in which greater professional autonomy can be restored to care & support work.***

Training, development, supervision and support are critically important but are often under significant financial pressure. The original National Workforce Strategy for care & support recommended 5% of service costs as a benchmark for investment in training & development, but this has rarely been recognised in funding arrangements. ***We would encourage the review to consider how to support wider recognition of the need for investment in these areas.***

Competitive tendering for social care contracts led to a significant 'casualisation' of the workforce, as staff were transferred from employer to employer under TUPE. This type of mass staff transfer has become less common since the introduction of framework contracts, however the risk remains, and framework contracts can lead to major problems of workforce planning & stability since they offer no guarantee of volume of business. ***We would encourage the review to consider the impact of competitive tendering, and of framework contracts, on the workforce, and examine alternative ways of commissioning care & support (see below).***

Health & social care partnerships and local authorities rarely support the third sector to implement all the dimensions of Fair Work – particularly pay, terms & conditions – that they implement themselves, as employers of their own staff. This is unjust, inequitable and in our view, indefensible in the context of a national approach to Fair Work and to professional registration, qualifications, standards and conduct. ***We would encourage the review to seek to dismantle the "two-tier" workforce and ensure parity of status, esteem and reward across all sectors.***

3. Regulation, scrutiny and improvement of social care

Whilst there are excellent (and poor) providers in every sector, third sector care & support overall is consistently awarded the highest proportion of “very good” and “excellent” Care Inspectorate gradings in all “adult social care” categories compared to its public and private sector counterparts. ***We would encourage the review to consider how best to capture learning from the third sector’s record of high quality, and use it to inform improvement initiatives across all sectors.***

A joint approach to health & social care regulation, scrutiny and improvement can prove valuable (for example, ongoing joint HIS and Care Inspectorate inspections in key areas). However, we strongly support the continuation of a discrete regulatory system that focuses on social care specifically, given the important distinction between health care (in particular, acute health care) and social care support. ***We would encourage the review to ensure that a focus on social care support remains in any future system, and that it is not subsumed by more clinical interpretations of safety, assurance and quality.***

The third sector supports the ongoing shift away from ‘tick-box’ regulation & inspection towards self-evaluation and improvement. We do not believe that quality can be “inspected in”, although we are mindful of the regulator’s role in protecting individuals and providing public assurance. ***We would encourage the review to ensure that scrutiny continues to develop its focus on self-evaluation & improvement and improves, in turn, its own ability to measure performance & quality on the basis of experiences and outcomes for people, rather than provider compliance with policy and process.***

The regulatory system and its powers of enforcement focus almost exclusively on “services” rather than on the system more broadly: there should be much more robust critical challenge in other areas including assessment processes, resource allocation and commissioning & procurement. ***We would encourage the review to revisit, extend and strengthen both the scope and the powers of scrutiny bodies along these lines.***

4. Human rights and ethics in social care

Social care support is a human rights issue: without social care, people with support needs may be unable to access or exercise their human rights (eg. to work, to family life, to freedom of movement, to democracy). ***We would encourage the review to ensure that any future social care system is aligned with relevant UN Conventions (including UNCRC and UNCRPD).***

There are long-standing concerns about the extent to which people's human rights in the context of social care support may be re-interpreted in the light of budgetary considerations. Probably the most stark example of this was played out in the case of R vs. Royal Borough of Kenginston & Chelsea (we understand that there have been similar instances in Scotland). ***We would encourage the review to consider this case, and others like it, and to clarify where it believes a Scottish future social care system should stand, in particular on the question of how far the human rights of individuals should be considered subordinate to the needs of a population to have basic social care needs met, within a limited budget.***

Social care support itself must adhere to high ethical standards and human rights principles. In this context, we are concerned by the issues that arose in relation to Covid-19 including, for example, access to hospital care for older people receiving social care support; application of 'DNR' orders for disabled people using social care services, without consultation; restrictions on family contact for care home residents; lifting of assessment requirements under emergency legislation, and so on. As noted in (1.) and (3.) above, there is little critical challenge to these decisions and practices, and insufficient access to independent advocacy in relation to them. Added to this, successive reports on human rights breaches in the context of social care (the most recent being the SHRC report on social care during Covid19, published in October 2020) tend not to be followed up by any significant change. We believe that without enforcement, a human rights position is ultimately meaningless; yet court action is out of reach for many. ***We would encourage the review to consider how best to introduce greater, rights-based critical challenge, beyond court proceedings.***

Considerations of ethics in care & support commissioning & procurement have been usefully addressed in Unison's "ethical care charter". Whilst we are generally supportive of the charter, it doesn't address head-on the need for commissioning authorities to pay a competent rate for care, particularly if providers are to implement better pay & conditions, and Fair Work. ***We would encourage the review to establish a clear line of sight between high ethical standards and the level of budget required to underpin them.***

5. Commissioning and procurement

Most approaches to procurement, as currently conducted, are antithetical to the principles of self-directed support, since they position care services primarily as business opportunities for providers, not as a means to good lives for people; and they place decision-making capability squarely in the hands of public authorities, not the people we support. ***We would encourage the review to interrogate procurement policy & practice, and those who advocate for their application to care & support, with respect to the suitability of these processes to care & support as we have conceptualised it.***

In the context of the dominance of competitive tendering as the primary means of arranging care & support provision, we have adopted two responses: first, to ensure that if competitive tendering is the approach taken, then at the very least it must be conducted in accordance with guidance (guidance issued by CCPS); and second, to explore the potential of alternative, more collaborative approaches to commissioning. ***We would encourage the review to focus primarily on the second of these, rather than the first.***

In the context of commissioning & procurement and proposals for reform, there are a number of myths about providers that we are keen to dispel, including for example that there are “too many providers”, or that providers are incapable of collaborating with each other. In our experience, the “too many providers” narrative is most frequently adopted by authorities whose primary concern is to reduce their transaction costs, rather than to offer choice & diversity to people; whilst the record of collaboration among providers, considering that they are encouraged to compete against each other, is very strong. ***We would encourage the review to interrogate and challenge these and other myths, should they be encountered in the course of your work.***

In order to shift commissioning practice & culture away from competitive tendering and towards more collaborative approaches, we believe that it will take a major change programme: well-funded, well-led, with buy-in from all stakeholders. ***We would encourage the review to recommend the establishment of such a programme as a key plank of reform of the Scottish social care system.***

6. Finance

As a single provider Sacro has no fixed organisational view about how any additional investment in care & support should be financed, be it through higher tax rates, altered priorities, the introduction of specific insurance schemes, and so on. We believe that this is a question to be addressed by political leaders in full consultation with the public. ***We would encourage the review to approach this question from the perspective of a renewal or renegotiation of the ‘social contract’ between the state and citizens.***

Third sector providers are rarely in a position whereby the funding they receive (under contract or other arrangement) covers our full costs. Research findings over many years have consistently indicated that third sector organisations either run a fair proportion of services at a deficit, and/or subsidise them from other income sources, including reserves. From our perspective then, there is not enough money in the system – at least, not enough of it is coming way of the Third Sector. What we cannot say with any confidence is that resources are always applied efficiently throughout the system: we are aware, for example, that many services provided by local authorities directly are vastly more expensive than comparable services we provide ourselves, with no commensurate increase in quality. Similarly we know that our sector provides a much greater proportion of care & support in some areas (for example, learning disability) than the proportion of the overall budget that it receives. ***We would encourage the review to seek analysis of spend in terms of volume, efficiency and outcomes achieved, by sector, as well as addressing the matter of overall funding levels.***

Accountability, transparency and equity are key financial issues for our sector. As noted, we see significant problems with the current ‘two-tier’ system in which ‘in-house’ care & support is routinely funded more generously than commissioned support; and we experience major problems with the absence of any effective ring-fencing of resources or monitoring of spend. This is very starkly revealed by the huge difficulties that third sector organisations have experienced in accessing the multi-millions allocated to public bodies to support additional social care spend arising from Covid-19. In general, third sector finances are minutely scrutinised whilst comparatively little independent scrutiny is applied to public expenditure on social care. ***We would encourage the review to address these issues as a matter of urgency: every citizen, regardless of who provides their care & support, ought to be confident that the same financial rules and standards apply to all organisations in all sectors.***

7. Potential national aspects of a social care system

A number of figures and organisations have proposed the establishment of a National Care Service. We are cautious about these proposals, both because they appear to lack any substantive detail about how such a service might operate in practice, and because they appear to over-simplify either the problem (for example, private care being inherently ‘wrong’) or the solution (for example, that social care should in effect be ‘nationalised’ and delivered by the public sector alone). ***We would encourage the review to resist ‘pre-cooked’***

solutions that do not address, in detail, long-standing flaws in the existing system, and that run counter to agreed principles (most prominently, the availability of choice & control for people over their support).

A further narrative surrounding proposals for a National Care Service relates to the perceived fragmentation of the social care system, containing as it does several hundred separate providers and employers, each one accountable to its own governance structure rather than a national structure as for the NHS. We hear that it was this fragmentation that led, for example, to problems of PPE distribution, and the introduction of effective infection prevention & control measures. We strongly reject this narrative: rather, from our perspective, we understand these problems to have arisen from an almost complete failure to treat third sector providers as part of the existing system, and as equal partners within it. Again, this is not new. Addressing this, we believe, would be a far better way of streamlining the system than the introduction of a top-down, command-and-control model of governance. ***We would encourage the review to interrogate such proposals rigorously and test their ability to solve the problems to which they present themselves as the answer.***

A key strength of the current social care system in Scotland is that the third sector can be mobilised to deliver high quality, localised support that people need & want in order to live good lives. In that sense there already is a National Care Service, or at least the framework for one, and a significant development in this regard would be to seek to standardise provision and quality of support to the level provided by our sector, and/or to support our sector to take on a greater role than its current one-third 'market share'. ***We would encourage the review to build on success, and explore how the system might support & enable providers of high quality care to do more.***

Registration & regulation of care was put on a national footing for the first time in 2001; since then, all providers – public, private and third sector – have been subject to the same regime of independent regulation and inspection against the same national standards. Prior to that, arrangements were largely local. There may be other areas of care & support where a move from a local to a national approach, with appropriate standards across the board, may be beneficial, for example: the application of eligibility criteria; availability of, and access to, specific types of support; implementation and operation of SDS; and approaches to charging for care. ***We would encourage the review to consider these areas.***

In the ongoing debate about what is best decided or organised nationally, rather than locally, we would want to question the extent to which local government or health & social care partnership boundaries are themselves an appropriate reflection of what people understand to be ‘local’. This has been a subject of debate since health & social care integration policy required the identification of ‘localities’ for planning purposes, and that debate remains live. ***We would encourage the review not to limit itself by considering ‘local’ decision making or discretion to be entirely synonymous with local authority decision making, but to consider further dimensions of locality.***

Thank you for taking the time to read and consider this submission.

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Sacro is a company incorporated under the Companies Act, limited by guarantee. Company reg. No. SC086651. Registered charity No. SC016293.

Scottish Ambulance Service

Scottish Ambulance Service Response to the Independent Review of Adult Social Care Services in Scotland

Thank you for the opportunity to respond to the first phase of the Review of Adult Social Care Services in Scotland. We have described below

1. what we think are the current challenges, in doing this we have sought views from our frontline staff who are dealing with these services across the country, in every community on a 24/7 basis and

2. what further opportunities could we provide as we develop our role in population health and preventative and anticipatory care

The Scottish Ambulance Service (SAS) in our unique position as providers of emergency services; our interactions at all levels with health and social care; and our growing contribution to public health, means we are well positioned to do more for patients and carers within Adult Social Care Services.

Our current experience of accessing social care support

- When our demand outstrips supply 'social care' calls may experience delays if the clinical acuity described is of a lesser nature than other 999 calls.
- SAS often takes people to hospital as a default option because primary and social care cannot be accessed at short notice. It is well documented that unnecessary hospitalisation of people affected by frailty is associated with subsequent loss of functional ability.
- Anticipatory care planning which should ideally include social care aspects is inconsistently applied.
- It is SAS experience that calls from Care and Nursing homes are subject to variation.
- It can be challenging to access Social Care at the point of patient contact.
- In relation to public protection there are some inconsistencies related to feedback where concerns have been escalated back into the system. The lack of feedback can discourage frontline staff from reporting in the future as they are left unaware of the impact of their intervention and therefore the opportunity to affirm appropriate escalation can be missed. There is a huge amount of effort across the system to make this better, however we are not always helped by the challenges of information sharing prior to concerns being raised.

- More people living in communities and closer to home with increasingly complex needs is to be welcomed but without effective integration of relevant care information can present difficulties for SAS staff.
- This is evident in many scenarios such as ‘failed’ discharges where SAS are often called to patients shortly after hospital discharge for both clinical and social care provision concerns.
- Similarly, in end of life care discussions, where concerns are raised while planning for palliative care are being introduced, people may default to an ambulance response as they lack confidence in care at home.
- While the points made above describe issues when things go wrong, for many people these services work very well, and where SAS is called, good planning documentation and communication are in place and it means that the wishes of patients and their families / carers can be met.

Our Contribution to making change - what can we offer?

- Many of our emergency and urgent responses have their origin in concerns that are a result of sub-optimal social care arrangements. For example, calls from alert systems, people unable to contact relatives and friends, people who encounter difficulties at home, people unable to mobilise or have slipped, fallen but are not injured. SAS has data broken down by every IJB for all of these coded events. Using this information effectively could transform these services.
- SAS has developed data sets and shared with many IJBs in order to better understand the needs of communities. While these are primarily focussed on clinical elements, SAS would welcome the opportunity to work to better understand the ways in which it can engage with people relating to their social care as well as healthcare needs as these are often interdependent.

We have attached with this response a sample of this dataset **(Appendix A)**

- Throughout the process of patient care SAS generates and collects a wealth of data (the above is just a small part of this) which gives the ability to provide insight into public health across Scotland.
- Recent work to improve use of a falls screening tool for further patient referrals has shown there is a willingness to work collaboratively with external services in trying to improve the ongoing health of patients who do not require the services of A&E.
- We are actively progressing the replacement of one of our Glasgow ambulance stations to include a health and wellbeing community hub. Focused on delivery 24/7 care to the local community by offering the space, our expertise and collaborations in supporting the local communities. This concept has been well received by the local community and links to Adult Social Care is critical in making this effective
- We are a key element of the health and care system, and are already engaged in working with IJBs in understanding and supporting the needs of people in these communities.

- As a national service national guidelines and operating arrangements, but delivered within local context, SAS is ideally placed to deliver quickly on the outputs of this review,
- SAS is open to changing its approaches to support people, to work with new digital innovations and to enable its staff to better support people and their families during periods when they are most vulnerable. We have seen fantastic developments in this space over the last few months and are keen to push this further, through video consultations with patients, prof to prof video links and development further of local pathways of care avoiding unnecessary ED attendances.
- As a national service, SAS is also in a good place to share best practice across the country, an important function where the make-up of community provision is localised and can at times appear fragmented.
- SAS is very much focussed on improving our contribution to the wider population health agenda and seek to add value where possible. We realise that making improvements in the preventative space will have longer term benefits not just for our emergency demand, but the wider health service, and the health of our population. We are keen to explore opportunities to improve access to social care support for both health care professionals and patients who require our help. We are already contributing to a local test of change scheme in Elgin whereby we assist suitable patients in signposting them to relevant assistance and services which are provided locally to them. These include health services and charity based services and allow the patient to understand what is available to them based on their needs identified by our staff when they are treating them.
- SAS currently submits data to the centrally held Unscheduled Care Datamart which is held by NHS NSS. This ‘Datamart’ links patient journeys across healthcare (SAS, NHS24, GP OOH, ED, Acute Admissions, Mental Health Admissions and Deaths) however does not currently include data from Social Care settings. It is a rich source of intelligence about patient journeys beyond the usual service boundaries and is widely used across the NHS to understand wider service changes. It is also used in SAS to understand the outcomes and journeys of patients SAS has attended. The addition of data from social care settings will widen the scope of the intelligence which can be gained from the linked data.
- We have been doing interesting work in identifying and supporting (through preventative care) people who are defined as high intensity users, efforts are being made in all areas to coordinate care and support to people who are considered high intensity users and we have undertaken a small test of change with significant benefits. We are happy to share the detail of this as we continue to progress this work further.
- In relation to the work we are doing to support people who are experiencing acute mental health challenges, whilst doing excellent work with Police Scotland and other health partners the enhanced ability to understand support infrastructures, would for frontline SAS staff at the time, be very helpful. Also what SAS frontline colleagues can access to support people with enduring mental health needs who access emergency services at times of non-emergency need can be challenging and established. Our work on developing pathways of care and support are being developed locally at pace however the challenges of working across local authority areas, with local differences can

sometimes create challenges for SAS. Ways to improve this would have significant benefits and we would be keen to engage in this area.

SAS is already considering, and in many places delivering its response with community partners. In respect of this SAS would welcome the opportunity to contribute to, and bring its perspective to the process of considering actions for change. This is fundamental as for most people when things go seriously wrong or often even when there is a concern that things might be going wrong, 999 is the default response.

Scottish Autism

Scottish Autism
Response to Review of Adult Health and Social Care

Thank you for the opportunity to respond to this review. Our response is understandably focused on autistic people and the challenges they face when navigating the adult social care system. However, those challenges are not unique to autistic people and so, in addition to this response, we have contributed to the submission by the Coalition of Care and Support Providers Scotland (CCPS) and wholeheartedly agree with their recommendations and observations.

The Scottish Government's review of adult social care offers us an opportunity to shape and improve services for autistic people and we welcome the review.

We are keen that any new system cannot be a one size fits all as supported people have diverse and individual needs and providers are diverse too, offering choice of approach to delivering services as well as the services actually delivered. We appreciate that Covid brought into sharp focus the needs of older people but the review cannot result in changes that meet the needs of this demographic but no one else.

We have seen countless reviews, and multiple legislation - now is the time and opportunity for real systemic change whether that is about making existing legislation eg SDS and the integration of health and social care work better or developing new approaches. Too often the legislation is full of good intentions in delivering choice and control to those who need services but the architecture that surrounds it and local implementation is inconsistent and in many cases non-existent. If there is a National Care Service, it should be about achieving consistency and equal access across the whole of Scotland. It should also be about consistent approaches to funding and commissioning services as well as what is procured and how as well as what is delivered.

The current system involves multiple agencies from the Care Inspectorate to the SSSC which confuses the pursuit of quality. Rationalisation is a must. The Care Inspectorate continues to assess care and support providers inconsistently with judgements still largely based on the interpretation of individual Inspectors. There needs to be much greater recognition of self and peer assessment which are tools many providers use to drive up quality. Scottish Autism has developed its own self-assessment tool, the Autism Practice Improvement Framework which has been independently evaluated yet is not considered by the Care Inspectorate or commissioners.

Above all health and Social Care services should take a human-rights based approach to support. Crucially, government, public services and social care providers should be held accountable for upholding and promoting human rights and should ensure advocacy for people needing care and support. This accountability gap must be closed as a priority and one way would be an Autism Commissioner or Commission.

For autistic people as well as others social care is not just about services for people at one given stage in their lives. It should be about supporting people throughout their lives.

We need all agencies, including health and social care, to consider and plan for a person’s whole life journey so that transitions do not become ‘cliff edges’ where services fall away or appear as traumatic points in a person’s life. We can and should invest to prevent crises that do not need to happen. Autistic people who do not have a learning disability have experienced these ‘cliff edges’ for decades as the system routes autistic people with support needs based on learning disability or mental health. When the autistic person has neither the accountability gap becomes a chasm.

To achieve this requires a shared understanding and holistic view of a person’s life and aspirations by health, social care, education and other services. Supported autistic people need to be involved in creating this shared understanding and be at the heart of shaping decisions about their lives from the outset. The integration of health and social care has not seen budgets shared. Professional silos have not been broken down and health services remain the dominant partner. Joined up service commissioning and provision will only come when this happens. A starting point would be a simply accessible single gateway into services so that those autistic people who do not have an intellectual disability, or acute mental health difficulty do not fall through the gaps in service provision.

These aspirations can only be achieved if the workforce supporting autistic people have the skills and knowledge coupled with professional values and standing. Generic, tick-box qualifications such as the SVQ do not provide such knowledge or skill. Indeed it is questionable whether the staff time and resource in obtaining SVQs is commensurate with the benefits particularly in specialist settings. Investment is needed in a professional, properly rewarded workforce who choose social care as a vocation as well as a career. This must be a focus of the review and we see a role for national oversight – perhaps a National Care Service to facilitate this. However we are concerned that a National Care Service that delivers and ensures more than national intentions would inevitably reinforce a command and control culture which would stifle innovation and creativity and potentially dilute the diversity of sector providers and the value that diversity provides..

Investment in the skills and career development of practitioners is also needed; resources for pay progression and differentiation; funded time to train and learn; and a model for service provision that includes the generation and exchange of practice knowledge. A well developed and supported workforce will deliver better outcomes for people than an undeveloped and unsupported workforce. These are not optional extras but fundamental to the provision of quality services, exploration of innovative and research based models of support and continuous improvement in all aspects of support for autistic people.

Importantly social care should continue to embrace the diversity and specialism offered in the third sector. This includes specialist autism providers as brokers of autism knowledge, and autistic-led organisations able to offer a community of lived experience, expertise and peer support. The ‘added value that charities like Scottish Autism bring needs to be recognised and valued. Never was this ‘added value’ - from delivering virtual support, to enhanced advice lines and coaching and counselling services - more evident than during the pandemic. These services are often funded via grants and fundraising yet they are key crisis prevention services which ‘save’ statutory health and social care commissioners, and other public services, money.

Whilst the funding envelop may or may not change we cannot get away from the fact that the current commissioning and procurement systems encourage a race to the bottom in terms of fees. Investing more in the current system would be counterproductive to achieving systemic and lasting change. Upstream investment in the right, innovative support at the right time can and does deliver savings in the long term as crises are avoided. The current failure of the system to invest in ‘preventative’ services results in greater cost for both the NHS, crises based services and indeed other areas such as the criminal justice system.

We offer these as starting points for a dialogue about social care reform and look forward to engaging with the review.

Dorry McLaughlin
Chief Executive
5th November 2020

Scottish Families Affected by Alcohol and Drugs

INDEPENDENT REVIEW OF ADULT SOCIAL CARE

Response from Scottish Families Affected by Alcohol and Drugs

Submitted by Justina Murray, CEO, on behalf of families, 6 November 2020

1. Scottish Families Affected by Alcohol and Drugs (Scottish Families) is a national charity which supports anyone concerned about someone else's drug or alcohol use. www.sfad.org.uk.

2. We were established in 2003 by families themselves, who came together to support each other and to campaign for recognition.

3. Almost 1 in 3 adults in the UK say they have been negatively affected by the drug or alcohol use of someone they know (Adfam 2020). Yet most families who are harmed by someone else's substance use remain hidden from sight. Even those closest to them – friends, work colleagues and other family members – can be unaware of what is going on. This is due to the secrecy, shame and stigma of addiction in the family, as well as a lack of visible and high quality local support, feelings of isolation and loneliness, and a sense of powerlessness and disconnection.

4. Since Scottish Families was created in 2003, families have repeatedly raised concerns with us about their experiences of supporting their loved ones to engage with alcohol and drug treatment services, as well as mental health services.

5. We hope the independent review of adult social care will listen to their experiences, and use this learning to ensure that any re-shaping of adult social care brings about real, tangible change for families affected by substance use alongside families affected by other health conditions.

6. We are submitting two key pieces of evidence from families to the independent review – 'Behind the Numbers' and 'A Letter from Karen'.

7. In 2019 we launched a series of short films called 'Behind the Numbers' to highlight the hidden role of family members affected by substance use in preserving and saving the lives of their loved ones. In the films, four family members (Sandra, Karen, Mhairi and Caroline) talk of the enduring and exhausting challenge of trying to seek help for their loved ones from services which appeared to judge and exclude; the lack of dignity and respect shown by services towards individuals and their family members; and the need for families to be properly listened to when they are advocating for the best interest of their loved ones. The films (including full transcripts) can be viewed at: https://www.sfad.org.uk/behind-the-numbers.

8. In 2020 we released a follow-up film and findings report called 'The Story of Behind the Numbers'. This identified 5 Key Recommendations for Change for services, based on family members' experiences, as reproduced in Appendix 1. This film and report are available at the same link as above.

9. The Letter from Karen is shared with her permission. It provides powerful testimony of a mother's relentless efforts to support her son to access substance use services, and shows the anger, frustration and exhaustion involved. Karen lives in East Ayrshire but in our experience this letter could be written by family members from many other areas of Scotland. Karen's letter has previously been sent to the Minister for Public Health and the Director of East Ayrshire Health and Social Care Partnership, and has been shared with the national Drug Deaths Task Force. Karen is a member of Scottish Families Family Reference Group.

10. We are not adding any further interpretation or analysis to this evidence from families, as they speak for themselves about multiple service failures in adult social care and what families want to see by way of improvements.

11. Thank you for the opportunity to share families' experiences, and we are happy to respond to any queries or link the Review in with family members directly.

Contact details
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Scottish Families Affected by Alcohol and Drugs
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APPENDIX ONE

Behind the Numbers - Key Recommendations for Change

LOVE	**1. RECOGNISE THAT EVERYTHING FAMILIES ARE DOING FOR THEIR LOVED ONE IS MOTIVATED BY LOVE.** There may be tension, conflict and anger, and sometimes family members will have to take a step back to focus on their own self-care and protection. But love has power and this can be harnessed by services too. Love can motivate service engagement and recovery, and inspires hope and compassion in the most challenging times.
WELCOME	**2. OFFER FAMILY MEMBERS A WARM WELCOME IN THEIR OWN RIGHT**, even if their loved one does not want family involvement in their care. Remember they know their loved one better than you – probably better than anyone – and can provide you with a significant amount of additional support and information to help with treatment and care. They will understand that you cannot share confidential information about their loved one, but there is no law against listening to their views and experiences. As well as this family-inclusive practice, services should offer one to one and group support for any family member who wishes this, in their own right. This may be delivered in-house or through partner organisations such as Scottish Families or other providers.
LISTEN	**3. LISTEN TO FAMILY MEMBERS.** You may not always want to hear what they say, but they will give you an honest and true reflection of any service performance issues, and how to improve your service. Remember they may be angry, frustrated, afraid and traumatised. All of this may influence how they communicate with you. This includes children and young people who are affected by others' substance use. They commonly describe being ignored when they are trying to shout out for help.
DIGNITY	**4. TREAT INDIVIDUALS AND FAMILIES WITH DIGNITY AND RESPECT AT ALL TIMES.** This comes at no cost and brings significant rewards. Each one of our family members talked about being judged and stigmatised by others, including those services who are paid to help and support others.
RISK	**5. SHARE THE RISK.** We understand that supporting people with alcohol and drug issues involves significant risk. Not supporting people increases risk even further, including risk of harm and death. Families and services can share risk by working together on treatment and care planning and delivery. This will help preserve and save lives, and reduce deaths. Share harm reduction information and approaches with families, including supplying naloxone where appropriate.

Source: Scottish Families (2020) The Story of Behind the Numbers
https://www.sfad.org.uk/content/uploads/2020/05/Behind-the-Numbers-Findings-Report.pdf

APPENDIX TWO

A LETTER FROM KAREN

As a mother of a heroin addict who is now in recovery with no support from addiction services and a fight at every twist and turn or hurdles to continually jump over. I am tired of fighting to keep my son alive. My son Lee has been involved with drugs since the age of 14 and is now 33. I have had enough misery to last me a life time. My son has been involved with addiction services for 9 years and this was also a turning point in his life as to come off methadone. All they have done for him is keep him on Methadone and valium. At one point he was prescribed 120ml of meth and 10 yellow valium per day every day. Why there was need for this i do not know. His worker quoted ' all we have done is keep you on Methadone we have done nothing else for you. How would you feel about going to Turnaround in Paisley for 6 weeks' to which he jumped at the chance as there was no problem with benefits and housing issues. This was his turnaround in life but was disappointed that his worker did not turn up for his exit review. He decided after leaving Turnaround that he would reduce his methadone as he felt his body was telling him that he no longer needed the amount prescribed to him as it was making him feel sick. I attended his appointment with him at Bentick Centre after his release from Turnaround and he stated to his worker that he wanted to reduce 30ml from 110ml to 80ml. Worker said it was a large amount but my son was adamant that this is what he wanted and should be supported to do so. Worker said she would go see if a prescriber was available but returned and said he didn't have time. I found this to be a shocking attitude. Is it not for services to get people stabilized and then reduce their methadone and be continually supported to do so? Anyway worker stated that Lee should ask for a measuring cup on attending chemist on the following day. Take 80ml and give the pharmicist the 30ml back and continue to do this for 2 weeks and see how it goes. Lee attended the chemist on the Thursday with no issues but on the Friday he phoned me in the afternoon in a panic stating the pharmacist told him there was no script for him. I arrived at the pharmacy asking what the problem was and was told that there was no script for Lee. I stated that there was and were phoned from the Bentick on the Wednesday regarding the procedure and she just shrugged her shoulders. I stated that she should take heed of the notice regarding behaviour on the door of the meth room. I phoned the Bentick regarding this issue and Jeff phoned me back saying he would sort it. Lizzie (a support worker) came to the chemist and Lee stated that she was probably picking his old script up. Pharmacist then stated it would be another 15 mins. Guy came in the chemist handed over script and walked straight back out and Lee told me that it was Jeff. He never acknowledged myself or my son. Lee then recieved his methadone after a 2hr wait. Lee also stated that hadn't I intervened he would probably went out and used and ended back down the slippery slope of drugs misery. All this could have been easily avoided had the prescriber done a new script instead of the power trip. Professionals have no right to abuse their power. There's only one God and they're not it!!! Why does it take a family member to sort things out? Why are people with addiction issues not listened to?

My son also has never been in jail which is a rarity for a heroin addict for 15 years. However he did get community service and yet again had to jump over hurdles to get his methadone on the Monday night to enable him to get to community service on the Tuesday morning at 8.45am (chemists don't open til 9am) I asked to speak to a worker regarding my son's recovery and was told 'no this is not a drop in centre' so once again went down the complaint route as this was hindering my son's recovery. The reason they gave for not giving him his meth on the Monday night was that he hadn't seen a worker for x amounts of months. His worker was on long term sick and no one had bothered to allocate him another worker so yet again through no fault of his own.

He was also asked to sign a waiver (after being at chemist for over a year) at the chemist to say that he would not bring anyone in with him when he was attending for his Methadone. I challenged Boots on this as my son and I both felt this was discriminating and stigmatising him for being an addict. Pharmacist stated that I could imagine if 10 people were in receiving their medication and they brought someone with them the shop would be too busy. I replied 'well I'm sure you can appreciate 10 Joe Bloggs in collecting their medication with a friend. Are they asked to sign a waiver?'. There was no reply. She stated that she wanted to continue to support Lee and I said that Lee needs continual daily family support so would he be penalised for bringing someone with him. She said 'No'. Then why the need for the waiver?

I have been supporting my son regularly for the past 2 years since he returned from Turnaround in Paisley. He has been asking for a suboxone detox since last year and was told when he got to 50ml then it would happen but again the goal posts have been moved. He was so fed up with services after being in them for 9 years he took it upon himself to not return to chemist or services. His friend Murray was also put off 55ml of methadone for no reason so the two of them are supporting each other staying 2 days at one house then the following 2 days at the other. They have also been buying df's to get them over the rattling off meth. My son Lee now has the determination of having a voice, largely due to family support, that he does matter. He is a human being and is rebuilding his life slowly with no thanks to services. He was also confident enough to make his own complaint as to why he was put back on a daily script and not notified about it til he got to the chemist. As a result of this complaint it was decided that clients will be notified prior to any change in scripts therefore why was this not implemented in the case of Murray Wilson (who is also a family friend) and is my son’s friend? Why did a doctor sanction this that had no dealings with this client?

I got so fed up with no family support since the Lighthouse Foundation received no more funding that I decided along with my friend julie, we would start a support group for families as there was no where for them to go. This is my therapy as we are all in the same boat regarding being on the receiving end of addiction. Yet again it’s a fight to be supported from anyone at local level. Aren't services to be family inclusive? It would serve services well to start from within regarding stigma, respect, treatment of people and listening to what choices people wish to make for the better and if we all worked together instead of against each other it would better serve the community.

I am also very proud of my son and what he has achieved in the last 2 years with very little help or support from services. However he has continually used family support of myself, his brother and sister, gran, papa and auntie. He also has no intention of returning to services. I hope he is well enough to come out the other side of this experience and be able to voice how treatment of services affected his decisions that he chose to make. He would also like to make sure that there is a change in services for the better and the same does not happens to others.

Unfortunately he did not come out the other end successfully. He never realised that the withdrawals from Methadone are horrendous. It is easier to come off heroin than methadone. He ended up back down the slippery slope of heroin addiction in which he hurt himself jagging his groin as he has no other usable veins left. He got an abscess which luckily enough subsided itself. He was suicidal that he texted me to let me know of his suicidal thoughts but hasn't got the balls to do it (I already have a family member commit suicide 28 years ago). Not a nice place for a mother and son to be in. Due to his mental health state he phoned Woodland View in North Ayrshire to ask the criteria for being admitted and was told they take people with addiction issues to drugs or alcohol or mental health but he would need a referral from his GP. He arranged an emergency app with his GP to which i attended also, which the minute you mention addiction issues the barrier goes up, plus the gp was very arrogant and spoke over us quite a lot. It’s not his place to judge. He stated ' I can't refer you to Woodland View. I can only refer you to the psychiatrist and he decides whether you get in or not'. Yes that is what we are here for. He said he would also refer my son to the crisis team. 4 months on there has been no communication from either Woodland View or the crisis team and ye wonder how people are dying?

Lee's GP had also re-referred him back into services the first week in June where he was assessed and was not to see the doctor til the middle of September- 12 weeks later and yet again you wonder why people are dying? Fortunately he involved his cousin who is deputy leader of the council and a short time later he was given an app for 2 weeks later. Why does it take a family member to intervene? Met with the doctor on the 26th of July '19 and Lee was restarted on 20ml of methadone to which he was pleased about as he didn't need to inject anymore. The doctor told him he would discuss Lee at the meeting on Monday morning regarding getting a new worker as his worker is going on maternity leave. His worker had told him at his app in first week in June that she would have a meeting with Lee to introduce him to his new worker before she went on maternity leave. Yet again this has failed to happen and no one from services has got back to him to say if he has a new worker or not. Again chaotic and letting people down.

I've had a meeting with the head of Health and Social Care Partnership in East Ayrshire and also the lead clinician of addiction services and both admitted they have got it wrong regarding myself and my son’s treatment within services, so my question to you is ' WHAT ARE YOU GOING TO DO ABOUT IT?' There is currently a crisis with drug deaths escalating every year. What are you prepared to do within services to help me keep my son alive? Services are keeping people addicted. Not everyone wants to be on methadone for the rest of their lives. My son for one does not. Why is there no treatment facilities for people wishing to come off methadone? There is one only in Paisley and you have to have commit crime to access it as it’s through the criminal justice system therefore in order for my son to return to this facility he will have to commit a crime or offence.

As a mother I am fed up talking and telling the same story time and time again. I have been telling the same story for 2 years and badgering services for change but I know it’s not their fault. It’s you lot at the top of the tree. You might have brains but no common sense. Its time you started listening to the families with lived experience as the Roads to Recovery never worked since the day and hour it came out. Now you have Rights, Respect and Recovery, to which it’s supposed to be family inclusive, and that is not being implemented at local level either!! Why is that?

Here in East Ayrshire when you phone addiction services, messages are not being passed on as there are no services coming from the Bentick Centre. They keep saying there is a problem with the phone lines but make no attempt to sort the issue. People accessing these services are being made to travel all over Kilmarnock to appointments as they have no central clinic. People with addiction issues are already chaotic they don’t need the chaos of the services added into the mix.

East Ayrshire addiction services are proud of the fact they have a 3 week referral process but then it’s another 12 weeks to be seen by a doctor to get a methadone script. This is not good enough and if you wish to compare it to your statistics then that would mean that 15 loved ones have died in the 15 weeks waiting to go through this process. Not good enough and it’s not rocket science to work out. Treatment has to be done within the week like in Midlothian so why not here? Get people stable and then work on the issues as to why they take drugs in the first place.Give them a care plan also as I was told there are none within East Ayrshire addiction services. Every other service has a care plan so why not in this service? Why is methadone the only option available within services?

It also concerns me that prescriptions are done generically. East Ayrshire addiction services generate a 1000 a month. Therefore anyone that wishes to reduce their methadone intake has to wait til the next script change at the 28th of the month. Again this is keeping people on high doses needlessly. This has to change. When people are ready to reduce it has to be done when they decide not when it’s convenient for services. This is not a person centred approach at all!! My son reduced 3 times in 18 months and each time had to wait til the script change apart from the first reduction mentioned in a previous paragraph. He was also continually asked if he wanted to go back up to his original amount and each time said NO. What is wrong with addiction workers. I just wish they would support people in their choices of recovery. Whilst they might not like their choices they are there to support no matter the choice.

My last paragraph is regarding the fore mentioned Mr Murray Wilson who is no longer with us. He was found dead in his mother and father's living room on return from their holiday to Bulgaria on Friday the 2nd of August '19. He had been lying for a few days. There has to be a post mortem and probably a toxicology report to establish the cause of death. I personally don't care what the cause of death is as had he not been put off his methadone in February (by a consultant who had no dealings with him or had ever met him) this boy would still have been alive and not returned to the slippery slope of heroin and other street drugs, which ultimately led to his premature death. He also refused to return to services as he was treated with no respect or dignity. This was my son's best friend and is distraught at the fact he will never see him again and will need bereavement counselling offered through Scottish Families. There is also 2 kids left without a dad. A mother and father without a son, brothers and a sister left without a brother. So terribly sad. When will you wake up and start putting changes in place to stop unnecessary deaths? Services are failing people.

I refuse for my son to be another of your so called statistics. We need a change and we need it NOW!!!

Karen McLeod

Scottish Mental Health Co-operative

ADULT SOCIAL CARE REVIEW
SUBMISSION FROM THE SCOTTISH MENTAL HEALTH CO-OPERATIVE

INTRODUCTION

The Scottish Mental Health Co-operative is a national charitable company operating as a membership body of local mental health service providers in Scotland. It was formed in 2010 and obtained charitable status in 2019.

The Scottish Mental Health Co-operative membership welcomes the review of adult social care in Scotland. We believe this is well overdue given major changes in Scottish health and social policy that continue to be challenging for people, families and carers seeking or receiving support, and also for service providers delivering support in local communities.

We seek assurance that the review in its deliberations of adult social care takes a broad view of community mental health services and approaches, whether funded through public tendering or grant funded, and expressly considers mental health service providers such as our members which deliver services that are person-centred and outcome focussed.

For this submission we have taken account of policy and practice relating to The *Social Care (Self-directed Support)(Scotland) Act 2013*, *The Public Bodies (Joint Working)(Scotland) Act 2014* (integration of health and social care), *The Carers Act 2016*, and the Scottish Government's *Mental Health strategy*, 2017-2027 that sets out key priority areas and actions.

Scottish Mental Health Co-operative member organisations share a common set of principles and values applying these to how services are locally developed, managed and delivered. It is this collective experience, built up over decades and our continuing relationship with thousands of mental health service users, their families and carers, local communities and our total and committed workforce, that has informed and influenced our submission.

We do therefore offer this submission to the adult social care review from the perspective of mental health service providers, member organisations of the Scottish Mental Health Co-operative, working as part of the wider Scottish third sector. We seek assurance that mental health is given fair and equitable consideration alongside other categories, namely older people, people with physical disabilities and people with learning disabilities, which together are typically classed as adult social care.

KEY CONSIDERATIONS

1.0 Mental Health

The Scottish Mental Health Co-operative, as a membership organisation of mental health service providers, operates within a paradigm of mental wellbeing and mental illness.

This can include people whose mental health is impacted by underlying needs associated with alcohol or drug addiction, physical and disabling conditions, challenging behaviours or who pose a high risk of harm to self and others, or who are faced with additional concerns resulting from homelessness, money and debt difficulties, the impact of COVID 19 on self and family, for example.

The Scottish Government's *Mental Health Strategy*, a key document setting out priority groups and actions does not provide a definition, or guidance, of what social care is or might be for people needing mental health support. Delegating implementation to local health boards and authorities, principally to integration partnerships, does show that community-based, non-clinical mental health support has to fit (by and large) within a highly prescriptive process and system of public procurement that has itself changed little over time but expects nonetheless more (for less funds) from its third sector service providers, in general. We quote from the Health Alliance's consultation with mental health service users where they refer to services and where they say *'…need to refrain from doing the same thing and expecting different results'* (5 October 2020).

Over the years there has been a general pecking order of priority client groups within the adult social care categorisation discussed on the previous page where mental health, in particular 'functional' mental ill-health is, more than not, ranked the lowest.

We strongly urge a thorough analysis of the broad category of 'mental health' to ensure that it encompasses all aspects of community service support and delivery, and includes:

- early intervention and preventative support
- people with low to moderate symptoms of mental ill-health
- people with long-term clinical mental illness
- rural outreach and access to appropriate services.

Broadly speaking, client referral routes include, but are not restricted to:

- NHS – Primary Care, Community Mental Health Teams, Psychiatry, Psychology and other allied professionals – health visitors, district nurses, occupational therapists etc.
- Local Authority – social work, housing, criminal justice
- Third Sector – range of organisations eg alcohol and drug addiction, housing associations.

Referrals include people who are:

- leaving in-patient psychiatric care, including people on compulsory treatment orders
- being readmitted into in-patient psychiatric care
- living in homelessness accommodation and now moving to their own home
- leaving through-care for young adults
- people transitioning from children & young people's mental health services into adult services
- transferring from addiction support services or criminal justice
- Out-of-hours support/emergency call out.

The above situational circumstances require better and improved discharge/ transition planning for clients returning home/ moving to independent living in the community.

Third sector mental health service providers often step in to provide ' care management' or, at best, to act as 'service anchors' to help clients to develop their potential as full and active members of their community. This exists whether there is consultant psychiatric support and/or community mental health (CPNs) or not. It is a fact that we take on additional roles and support activities relating to a client's total health and wellbeing, such as serious physical health issues, which will not be recorded in service monitoring, commissioning processes and systems or client care plans.

Our member organisations report examples where they are at the forefront of supporting clients for emergency appointments with their GP or during 'out of hours' to Accident and Emergency Departments where it may take many hours for clients to be appropriately triaged to mental health services. There is no reciprocity from commissioners in terms of payment for additional staff working hours (requires two staff) nor travel costs: all of which add further financial pressures on local mental health service providers. Situations of this nature result from poor 'out of hours' support to people experiencing sudden trauma or panic attack episodes.

The benefit of clients receiving support from local mental health service providers, such as our member organisations, is that we exercise 'internal' referral to other services we provide that augments the core support they already receive over the long term. For example, short-term counselling or peer support that helps alleviate intermittent/ circumstantial episodes of stress or anxiety.

Funding mental health service providers seriously needs to consider, firstly the person and their needs and how best to support them, secondly that public funds create rigidity and inflexibility that thwarts successful client outcomes.

We believe that early intervention and preventative approaches are valid services, offered as stand-alone support to offset risk of deteriorating mental health, but also as a short term support for clients experiencing fluctuations in mental well-being. This 'one-shop' approach to mental health and wellbeing is a support model that characterises the commitment of our member organisations to attend to clients' needs holistically.

1.1 COVID – 19. What can we learn for future planning of adult social care?

The Scottish Mental Health Co-operative believes it is essential to review and evaluate how support services continue to be delivered during this current pandemic and use the findings, from the perspective of third sector mental health service users and providers, to inform recommendations.

Anecdotally, we have baseline experience of how our member organisations quickly transitioned their operations to remote working while continuing measured client support, in-line with government guidelines, and all the challenges that ensued relating to IT capacity and safe practice for clients and social care staff. Importantly, the shift from in-person support to using Zoom, Facetime and telephone/text (including combination of one or more of these) facilitated service continuity for many clients, but for others it did not.

Third sector mental health service providers, our members included, showed immense initiative and innovation, including speed, in mobilising remote-working but also in prioritising and singling out clients who requiring home support ensuring that staff had sufficient PPE for safe working. Importantly, third sector service providers needed no directive from commissioners and funders but acted intuitively to protect clients and staff alike.

The nature of mental health, its associated stigma and fear of discrimination, leads many service users further into isolation and withdrawal and we should never aim to replace that direct in-personal contact, but we must further develop that IT capability for any eventuality that proposes risk to services being delivered.

This shift in working practices, while not ideal, has inevitably protected vulnerable clients and possibly saved lives. It strongly shows the resolve, determination and commitment of third sector service providers to provide the best solutions available, at that time, and work with them. An example given included reluctance from one local NHS health board to support one member organisation to using Skype to support rural based clients during winter months when travel conditions were prohibitive. Ironically, this did not seem to be an issue for dealing with the pandemic, even though there remain no clear guidelines of safe or shared use of NHS technology with third sector service providers.

The above has exemplified the under-resourcing of, and limitations, placed on third sector organisations, including mental health service providers. Again, we pose the question what can the NHS and local authorities learn from our mental health service providers about service continuity in adverse conditions?

Rather than acting as gate-keepers, should statutory bodies listen and support new ideas, that come from their service provider partners, or are we simply to accept, 'wrong time, wrong place'?

Different member organisations report delays in responses to where they have discussed and then submitted fully costed new service proposals to public sector senior managers for consideration, even where independent funds might be sought.

Where ideas originate from third sector service providers, it is often an uphill battle to open up discussion and present these ideas with lead officers and senior managers. This is but one area of where change is required in relation to partnership-working where we are treated as integral and 'co-partners'.

The pandemic has placed unprecedented demands on our member organisations. This includes existing clients who are experiencing relapses in their mental health symptoms, people with pre-existing mental health conditions whose mental wellbeing/ recovery has been exacerbated by the pandemic and also people who have not self-referred or been referred for mental health support before the pandemic.

We strongly urge that the adult social care review takes full account of the substantial increase in people reporting mental ill-health and considers how the experience of mental health service users and organisations, to date, can help to shape and redesign services that are truly person-centred, outcome-focussed, flexible and responsive, and timely.

2.0 **WHAT DO WE MEAN BY 'ADULT SOCIAL CARE'.**

Our member organisations suggest that if a new definition is to be considered that it begins with and is focussed on the person seeking help and support BUT not to the exclusion, where appropriate, of significant others in the person's life and social network. This can include their partners, families and carers, children and others.

Any definition, or indeed implementation of adult social care, should not be prescriptive of services, 'off the peg' so to speak, or of a setting in which such an activity takes place, but rather based on the conversations with the client, their family and carers, or significant others at the assessment stage.

This process is clearly implied within Self-directed Support policy where it states '….greater choice and control of the planning and delivery of their care, including options for managing their own budget'. However, the implementation of self-directed support, based on existing practices and client experience, falls short in many ways presenting as an idealised version of personalisation rather than a robust model of person-centred social care that meets with high quality standards and excellence.

Our member organisations are clear that they do not operate within a medical model of mental health support, but are social care providers and that their approaches should complement and work together with clinical mental health services. Moreover, how Scottish government, local authorities and integration partnerships use and apply this term, especially when procuring/commissioning services does not engender any meaning, or acknowledgement, to the full extent of how our member organisations approach each and every individual referral nor the scope and extent of service support, given, '*what they actually do'*, including the unconditional support to families and carers and 'significant others' identified earlier.

We would be wary of definitions of adult social care that are simply based around the existing template 'time and task' care plan approach commonly adopted by commissioners of adult social care.

It would be a serious omission to not consider, or explore, the range of services that our member organisations provide that are outside of commissioning regimes as this would negate the scope and wider understanding of what is adult social care.

The chair of the Adult Social Care Review Advisory Group, in video interview, for the Health Alliance AGM 2020, affirmed that housing and other interfaces that impact on meeting people's needs should be included within their remit.

Our member organisations provide further practical examples of where their approaches and activities, from the perspective of personalised mental health and wellbeing support and recovery programmes etc. provide added value that contributes to a more holistic benefit and improved outcomes for clients. *These include, but are not limited to:*

- housing support and home care management, including preventing eviction and homelessness/ resettling clients back into the community
- money benefits and advice, alleviating poverty and debt
- safeguarding children, in families with parent/s with complex mental health conditions and needs
- care and protection of vulnerable adults
- carer support
- supporting adults with incapacity, including learning disability
- client support at case reviews/ assessments
- client support to TAC (Team around the Child) and TAF (Team around the Family).

There should be a significant shift from the 'time and task' regime currently deployed by local authority commissioners thereby enabling third sector service providers to exercise autonomy and greater flexibility of support.

2.1 Enabling, Empowering and Partnership Working

Traditionally, adult social care has been characterised and defined by a set of deliverables subject to based on client hours, often referred to as '*Time & Task'* by commissioners and applied similarly across different client groups. Service providers are well versed in the use of key words such as *enabling*, *empowering* and *partnership working* often enshrined in health and social policy, but when used in practice, they can be seen as *tokenistic, patronising,* if not, *insincere*.

As third sector mental health service providers, our member organisations work within a context that is about building mutual trust and confidence between staff and clients, including their families and carers. It is an inclusive relationship where staff will invest time and energy to develop, show respect and dignity for the client, demonstrated by being always being on time, willing and focused on the job in hand.

Our member organisations, following unannounced inspection by the Care Inspectorate, are able to provide qualified feedback about the support they provide and what clients say about their key workers. Amongst the feedback, there is a common thread of clients trusting those by whom they are supported, and having confidence in the organisations providing the service. Both must be seen as key performance indicators of quality of care and support.

Member organisations report that they are not necessarily involved in the initial client assessment and that the whole experience becomes one of receiving automated care plans, followed then by meeting clients, possibly their family and carers, at a much later stage.

Enabling

Our member organisations suggest that ‘*enabling*’ is a critical approach but nonetheless challenging when supporting clients whose history of mental health support has been rigid and controlled. However, the norm adopted by our member organisations is based on a simple, ‘doing with not for’ approach that involves improving a person’s motivation and self-confidence, challenging as this may be. Through shared care planning between commissioners and service providers there should be clear account of common and consistent approaches which will further help manage client expectations and lead to better and improved client outcomes.

There is poor, or little, client sharing between statutory mental health services and their ‘partner’ mental health service providers that presents itself throughout the duration of the shared client’s care and support service. This does not augur well for good standards of adult social care and should be addressed.

Our member organisations place importance on staff exercising empathy and learning acceptance of when clients may relapse that sets them back in their recovery/ ability to self-manage. ‘Enabling clients to regain self-confidence and the will /motivation to work through their obstacles and barriers is a constant feature of our approach to social care.

Our member organisations also agree that supporting mental health clients towards recovery/ improved self-management is highly individualised and cannot be managed in fixed hourly/ weekly care plans.

Empowering

‘Empowering’ clients, especially people whose self-confidence has been greatly impacted by their mental ill-health is a further challenge for our member organisations. Mental health service users are not a homogenous group and therefore not all individuals have the ability to comfortably advocate for their own care packages (see section on Self-directed Support) nor to raise their concerns or make complaints about any aspect of their service support. ‘Empowering’ clients is about ‘enabling’ them to take responsibility in a planned and supported way to manage their day to day lives and work towards improving their skills of self-managing their mental health symptoms.

Partnership Working

Any partnership working is based on an understanding of the balance of power and control. In the case of clients and staff there must be mutual understanding and respect that operates within the framework of the client's care plan and self-defined outcomes.

As indicated earlier, social care is predicated on mutual trust and confidence in what is a highly personal relationship with people who are vulnerable and relying on this support with high expectations of recovery possibly.

2.2 Quality of Adult Social Care.

We believe it is important to define what we mean and understand by the term '*quality*' and '*quality assurance'* if it is in some way different when used in regulatory and inspection regimes that are legally required to take account of the Scottish Government's published health and social care standards in 2017, and implemented in 2018.

Using the Care Inspectorate as the benchmark of independent, unannounced inspection of third sector service providers for commissioned services, we single out three factors used in evaluating quality, although not all are assessed and graded at the one time. These include, *Quality of care and support*, *Quality of staffing* and *Quality of management and leadership*.

Achievement of Grade 6 Excellent in care and support is a formidable challenge for any service provider, as indicated by the Care Inspectorate when they state: *'An evaluation of* excellent *describes performance which is sector leading and supports experiences and outcomes for people which are of outstandingly high quality. There is a demonstrable track record of innovative, effective practice and/or very high-quality performance across a wide range of its activities and from which others could learn. We can be confident that excellent performance is sustainable and that it will be maintained'.*

When discussing 'quality' and 'quality assurance' the adult social care review should consider the current criteria used by the Care Inspectorate in its regulatory role and function of assessing service providers against performance indicators. It should also take account of the Scottish Social Service Council (SSSC) because of its role in regulating the workforce and employers. Where the emphasis may be different, of each of these two bodies, together they perform and deliver evaluation of service providers, adult social care included.

It is then a serious concern that quality is rated below cost and that service providers, despite consistently obtaining Grade 6 – Excellent, may be relegated to the second tier in commissioning frameworks.

The importance of quality was frequently raised in video interview at the Health Alliance AGM by the chair of the Adult Social Care Review Advisory Group, in response to many and varied questions asked of him. In this context, we note expressed support of a national definition of what we mean by 'high quality' social care coupled with a national approach to learning systems; plus, that where best practice is identified it can be scaled up.

With the latter we have no issue, but we would be somewhat cautious about introducing a national body, or a commission, to oversee quality in adult social care. This approach could, unintentionally, introduce equality measures and performance indicators without a sound understanding of the local contexts in which service providers operate and fall within the 'one-size fits all' mode.

We would expect there to be a robust examination of all manner of assessing performance indicators that relate to commissioned service outputs and outcomes, best value (cost will remain a huge factor), training and support for third sector service providers, including shared software for submitting monitoring and evaluation reports.

As commissioned services are served under formal contracts that set out target client numbers, against defined service outcomes, we would question how 'quality' is being assessed, if at all. In reality, if services cannot meet the 'Time and Task' targets and conditions and the hourly rate is considered high, there is a reasonable risk of the service being de-commissioned.

3.0 SELF-DIRECTED SUPPORT

The Scottish Mental Health Co-operative, in partnership with the Mental Health Foundation (Scotland), developed a three-year project, *Self-directed Support in Mental Health: Capacity-building for third sector mental health service providers* (2012-2015).

This was a pro-active project to help local mental health service providers prepare for/ transition their services to a personalised, self-directed support. We would add that for local, third sector service providers, the 'personalisation approach is not new but rather a confirming statement of their established practice' (Page 3, *Self-directed Support: Planning for a self-directed support service*, Scottish Mental Health Co-operative, 2015).

We express our huge disappointment in the implementation of self-directed support across Scotland that continues to create inequalities of access, in particular, and delivery that is not consistent across localities in Scotland. Disaggregating data of uptake of SDS by different client groups, including mental health service users, should be mandatory for all local authorities. Data should be available of clients who do not meet eligibility criteria and what, if any, signposting is then given to them or what other actions follow ie are clients referred elsewhere?

Our member organisations express huge concern with the eligibility criteria whereby commissioners will assess clients against Substantive and Critical factors, sometimes referred to as ' life and limb'.

To say this is counter-intuitive to the defined principles of self-directed support, namely that clients have choice and control over their care package, is an understatement. We further cite as example, statutory funders commissioning services mainly on *Option 3 – Arranged Service* – maintaining the status quo that effectively has changed nothing.

On a positive note, one of our member organisations, gives example of good practice where clients have co-produced service specifications, supported by third sector service providers with commissioners.

For clients failing to meet the criteria, and here we would add that where priority may be given to people because of immediate urgency, this displaces clients who need support because they are experiencing a mental health relapse and need help then to get back on track (this relates to earlier point).

Given the high percentage of service providers dependent on public funding through competitive tendering, where is the funding to support the 'fall-out' of clients failing to meet self-directed support eligibility criteria, levels 1 & 2?

4.0 CREATING A SOCIAL CARE WORKFORCE

We cannot fail to know that there is a general crisis across Britain in securing social care staff, men in particular. There is further risk to staff shortages with forthcoming Brexit.

Traditionally, social care is low paid (Scottish Living Wage) with poor career progression, and low staff retention for some employers. It can be used as a stop-gap for some people until they find something better, or as pre-professional work experience for nursing or other health related field.

The status of social care staff has however been changing over the years, particularly because of increased expectations that they must achieve SVQs in health and social care at Levels 2 or 3. This applies specifically to commissioned services where this is a contractual requirement. Social care staff are also required to be registered with the Scottish Social Services Council which oversees workforce regulation, including training.

The adult social care review should include whether existing training for health and social care staff is fit for purpose for whatever may ensue by way of recommendations for the new vision of 'social care'. We must ask what is it we should provide to train people to fulfil social care in its fullest and best definition, what are the skills and experience required, and how do we build a unified social care workforce that has status and valued recognition.

We would add that given that 'social care' consists of a broad and wide ranging portfolio of services, activities and approaches, in addition to the more traditional model of commissioned service (in general), our member organisations wish it to be recognised that our working environments include staff with multiple skills, experience and qualifications, ranging from mental health nursing, training in person-centred counselling, CBT, mindfulness, community work and so forth. It is therefore important that the review takes account of these and additional professional registrations governing standards staff working in community-based social care are required to fulfil.

We should not exclude the professionalism and competences of lead officers and senior managers and of the multidisciplinary workplaces which our member organisations have created and within which they operate.

We believe this is now the time to ensure that there is equality and parity of 'professionalism' between statutory colleagues and those in the third sector.

We would add that our member organisations believe there is a strong need to examine the role of community psychiatric nursing in relation to what social care staff do, assessing what is the same or different between the two disciplines, setting aside that one is NHS and the other third sector mental health service providers.

4.1 Volunteering in Social Care

A singularly important and defining characteristic of the third sector is its long established practice of recruiting, training, deploying and supporting volunteers in various activities, especially within the broadest sense and understanding of social care.

We believe that the review SHOULD NOT omit volunteering from its deliberations as this area of activity is integral to many, many social care activities. We issue caution when we say that the volunteer role is not a replacement of what social care staff do, nor is it a cost saving measure although many, many examples of volunteer-based support are cost-effective. We strongly assert that using volunteers involves investment and should be considered as an additional tier within social care.

Our member organisations can provide many excellent examples of successful local volunteering projects and services that range from befriending and mentoring, social and skills development groups, activity groups such as walking, arts and crafts etc. Enabling mental health service user to participate in volunteering opportunities for which they may have an interest is part of promoting mental wellbeing. Peer support volunteering is also a key approach deployed by our member organisations.

One example, relates to two of our member organisations, based in two geographical locations, working in partnership with the Mental Health Foundation where they created and developed a new and innovative approach to supporting mental health carers using a peer mentoring model. This three-year pilot service was evaluated as highly successful pilot and applauded by funders, the Big Lottery. However, introducing this carer support model to a local integration Partner was seemingly not given much consideration after being approached.

As previously intimated, there is a disconnection between what third sector organisations trial and pilot in terms of new and innovative approaches to social care, in this instance, carer support and how successful models can be adopted and replicated across Scotland.

Moreover, the offer by an elected third sector representative to the Strategic Planning Group of a local Integration Partnership, following publication of the King's Fund report, Volunteering in health and care: securing a sustainable future (2013) to produce a discussion paper on volunteering was not greeted with any enthusiasm by statutory senior managers. Again, we cite this as a significant example of the barriers to progress and disregard what third sector service providers excel in.

5.0 PUBLIC COMMISSIONING AND PROCUREMENT

This submission has made reference to how social care is procured and commissioned is the single, dominant feature of community-based social care. We estimate that about ninety-eight per cent of gross annual income amongst many of our member organisations is derived from statutory procurement and commissioning of local services.

As third sector organisations this can be a precarious position for our member organisations, especially because any single commissioning framework may now place as many as 40-50 service providers in order to create competition and drive down the hourly/unit cost.

One example, given by a service provider, included a commissioner approaching more than 25 service providers before finally awarding them the contract. We would ask how cost effective it is for a senior manager to spend their time to save 'pennies' on an hourly rate than to offer the contract to a well-organised, Grade 6 – Quality of care and support provider?

Where the chair of the adult social care review in video interview for the Health Alliance AGM said that procurement (cost) and quality are important areas for consideration, and that this includes the relationship between provider/purchaser specifically; person-centred and 'asset based' were further considerations in what might be introduced. One of our member organisations commented that '*outcomes-based*' commissioning was now gaining some momentum, but added that a*ny* contract for services should have longer times and built in flexibility to ensure services can adapt to meet people's needs.

Notwithstanding the above, we remain concerned that competitive tendering will remain the norm and the main means of funding social care services, disregarding any other type and form of partnership funding. We are confident that the review will find 'time and task' an outdated model that does little to provide what clients may actually need or want and, by its nature, belies the principles of self-directed support. The review must assess the extent SDS Option 3 is used in commissioning, particularly for mental health service users.

Where we have commented earlier on the implementation of self-directed support, we are resigned to the fact that this will underpin any future operation of adult social care in Scotland. It should therefore be the driving catalyst for determining how social care will be funded and delivered.

6.0 FUNDING

It is fair to say that funding for social care is the one-single dominating agenda item at Integration Joints Boards, and where decision are made about how funds are allocated to different client groups and for what.

Our member organisations share experiences of facing significant challenges in funding and resources citing changes resulting from, for example, the removal of ring-fenced funding for ‘Supporting People’.

Commissioning services based on an hourly rate cannot fully cover the additional financial burden placed on service providers resulting from increased scrutiny and regulation of their services to appearing in court proceedings in support of a client, formal service reviews etc. New training to comply with Duty of Candour, GDPR, refresher courses in adult support and protection, safeguarding children have a cost in staff time particularly, for which service providers are not able to be recompensed. Also, the increase in insurance premiums as a contractual condition to cover public and employer liability have increased considerably over the years as local authorities have increased the liability amounts.

Cost-saving measures by local authorities and health boards, not to mention increasing deficits within Integration Partnerships, make for difficult decisions in deciding how funds are allocated and to which client categories. Our member organisations provide experience of long delays in receiving funds, especially for services operating under service level agreements that are increasingly given on a year on year basis, rather than on 2 or 3 year contracts is less than helping to plan and deliver long term. Slow processing of care plans impacts on clients left waiting for support to start, and also on their financial contributions towards their services are not always collected in a timely manner, leading to a build up of arrears and client debt.

Funding and the backroom operations are often not sufficiently considered if service providers are to be considered as ‘partners’ to the public sector.

We cannot offer any suggestions as to how new funds can be generated, other than adding that where third sector service providers fundraise on their own behalf to meet shortfalls in funding (not through poor financial management but increasing core costs) they are proactively trying to create new and additional funds to sustain themselves in the long term.

We would however ask that how funding is decided, its sources and allocation is open, transparent and held to account.

Thank you for your time and consideration of our submission to the Adult Social Care Review. We warmly welcome any comments or queries to our submission.

We express disappointment that we were unable to secure a meeting with Derek Feeley, Chair of the Adult Social Care Review Advisory Group following our emails and tentative response from the Secretariat to facilitate a meeting. Please note that we would still welcome the opportunity. Contact details are given below.

The Scottish Mental Health Co-operative

Current members
East Dunbartonshire Mental Health Association
Flourish House, Glasgow
Glasgow Association for Mental Health
Health in Mind
Lanarkshire Association for Mental Health
Recovery Across Mental Health

Registered Office:
17/19 Cadzow Street
Hamilton
Lanarkshire ML3 6EE

Scottish Partnership for Palliative Care

Scottish
Partnership
for Palliative Care

Submission to the Independent Review of Adult Social Care

Key Takeaway Messages

- Scotland's health and care system is generally dominated by narratives of prevention, treatment and cure. This often inhibits consideration of how best to support people during the unavoidable but enormously significant end stages of life.
- The vast majority of care home residents, and many people supported by care at home services are approaching the end of their lives. The Review should explicitly consider how people can be supported to live as well as possible until the very end of their lives, and also receive the care needed to die well.

About SPPC

The Scottish Partnership for Palliative Care (SPPC) brings together health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people's experiences of declining health, death, dying and bereavement. We also work to enable communities and individuals to support each other through the hard times which can come with death, dying and bereavement.

SPPC was founded 30 years ago and has grown to be a collaboration of over 100 organisations involved in providing care towards the end of life. SPPC's membership includes all the territorial NHS Boards, all IJBs, all Local authorities, the hospices, a range of professional associations, many national charities and social care providers.

What is palliative care and when is it relevant?

Though more specific definitions can be helpful, one way of thinking about "palliative care" is to talk in terms of providing 'good care' to people whose health is in irreversible decline or whose lives are coming to an inevitable close. Perhaps what differentiates 'palliative care' from 'just good care' is the awareness that a person's mortality has started to influence clinical and/or personal decision-making. However, palliative care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

Palliative care encompasses spiritual care, the importance of which is increasingly acknowledged in Scottish Government policy which upholds the World Health Organisation's definition 'that health is not just the absence of disease but is a state of physical, psychological, social and spiritual well-being" (1948). Understanding the spiritual needs of an individual is fundamental to person-centred care. "Spiritual care is that care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness"[i] and is as important as good physical care.

Annual deaths in Scotland are projected to increase by 15.9% from 56,728 in 2016 (32.8% aged 85+ years) to 65,756 deaths in 2040 (45% aged 85+ years). People will often live with palliative care needs for several years before they die. A recent study in Ireland estimates that "older people living with a serious disease outnumber those in the last year of life by approximately 12:1".

The Significance of Social Care Towards the End of Life

People and their families want the care and support they need to live their lives in difficult circumstances. Their needs will be varied and individual and will change over time (often quite quickly and unpredictably). They do not generally differentiate between what the system chooses to define as "health care" or "social care".

The provision of adequate social care can make it possible for someone living with serious illness to maximise independence and quality of life, even as their health declines. Social care also supports people who are informal/family carers, often making the difference between a role which is tough but sustainable or a role which ends in crisis and collapse. Social care staff can also play an important role in anticipatory care conversations and planning. Key social care supports to people approaching the end of life include care homes, care at home, respite care and housing support.

In an average week around 60,000 people receive around 700,000 hours of care at home. Well over half of these are frail elderly people[ii].

At 31 March 2017, there were nearly 33,000 older people living in a care home. This compares to just under22,000 available staffed beds in all specialities in the NHS[iii].The percentage of long stay residents living with dementia (either medically or non-medically diagnosed) in a care home for older people was 62%[iv].

There has been a general tightening of eligibility criteria to access social care (other than on a self-funding basis). People entering care homes now do so with high levels of acuity and at an older age than used to be the case.

In terms of levels of need care homes are now closer to being mini hospitals than to the retirement homes of old. The median completed length of stay for people living in care homes for older people is 18 months (2017)[v].The vast majority of people in care homes for older people have palliative care needs. 20% of deaths in Scotland are in care homes.

Current Challenges

As the Review will be acutely aware there are a number of serious, interrelated and well-rehearsed[vi] challenges impacting on the quality, accessibility and sustainability of social care. These challenges impact on people approaching the end of life, affecting the palliative and end of life care provided by care at home services and in care homes.

Financial Pressures

There has been a longstanding failure across the UK to put the funding of social care for older people on a sustainable footing. Since 2010 this has been compounded by the impact on the public purse of the 2008 global financial crisis. In addition, as explored elsewhere demographic trends have seen (and will see further) increases in older people with care needs. Hard-pressed local authorities (now IJBs) have responded to acute budgetary pressures with procurement processes which have exerted downwards pressure on provider costs, eventually impacting on quality of care. Financial pressures have also led to a tightening of eligibility criteria, in turn restricting access to social care. Typically, social care is now only available later and at a higher level of need – opportunities for prevention are missed. Tightened access to respite causes carer collapse, avoidable crises and unnecessary hospital admission.

Tightened budgets to commission social care are making it difficult for providers from the independent and 3rd sectors to continue providing support. A recent survey found that 86% of care at home providers are worried about sustainability and survival, with 24% extremely concerned[vii]. Some 3rd sector providers are being forced to withdraw from contracts because they are running at significant financial deficits and because the level of funding available doesn’t allow support to be provided in an acceptable way and to acceptable standards[viii].

Approaches to Commissioning

Linked to (and compounding) financial pressures the mode of funding social care has created further problems. For care at home strategic commissioning has been implemented through procurement processes which specify time and task rather than person-centred flexible care.

Such approaches make things simpler for devising, monitoring and managing contracts and driving down costs. However, they result in services which are unresponsive to individual needs and circumstances, exemplified by the 15-minute visit.

The procurement of care home places has failed to adequately reflect the rising level of need of most residents.

Workforce

Recruitment and retention of staff are very difficult in the social care sector. Rates of pay remain low and this reinforces the positioning of social care as a low status career with limited opportunities for progression. The UK government's approach to immigration (Brexit and the proposed replacement regime) make recruitment more difficult. Staff shortages and high turnover impact on continuity of care. Staff training and development is also made more difficult –it is harder for staff to build the skills and confidence to provide palliative care, and even when this is achieved staff turnover undermines the building of sustained capacity. To further improve recruitment, retention and quality of care the mental health and emotional wellbeing of social care staff needs to be better supported. Working predominantly with frail elderly people, these staff regularly experience the death of clients. The individual and cumulative impact of these losses increases staff absence and harms retention. Just as spiritual care is important in the care of individuals, so it is for staff who must be supported when their work embraces end-of-life care, dying and death, and the demands of a stressful environment. The Scottish Care Report 'Trees that bend in the wind' (2016)[ix] highlights the role played by staff in considering someone's end-of-life issues, and in triggering those important conversations. But this staff role "has to be recognised, nurtured and valued". A greater understanding of the spiritual dimension can help to increase confidence in these conversations which includes religion but acknowledges that it is so much wider.

Inadequate Integration

Although neither residential nor nursing homes are clinical settings many residents have significant clinical needs. It is important therefore that care homes have effective relations with, and adequately resourced support from, local primary care teams, but this is not always the case. Similarly social care services need to be more rapidly accessible to other parts of the health and care system. People approaching the end of life may have needs which change quite rapidly, so support needs to be flexible and responsive. Some hospital admissions may not be necessary where adequate social care can be put in place rapidly. Currently many discharges from hospital are delayed whilst social care support is put in place. In 2018-19, 35% of delayed discharges were caused by people waiting for care arrangements to be complete; 26% were waiting for a care home place and 16% were waiting for a community care assessment. Around 400 people died in hospital whilst waiting to be assessed for social care or for care arrangements to be made.

Whilst the broad philosophy of self-directed support is right, for many people approaching the end life, with poor health and rapidly changing circumstances, self-directed support as currently embodied in slow, unresponsive, bureaucratic systems of direct payments is not an attractive proposition.

What Should be Done?

Funding

The potential models for sustainable funding of social care have been well explored by government and think tanks over the past 20 years. It is beyond the scope and competence of this submission to make a specific recommendation about something which requires a fundamental shift in the relationship between the individual and the state. However, it is clear that without action to address the adequacy and sustainability of funding social care (including the palliative and end of life care) will deteriorate. Since good care towards the end of life is a basic human right funding arrangements must support equity and social justice.

Workforce

Immigration - The UK government's new immigration regime should be revised to reflect the vital ongoing contribution of migrants to the provision of social care. The UK government's approach seems to be that recruitment and retention issues in social care should be addressed via reforms to the sector (e.g. improved pay and conditions). However, since this will take time (and it is not clear how it will be achieved), transitional sector-specific arrangements should be put in place. Bespoke transitional arrangements have been used in other sectors, for example with seasonal agricultural workers. Social care roles should be acknowledged as an area of occupational shortage. Salary thresholds should be lowered so as to include social care roles. Social care roles should not be characterised as "unskilled".

Pay, conditions and status - Pay and conditions need to be improved, and clearly this will require changes in funding levels. A continuation of the "professionalisation" of social care roles should be continued. The scale of efforts to market social care roles as valuable, rewarding and rewarded should be increased. There are opportunities to build upon the public's recent wider recognition of social care workers as "key workers" who make a vital and sometimes heroic contribution to the lives of the most vulnerable in society.

Training and Development - Care at home support and care homes often provide very good palliative care. The skills, knowledge and confidence of staff are key components, and these can be supported through training and development. There should be further investment in training and development for social care staff, and funding to enable this should be a core component of future planning/commissioning processes. More use should be made of virtual learning approaches (such as ECHO), and formal and informal face-to-face training opportunities as part of improved integration with primary care and specialist services (see below).

Planning and commissioning

Planning and Commissioning processes should assess local population needs for palliative and end of life care, and address explicitly how these will be met, considering and encompassing the recommendations in this submission. The Scottish Government's Health and Social Care Standards provide a good framework for commissioning outcomes. Services should be commissioned to deliver the outcomes set in the standards. Commissioning processes should be assessed on how well they embody this approach. Commissioning processes should encourage, support and require integrated services and partnership working. Alliance commissioning and contracting is one way of encouraging these ways of working, and recognise that a mix of 3rd sector, independent sector and statutory services may often be involved.

Rapid Access to Person-centred flexible care

Planning, commissioning and procurement frameworks need to enable the provision of person-centred flexible support. Referral, assessment and delivery processes need to ensure that social care support can be put in place quickly to prevent crises, reducing inappropriate hospital admissions and delayed discharges.

Places for Care

Planning and commissioning processes need to take account of the increasing need for palliative and end of life care over the next 10 years, together with projected changes in household structure, and take a strategic approach to the adequate provision of places for care. Depending on local needs this may involve increasing care home capacity, care at home capacity, housing support, and flexible models such as "care villages".

Care Homes Integration

The integration of care homes as part of the health and care system should be improved. Primary care services need to be adequately resourced to provide support to local care homes. Providers of specialist palliative care should be resourced to provide education, advice and support to care homes. Information systems should enable sharing of data between health and care settings to inform care. There needs to be adequate support for all providers to ensure adequacy and compatibility of technology. At a local level opportunities to co-locate health and social care staff should be exploited.

Advanced Dementia

Support for people in care homes should encompass the specific needs of people with advanced dementia. This should include proactive and holistic approaches such as the Namaste Care program[x] and Adaptive Communication[xi].

Technology to Enable Care

The introduction of technologies which promote independence, choice and control should be supported. However, there are complex ethical and practical issues surrounding the introduction of new technologies into care. SPPC supports Scottish Care's call for a human-rights based Ethical Charter for Technology and Digital in Scotland, which would provide a framework and guidance to support local decision-making. This is particularly important where cost pressures provide drivers to introduce technology. Technology should not be used to replace human relationships which lie at the heart of social care:

> *"Social care is a human interaction which goes far beyond the carrying out of particular functional tasks. It is not solely about the maintenance of health, but rather the fullest achievement possible of individual potential in a manner which is holistic. The relationship dynamic involved is one which is mutual, reciprocal and trust-based."*

Techrights: human rights, technology and social care.

Scottish Care (2019)[xii]

Mark Hazelwood
CEO
Scottish Partnership for Palliative Care
November 2020

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[i] NHS Education for Scotland, (NES 2007 Spiritual Care Matters)

[ii] https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2019-06-11/2019-06-11-Social-Care-Report.pdf

[iii] https://scottishcare.org/wp-content/uploads/2020/08/Social-care-inquiry-SC-response-Feb-2020.pdf

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[iv]https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2018-09-11/2018-09-11-CHCensus-Report.pdf

[v]https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2018-09-11/2018-09-11-CHCensus-Report.pdf

[vi] https://scottishcare.org/wp-content/uploads/2020/03/Joint-social-care-inquiry-response-formatted-with-logos-FINAL.pdf

[vii]https://scottishcare.org/wp-content/uploads/2019/11/Care-at-Home-Contracts-and-Sustainability-Report-2018.pdf

[viii]http://www.ccpscotland.org/wp-content/uploads/2019/05/Handing_Back_report_CCPS.pdf

[ix] https://scottishcare.org/wp-content/uploads/2019/11/Trees-that-Bend-in-the-Wind-Exploring-the-Experiences-of-Front-Line-Support-Workers-Delivering-Palliative-and-End-of-Life-Care.pdf

[x]https://namastecare.com/welcome-to-namaste-care/

[xi]https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5538738/

[xii]https://scottishcare.org/wp-content/uploads/2019/11/TechRights-Human-Rights-Technology-and-Social-Care.pdf

Scottish Public Services Ombudsman

Submission to the Independent Review of Adult Social Care by the Scottish Public Services Ombudsman.

About the SPSO

1. The Ombudsman has a number of different functions under the Scottish Public Services Ombudsman Act 2002:
    1.1. the final stage for complaints about most devolved public services in Scotland including councils, the health service, prisons, water and sewerage providers, Scottish Government, universities and colleges.
    1.2. specific powers and responsibilities to publish complaints handling procedures, and monitor and support best practice in complaints handling.
    1.3. independent review service for the Scottish Welfare Fund with the power to overturn and substitute decisions made by councils on Community Care and Crisis Grant applications.
    1.4. the role of the Independent National Whistleblowing Officer (INWO) for the NHS in Scotland. (Due to take full effect from 1 April 2021).
2. The SPSO adds value to Scottish public services in many ways, such as helping people, particularly the vulnerable, in crisis or need, promoting local resolution, improving consistency of decision-making and promoting the value of good complaint handling. In particular, we encourage learning for improvement, to enable more effective delivery of Scottish public services.

SPSO's role in social work complaints

Setting standards

3. The SPSO developed a model complaints handling procedure which sets out how all local authority complaints, including social work complaints, should be handled. The procedure is closely aligned with procedures for health and integrated joint boards to reduce barriers to effective complaint handling within integrated services.

4. The procedures are supported by advice and training. A revised model was issued in January 2020 with greater emphasis on support for vulnerable complainants and ensuring the complaint is fully understood before investigation begins.

Complaints handling

5. As the final stage for complaints about local authorities, social work is under our jurisdiction. Following concerns about the previous scheme which required complainants to attend an internal complaints review committee, the Scottish Government abolished the previous statutory scheme and we were given additional powers. As a result, from 1 April 2017 we have been able to consider both the process followed and the merits of

professional decisions made by social workers and others in the exercise of social work functions.

Our experience

Volume and key figures[1]

6. Since the change in the social work procedures and our jurisdiction we have seen a rise in the number of complaints made to us. This is what we would have expected given the change simplified the process and reflects what we have seen in other areas when complaints processes are made easier for people to complete.

7. A significant change has been the reduction in the number of premature complaints. Premature complaints are complaints made to us before they have completed the local, internal process. We use this as an indicator of people's experience in navigating and accessing local procedures. Social work had one of the highest premature rates and it is encouraging that the service is now in line with the average for local authority complaints. This suggests that service users are able to use and access complaints procedures, and that organisations are responding to them (although we recognise there is always scope for all of us to develop and refine our approach).

8. Another indicator of the benefits of the change is the number of complaints we receive that we can now investigate. This has significantly increased because we can look at the merits of the decisions. This means we have been able to look closely at more complaints, resulting in a significant increase in the number of decisions where we have upheld and supported the position of the complainant.

9. The uphold rate is now similar to health where we also have this extended jurisdiction (to look at both process and merits).

	2016/2017	2017/2018	2018/2019	2019/2020
Volume received	219	340	361	329
Premature rate	53%	25%	22%	20%
Number investigated	9	21	51	54
Uphold rate	37%	66%	66%	65%

Our findings

10. We publish summaries or full reports of cases investigated enabling us to share some of the detail of our findings and recommendations. These examples, published since January 2020, demonstrate some of the key themes we see across adult social care.

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[1] These figures are for all social work but the trends are consistent across all subjects.

Failure to take the views of family members into account

11. This case showed a lack of consideration of a plan by a family to help an adult stay in their own home and significant errors in the assessment report. https://www.spso.org.uk/decision-reports/2020/august/decision-report-201901564-201901564

12. In this case a failure to listen properly to a family member meant that the social work assessment was inadequate and the package proposed not appropriate. https://www.spso.org.uk/decision-reports/2019/march/decision-report-201802641-201802641

Failure to provide accurate advice about financial assessments.

13. In this case there was a failure to provide advice about financial assessments which led to a couple building up a considerable debt. https://www.spso.org.uk/decision-reports/2020/july/decision-report-201903474-201903474

14. In this case there was repeated misinformation but also it took 8 months to resolve the complaint. https://www.spso.org.uk/decision-reports/2019/july/decision-report-201805111-201805111

Failure to properly assess alternatives to support at home.

15. When the package to support someone at home becomes expensive, there appears to be a tendency to treat the option of residential or supported accommodation as the only realistic outcome. This means that not only are preferences not taken into account but sometimes assessments are not being conducted properly. In this case we had real concerns that the decision a public body could no longer support care at home did not reflect the reality of the individual's needs and that the alternatives suggested were likely to break down. https://www.spso.org.uk/decision-reports/2019/march/decision-report-201802641-201802641

Conclusion

16. While the figures indicate the new complaints process is more accessible, the impact is more people are complaining to us. This is positive in that we are achieving more for them, and that is welcome. Notwithstanding this, I am of the view that the wider issues we see are likely to be indicative of issues across adult social care.

17. Resources are a significant factor both in the decision making of social services and for families and individuals. Whether evidenced by assessments failing to reflect important matters that would not support a less resource intensive option or by failure to ensure people are aware of the financial impact on them.

18. An area that concerns me by omission and what I am *not* seeing is evidence of a rights based approach to decisions about service and care. This is perhaps understandable in that consideration has to be given to the affordability of services, but it appears to me that on occasions resources predominate at the expense of balancing wider rights. For example, we would expect to see equalities and/ or human rights impact assessments

carried out when policies are being written or updated, and / or responses to complaints or other concerns raised about rights be demonstrably and expressly addressed.

19. Not all of our experience is negative as some complaints provide evidence of good practice which we feedback. For example the importance of good advocacy advice and support, particularly when individuals are choosing between self-directed support options and considering managing their own budgets and taking on responsibility for employing support staff.

Scottish Socialist Party

The Scottish Socialist Party’s submission to the Independent Review of Adult Social Care

November 26th 2020

INTRODUCTION

The Scottish Socialist Party welcomes the opportunity to contribute to this Review of adult social care services in Scotland. We are aware this issue has been the subject of several UK government Reviews, Reports and Enquiries over the past twenty years and believe this reflects the widespread public concern there is over the present model of care.

We note this Review intends ‘taking a human rights based approach’ to develop a ‘deep understanding of the needs, rights and preferences of people using social care services’ to ‘consider what change is needed’ in ‘funding, governance and regulation’ and we will address these issues in this submission.

We would like to state at the outset that the Scottish Socialist Party favours an approach to these questions which protects the underlying philosophy upon which the National Health Service was founded. We support the establishment of a national care service that is also free at the point of need, paid for out of general taxation and publicly owned and run.

This Review will be aware the Scottish Socialist Party supported the introduction of free personal care in 2002, presented the Bill to abolish NHS Prescription charges in 2005 - which led to that particular health injustice being eradicated in this country at least after 60 years – and was at the forefront of opposition to the use of Private Finance Initiatives [PFI’s] in Scotland’s health services over the past 20 years.

Scottish Socialist Party activists are today campaigning in communities across Scotland for a national care service because we believe the current model of adult social care is not fit for purpose. Not if the purpose is to provide quality care for an ageing population appropriate for the 21st century.

THE COVID PANDEMIC

The public outcry over the number of people who died of Covid-19 after being transferred from state of the art NHS facilities into residential care homes ill-equipped to look after them is, we believe, the reason the First Minister launched this Review.

Few would suggest that the Covid-19 pandemic caused the current crisis in residential social care because it was unfortunately well established before that. Nonetheless the latest figures show almost half those who died did so in residential care homes [5,135 Scots had Covid-19 mentioned on their death certificates as of 15th November 2020 with 2,157 occurring in care homes]. Whatever else may be said about the virus it is a disease that affects elderly Scots particularly badly and our care homes were simply not equipped to withstand what befell them.

THE REMIT OF THIS REVIEW

The First Minister announced this Review on September 1st and asked that it complete its deliberations by January 2021. Given the magnitude of the issues involved we have concerns that this timetable will not allow for the wide-ranging investigation these matters demand.

We also fear the 'human rights based approach', as welcome as that may be, infers a rather narrow, legalistic enquiry is to be conducted here into the way residents are to be consulted and treated rather than the root and branch improvement of a care service that is patently and profoundly inadequate.

'THE NEEDS, RIGHTS AND PREFERENCES OF SOCIAL CARE USERS'

The Scottish Socialist Party believes anyone with a 'deep understanding of the needs, rights and preferences of people who use social care services' will see there is both an overwhelming need for, and public support behind, a national care service that is free at the point of need. Equally we believe Scots want such a service to be publicly owned and run and therefore enjoy greater levels of public trust and democratic accountability than the private sector model. Any robust examination of social care today cannot, in our view, fail to see the deficiencies in the present system. The need for significant improvement can surely be taken as read. Otherwise there would be no need for this Review.

A ‘NATIONAL’ CARE SERVICE

The dislocation inherent in a sector with 1,100 different care home providers all competing with each other for ‘customers’ means we have no ‘national’ care service to speak of. Rather we have a set of commercial companies all with a fiduciary responsibility to their shareholders that is a more powerful obligation that any other. That position was certainly evident when Southern Cross went bust in 2014 and left residents and care staff at the end of the queue of creditors.

Proposals to amalgamate the exiting 31 ‘Health and Social Partnerships’ across Scotland into one and call that a ‘national care service’ are known to be favoured by some parties to this debate, but this does not in our view provide a meaningful solution to the profound problems faced here. Such bureaucratic window dressing will be not satisfy care recipients, staff or an anxious public looking for more substantial improvements.

FIT FOR THE 21st CENTURY

The present model of adult social care is, in our view, simply not fit for purpose. The quality of provision is to say the least inconsistent. This committee will not need to be reminded of the appalling conditions found at HC-One’s Home Farm facility on the Isle of Skye this summer which resulted in its closure. Nor will the October report of The Care Inspectorate of Scotland come as encouraging news with its depressing litany of ‘poor’ and ‘inadequate’ classifications given to several facilities after the series of unannounced inspections it carried out.

Whilst some care homes are undoubtedly good many are not. And the public has grown impatient of the poor reports that have emerged recently both from inspectors and undercover TV and newspaper investigations.

An honest appraisal of adult social care services in Scotland today must conclude that the status quo is simply not an option here. The issue facing this Review then is what type of changes are necessary.

The Review documents ask contributors to focus primarily on funding, governance and regulation recommendations and this we will now do.

FUNDING

Chairing the Intergovernmental Commission on Climate Change in 2015 Lord Stern famously concluded that ‘The cost of doing nothing is the most expensive of all’. The same can be said of the challenge facing adult social care in Scotland today. The cost of doing nothing, as the COVID pandemic has once again shown, is proving to be the most expensive option of all.

Sir Simon Stevens, Chief Executive of NHS England, spoke for many when he said [5/7/20] ‘After at least two decades of talking about it, we do not have a fair and properly resourced adult social care system in this country with a proper set of workforce supports.’

That failure has meant thousands of elderly people in Scotland died before their time as Covid deaths took their toll.

Failure can also be counted in the number of our senior citizens routinely left in filthy and squalid conditions unloved and uncared for by the current ill-equipped, under-resourced and commonly understaffed model. Such conditions recorded by The Care Inspectorate in Scotland on a daily basis cannot be acceptable in a civilised, developed nation like ours.

Neither does the ‘self-funder’ option satisfy. It is common to find private care homes in Scotland advertising fees of £1,300 per week or more for their facilities. For those who don’t have £68,000 it means local authorities pick up the bill, but they go for the cheapest options. The ‘self-funding’ option therefore undermines the ‘universality principle’ underlying the NHS care model and fails the majority.

What we can agree on is that trying to provide quality adult social care on the cheap has failed. Speaking on BBC Radio 4’s ‘Start the Week’ programme in August the former UK Government Health Secretary Jeremy Hunt MP calculated the cost of improving care in Britain, sufficient to cope with expected future demand and keeping care staff in the profession by increasing their pay to £10/hour, to be an extra £10bn per annum.

The SSP believes this figure is too low because care staff need more than a few pennies more to stay in the service and Mr Hunt’s vision of the service in the 21st century in our view goes nowhere near making it fit for purpose from this point. Nonetheless Mr Hunt does argue for an increase in income tax [for those over 45 years of age] and national insurance contributions to pay for his limited improvements. We agree with him on this approach at least, although we would insist on a graduated rate of taxation where the wealthier pay more. It will certainly take public taxes and significant investment to ensure there is universal access to the service.

The Scottish Socialist Party believes the cost of providing a national care service like the one we envisage running to £2.5billion pounds more in Scotland annually. And we believe that obligation must fall on us all as taxpayers if we are to ensure a service fit for the 21st century is available to everyone.

GOVERNANCE

We envisage a new national care service being publicly owned like the NHS, but we recognise there is also a lack of accountability and democracy there. Just as the NHS has some way to go to live up to the democratic philosophy Aneurin Bevan envisaged in 1948 we would like to see the national care service start from there with its representatives protecting the interests of recipients, carers and taxpayers as a whole from the outset.

We see a national care service being closely aligned with the NHS and other public bodies to ensure social care is given the holistic support such genuine democratic partnerships deserves.

REGULATION

Whilst The Care Inspectorate in Scotland plays an important role in assessing the condition of present care homes, we feel it is not sufficiently resourced to do that job properly.

The private ownership of the majority of care homes also impedes its authority and reach.

In the meantime it would help if its reports to parliament and local authorities were more widely circulated to ensure greater engagement by the public and communities throughout Scotland.

FINALLY, ON THE STAFF EXPERIENCE

The Scottish Socialist Party reached the conclusion we as a society cannot provide residential care ‘on the cheap’ some time ago. Others seem to be lagging behind in their attitude to this. Yet poverty pay, poor working conditions, casualisation, low morale, high turnover and poor career progression are now endemic in the present model.

What more graphic illustration of a failed model do we need when one third of our most dedicated, valuable, hard-working and motivated carers leave the profession annually? What impact do we think their departure has on the quality of care recipients receive? Scotland as a nation, as well as the individual care staff themselves, deserves far better.

The Scottish Socialist Party therefore advocates a transformation of the employment practices in this profession. We support a £15/hour living wage [including a carers premium] for all qualified staff with a guaranteed number of hours available each week as Unison and the GMB advocate. Contracts of employment that respect and attract employees rather than repel them must become the norm. Career-long training programmes with plenty opportunity for progression must also be introduced urgently. Attracting young men and women into the profession must also play a part in solving the chronic recruitment and retention challenge. We must champion the tremendous rewards that await those inspired by such human to human support and empowerment.

The Scottish Socialist Party noted the remarks of the Bank of England Chief Economist Andy Haldane recently who noted ‘The biggest potential growth areas for humans lie in the care professions’’ before asking ‘What would Oxford University look like if emotional intelligence was at the heart of all its degrees?’ Quite so!

CONCLUSION

The Scottish Socialist Party believes that this Review has a great responsibility to discharge. Public patience is running out with those who refuse to accept the need for far reaching change in adult social care provision in this country.

We are convinced that the overwhelming majority of Scots accept that the present model of adult social care is not fit for purpose and wish to see meaningful change. They have made it abundantly clear, as far as we are concerned, that they expect their political leaders to get behind the call for a national care service that is free at the point of need, publicly owned and run and fit for the demands of the 21st century.

If the Covid-19 pandemic is to leave any lasting legacy let it be that it marked the moment we finally agreed on the need for a national care service that transformed the quality of care we provided for our most vulnerable citizens. Such a service could become a source of pride and international admiration rather than one which presently achieves neither - a national care service to complement and equal the NHS, itself set up after a time of great adversity.

Colin Fox,
Joint national spokesperson,
Scottish Socialist Party,
Edinburgh
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Scottish Women’s Budget Group

Scottish Women's Budget Group Submission to the Independent Review of Adult Social Care

November 2020

The Scottish Women's Budget Group (SWBG) is an independent analysis and campaign group that aims to promote gender analysis in public policy and public finance decisions through budgetary processes. SWBG brings together a wide range of women from across Scotland who have an interest in women's equality and want to achieve better gender equality in our society and has focused on encouraging active gender analysis in the Scottish policy and budget processes since 2000.

As part of the UK wide project, the Commission on a Gender Equal Economy, we are pleased to bring to the Review panel's attention Creating a Caring Economy: A Call to Action, the Commission's final publication. This report sets out eight steps to create a caring economy, based on gender equality, wellbeing and sustainability, in the recovery from Covid-19. We share this alongside our brief submission and urge the panel to review the key recommendations of the Commission and consider their inclusion in the adult social care review. The eight steps to creating a caring economy are:

- Re-envision what we mean by 'the economy', so that the centrality of care to the economy is recognised;
- Invest in social and physical infrastructure, so that public services address diverse needs on an equal basis;
- Transform the worlds of paid and unpaid work, to provide not just more jobs, but better jobs;
- Invest in a caring social security system which is based on dignity and autonomy;
- Transform the tax systems across the UK, to make them more progressive and fair;
- Refocus the overall fiscal and monetary policy framework on building a caring economy;
- Work to develop a trade system that is socially and environmentally sustainable;
- Work to transform the international economic system so that it is supportive of the creation of caring economies across the world.

Context

Care work is overwhelmingly carried out by women and is a key sector in our economy. Although it is not often formally recognized and valued as a key economic sector, care work underpins Scotland's economy. Yet, because it is overwhelmingly carried out by women, it is undervalued and has suffered from chronic underinvestment. This lack of investment must be recognised as both a cause and consequence of an unequal society.

The majority of adults who need care are women; the majority of those responsible for organising care for family members are women.[1] In Scotland 85% of the care workforce identify as female,[2] many are migrants or from black, Asian and minority ethnic groups, and the majority of unpaid carers are women. Clearly issues relating to social care are highly gendered and require a strong gender analysis as part of the response in policy making and budgeting.

The Covid-19 pandemic and resultant lockdown and economic crisis have highlighted and sharpened existing inequalities within our society. Women, black and ethnic minority communities and disabled people are economically the hardest hit by the crisis and the risk of deepening existing inequalities is

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[1] Women's Budget Group (2020) Creating a Caring Economy

[2] Scottish Government (2020) Implications of labour markets for the social care workforce: report

high. As highlighted by the Women's Budget Group (UK) and feminist organisations in Scotland, women have been on the frontline of the Covid-19 crisis, making up the majority of health and care workers and the majority of workers at high risk to exposure to Covid-19. But all too often in jobs that are underpaid and undervalued. The lack of investment in social care reached life threatening levels. As key workers, social care staff had to battle to have access to appropriate levels of personal protective equipment (PPE), and there is evidence of higher mortality rates among care staff than the rest of the population.[3]

Perceptions of care work have changed through the course of this pandemic. Highlighted as key workers, continuing to work while many other sectors of the economy had to be brought to a halt. People across Scotland stood at their windows or on their doorsteps to clap for all carers. Yet this has brought little real change for those working in social care who continue to feel undervalued in the workplace.[4]

At the same time people relying on these services have faced cuts to provisions, uncertainty and, as Glasgow Disability Alliance have stated, pre-existing inequalities are becoming supercharged by the pandemic.[5] 47% of the people GDA spoke to were worried about their social care support during the pandemic and approximately 2000 disabled people in Glasgow had their care reduced or completely withdrawn.[6] People don't know if their care will be reinstated. The fragility of the social care system could not cope and demonstrates the urgency of reform to the system.

The current challenges facing social care services and the impact of the pandemic on these services, demand for health and social care services is expected to increase by 18-29% by 2030.[7] The time for transformation of how social care is delivered is now.

Alongside this review, we also call on Scottish Government to make critical investment now on the structural, financial and human elements of providing quality care within Scotland's economic and social recovery from Covid-19, centred on building a caring economy. As made clear by the Commission for a Gender Equal Economy *a substantial increase in funding is urgently needed but ultimately, the sector needs to be reconfigured to fully meet all social needs, with well-trained and well-resourced workforce.*

What change is needed

We recognize the scale of the task at hand for the social care sector to deliver for 21st century Scotland. At the heart of this response is investment in the sector to deliver for people all across Scotland. This investment must be seen as investment in people and the economy. Analysis by the Women's Budget Group demonstrates that investment in care would produce 2.7 times as many jobs as the equivalent investment in construction acting as both a way to stimulate employment and reduce the gender employment gap, however, care workers must be better paid and better trained as part of this investment to avoid reinforcing occupational segregation and pay gaps[8].

Tentative steps have been made to increase investment in the sector, for example the Scottish Government commitment to increase pay for social care workers to the Real Living Wage. This must be maintained and built upon during the recovery from Covid-19 to recognize the value that should be placed on care work.

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[3] The Guardian (2020) Social care workers at increased risk of death from coronavirus, ONS finds. 26 June. https://bit. ly/33UjI7u

[4] GMB Scotland (2020) Show You Care

[5] Glasgow Disability Alliance (2020) Supercharged: A Human Catastrophe

[6] Ibid

[7] Audit Scotland (2020) Transforming health and social care in Scotland. https://bit.ly/3j0aCw4

[8] Women's Budget Group (2020) Creating a Caring Economy

At present staff retention in social care is low, poor wages, zero hours contracts and little training or opportunities for career progression[9]. The Fair Work Convention has reported that fair work is not consistently delivered in social care and often the failure to deliver fair work is driven by funding and commissioning systems.[10] A recent survey of GMB members in the care sector found that 77% of respondents had seriously thought about leaving their social care job with 60% giving the reason of not feeling valued by management.[11] A valued and well paid workforce is more likely to keep staff in their job and keep skills within the sector. It is vital the social care workforce is invested in, and professionalised, improving its status, working conditions and pay, implementing training programmes and developing career pathways.

An inadequate social care system has a huge impact on unpaid carers, a majority of whom are women. If people have to drop out of employment or reduce hours to carry out unpaid care, it reduces their ability to earn and save for the future. As recommendations are made into the delivery of social care the commission must be conscious of where care is not provided, what is not part of the national care service, and the impact that has on the need for unpaid care. These decisions, in turn, are clearly gendered in nature and require analysis of the impact they have.

While it is clear investment is needed where the investment goes is another element for the complex provisioning around social care. 58.6% of Scotland's care homes are private for profit organisations,[12] while many of these are small family run businesses there are a growing number of large organisations involved in the care sector. The Women's Budget Group discussion paper[13] provides wider analysis of the privatization and financialization of the care sector and how this model of privatization is particularly unsuited to the social care sector. Where profits and shareholders are the underlying stakeholders in a system, quality provision and fair work get squeezed out. As private provision has increased funding to local authority led services has decreased, with local authorities now running only 14.3% of care homes in Scotland.[14] Local authorities need to be properly funded to deliver a range of care service and in turn work to the principles for delivery outlined below.

Alongside the myriad of social care providers has come a complex commissioning and procurement process. As mentioned above, the commissioning process impacts on quality of work for those in employed in social care, the ability of services users to participate in decision making processes and creates a focus on outputs rather than outcomes. A more flexible approach to commissioning services and procurement within services is needed, part of this process should include the need for integration of gender equality to identify existing inequalities and opportunities to address these through service design.

In order to provide the investment needed to deliver a social care service to meet Scotland's needs additional funding mechanisms will need to be adopted. Recent polling across the UK for the Women's Budget Group found that 75% of respondents say they would pay more tax to support investment in free social care for all adults over 65 and disabled people.[15] A variety of tax options would be available and need to be given due consideration to ensure they are progressive, redistributive and take the opportunity to build towards gender equality. What is vital is that a sustainable model for funding is developed that provides reliability to ongoing investment in social care.

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[9] Ibid

[10] Fair Work Convention (2019) Fair Work in Scotland's Social Care Sector 2019

[11] GMB Scotland (2020) Show You Care

[12] Bayliss, K. & Gideon, J. (2020) The Privationisation and Financialisation of Social Care briefing for the Commission on a Gender-Equal Economy available at: https://wbg.org.uk/wp-content/uploads/2020/08/Privitisation-of-social-care.pdf

[13] Ibid

[14] Ibid

[15] https://wbg.org.uk/media/press-releases/new-polling-public-wants-an-economy-that-prioritises-care-and-equality-and-they-are-willing-to-pay-more-tax-for-this/

Sustainable delivery model

There are different models and understanding that could be taken from the phrase National Care Service. We'd like to share some key principles we believe are important in the review of adult social care and considering the appropriate model for sustainable delivery:

- Developed and delivered with a human rights approach, at the heart of decision making must be the fundamental human rights of those in receipt of all forms of social care and for this to be delivered with dignity and respect;
- Gender analysis is central to decision making within this highly gendered sector;
- Care is valued and invested in, with a sustainable and reliable funding model;
- Universal access to quality services;
- Participation of service users, unpaid carers and local people in decision making;
- Local flexibility to take into account the variety of needs in difference places across Scotland;
- Transparency and accountability in governance and financial arrangements with flexible approaches to commissioning that meet the principles laid out above.

We appreciate the opportunity to provide this submission to the Review Panel and once again would like to highlight our support for the calls made through the Commission on a Gender Equal Economy, in the publication Creating a Caring Economy: A Call to Action.

SDS Collective

SDS COLLECTIVE
INFORM • • • EMPOWER • • • IMPROVE

SDS Collective – Response to Independent Review of Adult Social Care

Background

The SDS Collective was launched in 2019. Recognising that Self-directed Support is the mainstream form of social care provision in Scotland, the Collective is about positively promoting the implementation of Self-directed Support, in line with legislation and national policy including the Social Care (Self-directed Support) (Scotland) Act 2014. The Collective is for anyone who might be receiving social care support, carers, and third sector organisations that work on social care issues.

Summary

This paper presents an overview of the points raised during the discussion with Mr. Feeley during the meeting held on 25th November 2020. The main points are:

1. Current SDS legislation and guidance is valued by Members. Alongside early access to independent support, the implementation of the legislation should be a main focus of the Review's recommendations.
2. Current HSCP structures and mechanisms in place to facilitate access to SDS are often burdensome and do not create an environment for equal partnership and creativity. By enabling 'frontline decisions'; through the true integration of the third sector as valued partners and via supportive systems to enable people to use their SDS creatively to meet their outcomes, the SDS values and principles have a greater chance of becoming a reality for more citizens.
3. Specialist support during transition from children's to adult services is required for all young people and their families who access, or may require SDS during this critical stage in life.
4. Emphasis should be placed on making social care a 'career of choice,' starting with pay structures that reflect the skill and expertise required by the workforce.
5. A common approach across all local authorities is required to ensure parity. An individual should be able to move from one local authority to another which no change or interruption to their support.
6. A focus on preventative support, rather than the current model of support being provided only for those in substantial or critical need, should be implemented across all local authorities, in line with the Scottish Government's Statutory Guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013.

Issues Members raised:

What is working well?

- Celebrate the Self-directed Support Act – it is shifting the balance of power & control in the right direction. Yes, changes are needed but don't throw away the transformational vision. Ok it is not fast enough, but build on its success – do not threaten the positives, build on the learning and confidence in positive practice.
- Early contact with independent advice as Adult Social Work develops early joint visits – social worker and a SiRD project worker to explore what matters to you & how that can be realised in a way that makes sense to you, talking about worries not risks then exploring ways to reduce those worries (becoming more of a partnership approach).
- More people during Covid have been supported to explore Option 1 especially for replacement of closed day care services and respite and finding greater choice and control.
- The agility of third sector seen as early interventionists and having vast experience of creative community-based solutions.
- Choice and control over support.
- Any activity where people with support needs are at the centre of running things and calling the shots is working well.
- Support where people have a direct link with their carer; i.e. Option 1, 2 SDS appears to have been more flexible, resilient, responsive and better able to deliver care during the pandemic.

What is not working well:

- Lack of trust.
- Social Workers being expected to "police the money " of Option 1, waste of resources, waste of creativity.
- Over-monitoring of Direct Payments, with an unspoken falsity of having to ask permission to spend your own budget in different ways.
- No mechanism to challenge decisions except the complaints procedure which is protracted and exhausting.
- Having to have a social worker to access a direct payment, yet if you accept what the council run services offer you do not need a social worker. This pulls more people into an already stretched system - not every Option 1 is complex or risky.
- People still tending to be working in silos – children's social work, adult social work, education.
- Lack of autonomy for social workers to do what they are trained to do.
- Limited to critical personal care/end of life care only. Those with critical needs that are not personal care have had their support removed over the past couple of years. This has had a particular impact on people with mental illness and those with autism who do not require help with personal care. Variations

between different council areas – some fund substantial and others only critical – and variations between what each criteria means.
- Very long waiting lists for people opting to ask the council to arrange their support – anywhere from 6 months+.
- The massive disconnect between what the law and National Standards say people should be getting and what they actually experience on the ground.
- Lack of knowledge and support to fieldworkers within HSCPs about SDS and how to make it a reality for more people.
- The low pay of the people doing the most important job (delivering care & support). They are told “we value you” but if you are paying low wages, you are not “valuing” people.
- Why is an unmet need not accurately recorded and totalled up (costs and actions needed)? If we recorded all the things people need (in order to live an ordinary life) but we cannot provide, then we have a mandate to ask for better funding and services.
- The cut-backs to all our universal provision; libraries, leisure centres, community projects, day centres etc. has a disproportionate negative impact on those who need support. Public “luxury” (good parks, high quality civic amenities, good access to buildings…) is a very, very efficient way of increasing quality of life for ordinary people. Much, much cheaper than trying to counteract the results of austerity with specialist services.

One thing you would like to see as a result of the review:

- There should be a mechanism of reaching into children’s services by adult services so those transitional conversations start earlier – however there should be recognition that this could be a SiRD worker based within schools with disabled children to explore what opportunities to build relationships to carry you through the choppy seas of leaving school.
- Relationships are key – we form relationships through shared equal experiences - remember that support is reciprocal.
- National criteria for adult social care so you can expect and receive the same support no matter which local authority you live in. Support for adults who have critical needs that are not personal care.
- Well-funded, permanent bodies run by “disabled” people, for disabled people that are independent of government and enabled to shape what social care becomes. This will evidence the power shift.
- Government and care services need to become the tool of people with care needs; their willing servant who works to remove all the barriers we have created to people who just want an ordinary life.

Suggestions to ensure changes are implemented:

- I found the Social Services Scotland Experience panel was a positive experience that did feel like co-production. If this model can be followed for Social Work review - small working groups - this would provide very different systems.
- Peer support needs investment.

- Partners in Policy Making program, Chex or similar community education programs needs to be an integral part of Integration Joint Board funding.
- The Care Inspectorate should actively recruit, train and pay disabled people to be the inspectors (not voluntary lay inspectors).
- Change the language to Rights – Rights model with PANEL & FAIR report being built into systems to develop assessments and decisions.
- National guidance for social care.
- Make it law. Inspect and enforce. Put people who need support in charge.

Lived Experience Examples:

1. From a human rights perspective a participant shared some of her own experience directing her own support and noted the following key points based on the example she shared:

- Being disabled often results in you being stripped of your human rights.
- Other people then have the opportunity to make judgements about your capacity, risk-taking and vulnerability.
- Most people are vulnerable at some point in their lives but having a disability you are immediately classed as vulnerable.
- The term is used and applied in an exclusionary way and permits restrictions that non-disabled people don't experience.
- Vulnerability has an association with having a need for professional care when many people don't need care, they just need access to the resource to support their independent living.
- The only way to access the resource is through social work who gatekeep it, so you are immediately fed into a system that you cannot then get out of if your need for the resource is ongoing.
- Having to seek permission about use of budget is unfair when you have contributed your charge yet you cannot decide on spend without approval from Social Work. It's your money you've paid in but Social Work need to agree how you can spend it.
- The fear of litigation or organisational reputation influences decision making to the point it paralyses personal choice and control.
- The tension between protection and people's rights to self-determine always favours protection, which is understandable when needed but it's usually the case even when not needed.
- A system that's needed to protect a few people is applied to everyone and restricts rights.
- Application of charging policies includes assessment of partners income despite always being financially independent.

- Basically, we need to decide as a society about the position we take for meeting the costs of social care and whether it will be an individual's responsibility or if it will be a collective societal responsibility.

2. A second participant shared his experience of SDS and directing his own support. He echoed the above and provided additional points:

- Local authorities are the only organisation he has ever heard of who monitor their competitors.
- It's a strange and conflicting situation when you are assessed by the competitors of your social care provider, i.e. the Local Authority both assess need and provide social care.
- All disability benefits are swallowed up through charging policy application but disabled people have significant additional spend and this charge leaves them without funds for other purposes.
- The lowest cost always wins when the market influences the system and this affects quality.
- Some people worked and contributed fully to the system and they have been penalised for this through charging policies which are like a postcode lottery.
- Some HSCPs are charging for services they shouldn't be; since free personal care was introduced some individuals are finding they are being charged more for other services, leading to a higher overall charge than was in place prior to the introduction of free personal care.

3. A third participants shared her lived experience of directing her own support before and after falling into the 65+ age group:

- Concerns that despite all of the work going into SDS and the 4 options being the route through which social care is provided, many newly qualified social workers have either no or very limited understanding of SDS, raising concerns about their training and the priority given to this.
- Had SDS before becoming 65 and when allocated to an older people's team and new social worker was advised she would need to give up her SDS and receive homecare visits at fixed times.
- Discriminatory and prejudicial issues were arising between adult services and older peoples' services where not all SDS options were available and option 3 was pushed on to people.
- Some people who paid a charge and then were exempt from part of their charge because of the implementation of social care actually found themselves paying more when they understood they would be paying less and this has never been explained.
- The implementation of free personal care is not being fairly applied.

Comments from 25/11/2020:

Workforce

- It is important that the social care workforce is valued better. This includes people who can lead and manage well too!
- If we are really valuing people, trusting them, encouraging them to really direct their own support in the way that makes most sense to them we must show we value the people who provide the support.
- Good quality relationships make such a difference.
- The social care workforce needs to be better respected and their work recognised for the value of what they do.
- Recognition of the different treatment they [social care workforce] received during the pandemic and the incentives for healthcare staff from which they were excluded were noted.
- Social care needs to be given value and it should be promoted as a positive career option.
- There should be a clear strategy around recruitment that also offers good terms and conditions and rates of pay with a career structure.
- Zero hours contract should be abolished.

PAs

- Registration for PAs with the SSSC to give them the support and backing they need - feedback from a PA who has lost her SSSC registration due to moving from an agency to being a PA.
- It was also suggested that it shouldn't be required to register: voluntary would be the way to go to allow those PAs who want to register with the SSSC to do so. That's what the PA I talked to was looking for.
- The fees to join SSSC may be prohibitive if a PA is only working a small number of hours.
- Fees should reflect earnings.
- Even having free registration for lower paid workers and maybe even young people.
- There is also significant cost with registration in terms of qualifications in terms of time and finance. So voluntary registration would need to be revisited in terms of being on the register. SSSC is a large influential body who perhaps could be seen to have a vested interest.
- PAs and the job they do needs to be valued much more within the social care workforce.
- Mixed views exist and there is internal debate about the registration of PAs with the SSSC and the regulatory requirements.
- Don’t confuse registration with regulation. It’s often regulation around PAs that is feared because it depends on a reciprocal relationship that could be impacted negatively by regulation.

- If a voluntary scheme of registration for PAs there should be incentives and access to training might help.
- Self-employed PAs is an important option for people and needs to be retained especially where there are limited services/provider options available.

Learning from Social Security Scotland

- In terms of the supported person's experience, I think the Social Care system can learn a lot from the new approach from the Devolved Disability Benefits - individuals will be choosing the date and time of their appointments. Imagine if this was possible with SW assessments and the impact it would have?
- The Experience Panel that informed some of the Social Security Scotland work was really well done & did make significant impact on the systems.

Variation across Scotland

- We absolutely need to reduce unnecessary variation across Scotland whilst also recognising local democracy; plus, we need to have systems designed absolutely to give people choice and control, NOT get in the way of that. A new relationship; collaboration and partnership based on trust and openness.
- I would like to see a Scotland where local authorities acknowledge the legislation around SDS and do not make up their own rules that limit and block individuals' choice of options of SDS 1,2,3 or 4. Why does this happen now, and what are you going to actively do to change this.
- There needs to be a consistency with SDS across all local authorities that gives people the choice and control over their own support.
- There is also a lack of consistency across local authorities around Option 2 and how to implement this.

Social work involvement, care costs and budget control

- On a human rights point, why are the poorest individuals who are in receipt of benefits having to pay for their support. Can you see a Scotland where charging for care and support is abolished!
- The challenge here is whether there is an individual responsibility for care costs or if there is a collective responsibility for the costs of care. Disabled people are the only marginalised group who have to pay to remove the barriers that prevent them being included in society.
- When the SDS Pilot began I was persuaded to change from long term housing support to go on the SDS Pilot and receive a direct payment. Was told it would allow me to do a lot more and be able to get out and about and do the things I wanted to. Whilst the SDS team was in place this happened but when I was transferred to an adult social work team at my 2nd review (6 years after moved to SDS) my support was completely cut and I was told if I had still been on long term housing support my support wouldn't have been cut. I have since had to pay for my own care because I do not have a critical personal care need. I have other critical needs but just not personal care so

the support that allowed me to live independently was cut. I live alone so nearly half my part time salary goes on rent on council tax. After bills I have little money to pay for my care. There needs to be support for people who have critical needs that are not personal care. I have complex health conditions spanning physical, mental health & autism.

- Since last year, when people stopped being charged for personal care, they can now be charged higher amounts for their other care.
- Regarding being sucked into a system - my son never used social services BUT when we wanted Option 1 we had no option but to wait for a social worker (delayed the whole process) so we were then part of the "system" BUT if he had gone to 5 days a week day care then we would NOT have needed a social worker.
- There should be more focus on CPD for Social Workers, including SDS awareness and implementation.
- PA employers also don't have the training on how to be an employer - it bamboozles them but they are forced into it. It then affects the PA as the individual does not know how to treat them properly.

Further questions / comments:

- The Social Renewal advisory board members consists of 21 people, which includes experts in housing, disability, poverty, homelessness and the third sector. Two of the board's key values are equality and social justice. Would you agree that throughout pre Covid, and during Covid unpaid Carers' increased in Scotland from 800,000 to over 1.1 million – the equivalent of another NHS workforce? Therefore, would you agree that unpaid Carers' held the threads of social care together, invisible and undervalued?

  As a diverse workforce at the critical sharp end of care, upholding the values of social justice and equality, as an invisible national workforce, we ask to be represented on the advisory board. It's apparent from the diverse list of board members, there is a clear gap in the board's knowledge of unpaid Carers'.

- How do we raise the profile of the right people have to access independent support for SDS amongst all relevant parties and what can the Review do to support the necessary awareness raising?

- How will the Review make use of the good policies and initiatives already in place, including the Values and Principles of SDS and the National Health and Social Care Standards?

Contact

Please contact the SDS Collective via email - sdscollectivescotland@gmail.com.

Website: https://thesdscollective.wordpress.com/

Shared Lives Plus

shared lives plus

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Derek Feeley
Chair, Independent Review of Social Care

04 May 2021

Via Email to:
secretariat.adultsocialcarereview@gov.scot

Dear Mr Feeley,

Thank you for joining the Scotland Committee of Shared Lives Plus on 25th November to discuss the work of the Independent Review of Social Care. Our members found it very valuable to hear about the review group's work, and appreciated the opportunity to share our views about the role, impact and potential of Shared Lives as part of a reformed social care landscape in Scotland.

I am writing to follow up on some specific points that emerged during the discussion:

Scaling up Shared Lives

Shared Lives Plus has learned what works in scaling Shared Lives through:

- Our £1.5m social investment Shared Lives Incubator partnership with Social Finance.
- Our £1m+ partnership with NHS England and seven NHS Trusts.
- Our strategic advice work for around 30 UK areas including The Scottish Borders and the two regions of West Wales and Greater Manchester.

In recent years, a number of areas in England have invested in the development of Shared Lives, and these provide benchmarks for the level of expansion that is achievable.

Schemes that have been particularly successful in scaling up Shared Lives provision include Lancashire (with 261 Shared Lives carers) and Shared Lives South West (with 239). Within our meeting, we identified Lancashire as an area where 15% of known adults with Learning Disabilities are supported through Shared Lives. Greater Manchester Combined Authority, too, has committed to increasing their Shared Lives offer so that it comprises 15% of all social care provision for people with learning disabilities.

These figures demonstrate how Shared Lives can be scaled up when given sufficient investment and priority. For context, the largest scheme in Scotland, Shared Lives Fife, has 85 Shared Lives carers, and supports around 3.5% of its population of adults with Learning Disabilities through Shared Lives.

The majority of Shared Lives carer recruitment operates through word of mouth, and for this reason substantial scheme size is a critical factor in enabling carer recruitment and scheme growth. As Social Finance (2019) reported: “The more carers (and thus diversity) that a Shared Lives scheme has, the more possibilities for growth”.

More rapid growth could be achieved when supported with a national communications strategy.

It is also worth noting that Shared Lives Plus is currently undertaking a short-term project, funded by the National Community Lottery Fund’s Coronavirus Community Support Fund, to support the creation of an online platform to recruit and train Shared Lives carers – helping to speed up a normally lengthy process – to increase carer numbers during the Covid-19 pandemic.

Shared Lives Plus work in Northern Ireland

In Northern Ireland, Shared Lives Plus is working closely with the Health and Social Care Board to develop a consistent approach to providing Shared Lives across the country. This includes:

- A single brand identity and logo for Shared Lives Northern Ireland
- One payment model so that Shared Lives carers in Northern Ireland are all paid the same wherever they are
- One marketing and communications strategy
- A steering group convened by the Health and Social Care Board including representatives from all Health and Social Care Trusts
- A Shared Lives quality framework for Northern Ireland that all schemes must use
- Northern Ireland-specific policies and procedures

Turnover within the Shared Lives Sector

In contrast to other parts of the social care sector, Shared Lives experiences relatively low turnover. In the past year in Scotland, 3.8% of Shared Lives carers retired, or left the sector for other reasons. A further 6.9% of Shared Lives carers in Scotland joined the sector this year, meaning that carer numbers experienced a net growth.

This low turnover, combined with the relationship-based nature of the care, means that Shared Lives arrangements tend to be very stable. Across Scotland and the rest of the UK, there are numerous live-in arrangements that have been in place for many years, even decades. One particularly notable arrangement was recognised at the 2019 Shared Lives awards, where the Lifetime Achievement award was awarded to a carer from East

Sussex, who had opened her heart and home and shared her life with Pam for 43 years.

I hope this additional information is useful and would of course be happy to discuss further.

Yours sincerely

Ben Hall

Scotland Development Manager

Social Justice & Fairness Commission

Social
Justice
and
Fairness
Commission

Independent Review of Adult Social Care in Scotland:

Submission from the Social Justice and Fairness Commission

November 2020

Introduction

The aim of the Social Justice and Fairness Commission is to deliver a route map to the real prize of independence. That prize is a fairer Scotland that values and cares for everyone who lives here, from baby box to grave, and in which everyone can fully participate and have the opportunities they need to flourish.

Independence will empower the people of Scotland to build a better society, with wellbeing at its heart. Independence is an opportunity to think afresh about the kind of policies we could pursue, and how we make decisions at every level in Scotland.

Our ambition is constrained only by what we collectively consider is desirable, and the response to the current pandemic has been regarded as a good example of collective effort with public support in response to a crisis, of what we can achieve when we put our minds to it. Change is possible, and very few people want to return to the way things were. As we chart our recovery and rebuild, we must build something better.

No one should be reliant on a food bank to eat. No one should be without the basic human right of a home. No one should be shivering in the depths of our Scottish winters because they can't afford to heat their homes. As we move forward, and look towards a better future, we must accept that no one should be left behind in our new Scotland. We all have a duty to look after one another.

The world is changing, and we must keep pace with that change – all the while harnessing the benefits of progress and protecting that most vital of resources, the planet on which we live.

This submission examines how we can reform and reimagine the way we deliver social care and support people accessing care services to engage in everyday activities, paid employment, and family and social life. Among the challenges we need to address is how to care for an increasingly ageing population, and how to pay for that care, as faced by governments across the world without any easy answers. Right now, Scotland is no exception in that regard and nor would we be as an independent country. As a Commission, we are considering what action could be taken in the short-term, but also the more transformative changes we could deliver with the full powers of independence.

On the issue of social care, the following matters have been foremost in our considerations.

First, we are taking a human rights approach to this issue, as we are with all the areas we are working on in the Commission. So, at the heart of decision-making must be the fundamental human rights of those in receipt of all forms of social care and support. People in Scotland have a right to fulfilling lives, and to access services based on dignity, fairness and respect. In reforming our system of social care, we must continually reflect upon what we would expect for ourselves and our own families.

Second, we need to build a consensus on what is essential to our individual and collective wellbeing, and build a long-term, sustainable model for social care. How we care for our older and most vulnerable citizens is an issue that transcends party politics and conventional policy-making. This is an issue that requires us to come together as a society to agree the standard of care that is required, and how we collectively deliver that.

Third, we want to ensure that those working in the social care sector are better rewarded and recognised for the valuable work that they do. Providing good employment and investing in staff in the sector are central to delivering the very best in care. Raising the status of the care sector as a career with clear opportunities for progression is a key element of this.

Fourth, we consider investment in social care as an investment both in our wellbeing and our economy, in the same way that investment in childcare and early years education delivers on multiple outcomes. Care is integral to all our lives at some point and is so important it should always be a key priority for any government.

Finally, we are acutely aware of the funding challenges and the need to build consensus about the fairest way to pay for social care.

Structure of our submission

This paper details what the Social Justice and Fairness Commission has come to regard as the nine key principles of social care in Scotland. These principles are informed by extensive consultation with individuals and organisations in the sector. It provides a short discussion on each before moving on to discuss our perspectives on the introduction of a national care service and consideration of some innovative potential models for future delivery of social care in Scotland. The submission then concludes with a summary of our key findings and recommendations.

The Social Justice and Fairness Commission was established by Nicola Sturgeon MSP in her capacity as SNP Leader, with a remit to deliver a route map to a fairer Scotland with independence. The Commission consists of both SNP members and independent members. More details can be viewed on our website: www.socialjustice.scot

The Principles of Social Care in Scotland

Principle 1: The focus of care of a person's life should be on protecting and maintaining as good and fulfilling a life as possible, recognising the need for the person to maintain choice and control

The person being cared for should be the priority focal point of any care system - our independence and wellbeing as cared for individuals are paramount. Good social care support is essential to allow the human rights of people receiving care to be met, enabling them, as much as possible, to make unfettered choices about how they live their lives.

It is therefore critical that any discussion around the delivery of care – be that high-level strategic policy-making or local-level care planning for individuals – maintains this focus. The Social Justice and Fairness Commission believes that self-directed support is a fundamental pillar of the principle of protecting and maintaining a cared for individual's quality of life and their ability to maintain choice and control over it.

Scotland's progress in delivering person-centred care should be recognised. There are many examples of councils, third, independent and private sector organisations working hand-in-hand with professional and unpaid carers in local communities, delivering care tailored to and chosen by the people receiving it. This has required dedication, imagination and innovation, and it has provided examples to inspire and encourage.

But we must also acknowledge that there is still a significant way to go before the gap between aspiration and reality disappears, and that inconsistencies remain throughout the country in the application of standards and approaches relating to choice and control of a person's own care.

The Social Justice and Fairness Commission's research and consultation work has confirmed that the principle and delivery of self-directed support is a pressing issue in the minds of individuals and organisations in receipt of and delivering social care. We have found that:

- Satisfactory choice and control are not always being delivered through the current implementation of self-directed support

- Awareness of the self-directed support principle and the flexibility it should offer is not universal among carers and service users

- Local authorities are often unable or unwilling to grant self-directed support requests

- Funding and staffing restrictions inhibit the ability of authorities and organisations to fully deliver self-directed support

- Research by the ALLIANCE and Self-Directed Support Scotland suggests women are less likely than men to be given access to information about self-directed support

The Coalition of Care and Support Providers in Scotland is of the view that existing commissioning and procurement focused on competitive tendering and contractual obligations is "antithetical to a person-centred approach". The Social Justice and Fairness Commission has some sympathy with this perspective and is keen that decision-making structures that place a sharp focus on social care performance outcomes (i.e. quality of care and support for patients and families) – and not outputs (e.g. numbers of social care staff or hours spent with a patient) – are fully utilised to inform future decisions about funding.

Principle 2: Universality is key, with the diverse needs of all who require care and support being met

The principle of universality should not be confused with homogeneity. Rather, a truly universal care system is one that is flexible, adaptable and capable of meeting the needs of an extraordinarily diverse range of people and needs.

When we think about people in receipt of care, we often think about elderly people in care homes. Yet while almost four out of five adults receiving support in Scotland are indeed over the age of 65, over 20% are aged 18-64. And although around 40,000 people receive support in care homes in Scotland, more than double that number – around 90,000 – use self-directed support to enable them to receive assistance in ways that better suit their personal choices and circumstances.

As an example, the Coalition of Care and Support Providers in Scotland told us they support people who require mental health assistance, children in secure settings, adults living with learning disabilities and non-neurotypical people and adults to name but a few. Their members work with more than 200,000 individuals and their families in Scotland – work which employs over 45,000 people in total.

Diversity poses significant challenges for systems of care, particularly when the aspiration is to deliver high consistent standards of self-directed care for all service users, regardless of location or demography. The principle of universality – meeting the diverse needs of all who require support – is therefore straightforward to agree, but the application of that principle is a major challenge to grapple with and which the Scottish Government care review must consider carefully to address.

Principle 3: Our care system should be publicly funded, with the need for an inclusive open debate about how this is paid for

It is well known and understood that high quality care requires high levels of financial investment. But, more than that, investment needs to be smart to ensure it delivers the best possible impacts and represents value for money. The debate about how to do this is long-standing and complex, and there are no easy answers. In our consultation work there were widespread calls for greater resource to be channelled into social care in Scotland, but little in the way of detail or agreement about how that can and should be achieved.

As a Commission we are of the view that while private providers of care have an important role to play in providing care in Scotland and offering choice to service users, efforts to facilitate universal publicly funded care provision are a priority if we are to achieve the societal aspirations shared by most.

We seek to reframe the discussion about resources too. Rather than viewing care provision purely as an economic cost – a drain on resources – investment in social care should instead be seen as a financial stimulus that has the potential to generate economic growth as well as deliver social good.

The two most basic questions about any system of public funding are focused on how to collect or raise money, and how to distribute and spend it.

On raising money, our consultation proposed three general models to facilitate increased investment in social care: general taxation; full or partial hypothecated taxation (where funds raised are ring-fenced for a specific purpose); and social insurance, co-payment and mixed models. Given the complexity of this issue it is unsurprising that the only consensus our consultation revealed is that significantly more resources are required. There was little in the way of agreement or clear ideas on the best way to achieve that end and it is therefore a subject that will require significant attention going forward. We can, however, point to strong public support for hypothecated taxation or other models of funding where people contribute a little more in the knowledge that funds raised are being invested specifically and directly towards universal social care that benefits everyone.

Our engagement on the issue of how funds are distributed to achieve the best possible outcomes and value for money generated a number of clear ideas and areas of consensus. In particular, there is strong support for a general overhaul of commissioning and procurement structures and the ways in which funding decisions are made. For example:

- The Coalition of Care and Support Providers in Scotland argue that too often decisions on the provision and nature of support are made by contracting authorities rather than supported people which can cause them to lose support they are happy with. They also suggest that price competition drives down wages and creates a two-tier system because third sector and not-for-profit providers cannot match the pay and conditions on offer in the public sector.

- Close the Gap says it is currently not possible to satisfactorily provide high quality person-centred care with the resources available and that choice and control are frequently diminished by practical considerations around limiting resources.

- Marie Curie highlight the pandemic's effects in exacerbating long-standing, fundamental issues in social care, including lack of sustained financial support, and argue that a better understanding of existing and projected demands for the myriad forms of care provision is needed before we can decided how an improved system of social care can be funded. They also argue 12-month fixed-term funding contracts to deliver palliative and end-of-life care to terminally ill people bring uncertainty and should be replaced by three-year or longer rolling contracts.

Other issues raised by our consultation included:

- The need to recognise investment in social care as a sound and essential economic investment as well as a social one, with the potential to stimulate employment, reduce the gender gap and stave off the worst possible impacts of recession on women's job security.

- The perspective that social care should be brought within the scope of economic and skills development agencies, in recognition of the economic benefits investment in it can bring, and that it should be designated as a growth sector.

- An aspiration to reset the financial system of social care, with any surpluses being reinvested into the system.

- The ambition to implement self-directed support as intended with funding being awarded directly to individuals.

- A desire to prioritise local and collaborative decision-making and consider methods such as alliancing to enable providers and commissioners to work together to deliver support in an area, based on what people need and want.

Principle 4: Care should be of high quality and valued by those who receive it as well as by society more generally

The principle of high-quality care valued by the person receiving it is one of the most important. Just as Scotland aspires to be the best place to grow up, we want it to be the best place to be cared for too. This quality principle is inextricably linked to the principle of leading a good and fulfilling life and making our own choices, and much of the focus is again on the subject of self-directed support. In terms of the wider societal value of social care, we need to think more broadly about the structures in place that deliver care, and whether the creation of a national care service akin to the National Health Service is something we should be looking to pursue.

Earlier in this submission the Social Justice and Fairness Commission expressed support for future funding decisions being informed primarily by social care outcomes performance rather than by outputs: it is precisely because of our desire to see the highest standards and qualities of care that we have taken this stance.

As this paper has already highlighted, there are many examples of excellent practice and high standards already in place across the country, but there are also marked inconsistencies and limitations on choice for people receiving care in Scotland. So what are the impediments to universal high-quality, self-directed support at present? Our consultees provided a number of insights:

- Close the Gap told us investment in the workforce is core to providing high quality personalised care, but that the social care workforce is underpaid, undervalued and under-protected. They argue that questions about funding and staffing cannot be divorced from challenges in delivering a person-centred and needs-led service.

- Engender say that social care quality improvement cannot be adequately driven through competition models because of its dependency on its workforce. They state that 60% of care homes in Scotland are now private for-profit providers and that the primary focus of this model of delivery is not quality or improving pay and conditions for the social care workforce.

- The Coalition of Care Service Providers (CCPS) in Scotland argue that the public sector has driven and maintained the culture of competition in social care service delivery, which is at the root of many of the sector’s problems. They point to good Care Inspectorate quality gradings to make the case for third sector and not-for-profit organisations playing a greater role in future provision. CCPS therefore believe any care system reform should preserve, protect and build on third sector achievements and elevate its status in order to allow it to operate on an equal footing with the public sector.

- Marie Curie told us that greater standardisation of aspects of social care including training and education will improve quality and consistency of care. It will also, they suggest, enable accurate measurement and evaluation to make better future care projections and inform the delivery of resources required to deliver it through a place-based approach.

The question of whether or not a national care service would be an appropriate or desirable model to carry future delivery of social care forward is critical when it comes to levels of quality and the value we place on social care in Scotland. The Social Justice and Fairness Commission has found strong evidence in support of such a move, as well as a number of concerns about unintended consequences, and these are discussed in more detail later in this submission.

Principle 5: Dignity, respect and access to practical and emotional support must be offered to everyone receiving and providing care

Everyone receiving social care has the right to be treated in a dignified and respectful manner – at every stage and in every interaction – in that process. Once again, the emphasis on self-directed support is critically important here, with all decisions about an individual’s care provision being put into the hands – the choice and control – of the person in receipt of that care. Truly self-directed support is truly dignified and truly respectful support.

The right to be treated with dignity and respect does not apply only to the person who is cared for, but also to the people who help them. That means everyone working in the field – including caring professionals whose work is often hard and notoriously poorly paid – and, of course, particular attention should be drawn to Scotland’s army of thousands of unpaid carers, without whom our system of care could not function.

In terms of unpaid carers, opportunities to exercise choice and control over their situations are frequently limited. For example, Engender told us that in spite of the fact access to short breaks has been shown to be vital to sustaining the caring relationship and the health and wellbeing of carers, they are not available as a matter of course: fewer than one in five receive a break and provision is variable across Scotland. Engender also emphasised that only a quarter of unpaid carers receive practical support for care.

And just as important as practical support is emotional support. Receiving and providing care can be enormously emotionally difficult experiences but helping and supporting people to deal with the emotional pressures caring can bring is easily overlooked.

Marie Curie told us they believe the Social Justice and Fairness Commission should specifically reference the need for practical and emotional support for family carers, as well as social care workforces, which will help carers manage their mental health and grief. They are of the view that this will help to ensure it is embedded in our framework recommendations for social care in Scotland.

Principle 6: Gender inequality is a root cause and consequence of many of the challenges in Scotland’s care system and must be tackled

To quote from Engender’s response to our consultation on care in Scotland:

“The provision of care, both paid and unpaid, is closely and causally interlinked with systemic and harmful gender roles that constrain women’s lives. Women’s access to paid work, leisure time and power remains heavily constrained by the provision of care and gendered expectations around its value and delivery.”

The causes and consequences of gender inequality cannot be overstated when we examine systems of care in Scotland and, indeed, across the globe. As a country we must do everything we can to acknowledge and address this injustice, not only for the benefit of women and girls here, but also to set an example for the world to follow.

The problem is deeply ingrained and the challenge of overcoming it is enormous. The majority of care service users are female, the vast majority of social care workers are female, and most unpaid carers are female. As Engender suggest, if we are to develop effective solutions we must first understand the effects of low pay, undervaluation and low investment from a gender perspective.

The pandemic has brought how we rely on, value and treat social care workers into sharp focus. It provides us with the stimulus to sit up, take notice and act to ensure that care work - predominantly carried out by females – is supported and rewarded in ways that properly reflect its importance and value to society.

Women's disproportionate caring and domestic labour responsibilities inhibit their capacity for fair and equal access and progression in the labour market. Close the Gap pointed to research that shows women are four times more likely to give up employment due to multiple caring responsibilities and are more likely to take on low-paid part-time work to balance earning with caring. Action is needed to break this cycle and reduce the disproportionate pressure on women to carry out poorly paid and unpaid domestic labour, which can in turn force them out of the labour market altogether.

And just as the pandemic has drawn attention to the importance of social care work, it has also shone a unique light on the hard work, dedication and skills it demands. Care work comes with enormous responsibility and the tasks involved can be demanding and complex, requiring skills and capacities acquired through years of experience and training. But these skills and capacities have for too long been invisible, carried out and delivered independently by women in people's homes, locking in and exacerbating the predominant undervaluation of carers' work.

As Close the Gap told us, job evaluation is a critical tool to make women's skills valued and visible. However, no suitable mechanism has thus far been devised for undertaking job evaluation in the sector and for upgrading the pay of those with greater skills and experience, creating recruitment and retainment challenges for senior posts and managers. Workers are understandably reluctant to take on yet more responsibility for limited financial reward, so robust work evaluation methodologies and tools will have a fundamental role to play if we are to eradicate undervaluation of predominantly female care work.

Other gender dimensions, which are often deeply entrenched and self-perpetuating, were also highlighted by our consultation:

- The gender pay gap in health and social care is 27.8%, which is significantly higher than the national figure of 13.3%

- With 85% of social care employees being female, impacts of increased vacancies, poorer conditions and low pay have far-reaching societal impacts for women's equality and wellbeing

- Women in social care are becoming ever more reliant on the workings of the so-called 'gig economy', with lower levels of protection and access to rights such as sick pay

- Gig economy undervaluation actively stems from and maintains women's inequality, poverty and poorer wellbeing and contributes to the invisibility of women's skills and emotional labour

- The wages and status attached to social care are low because it is seen as 'women's work' while the provision of unpaid care undermines women's access to good paid work, education and wellbeing

- The presumption that care is a product of inherently 'female' traits and preferences continues to influence how we think care work should be assigned, and what it is worth

- The undervaluing of 'women's work' contributes to women's higher levels of in-work poverty: two-thirds of workers earning below the real living wage are women

- Women are less likely than men to be given access to information about their self-directed support opportunities

- Unpaid carers, 60% of whom are women, save Scotland an estimated £10.8 billion per year, or a third of the national budget

Principle 7: Careers in care should offer decent working conditions and better pay, training and progression opportunities

The issue of working conditions, pay, training and progression are inextricably linked to the gender principle detailed in the previous section. The care sector's predominantly female workforce requires and deserves much better.

That is not to say that the Scottish Government does not deserve credit. It has spearheaded and prioritised efforts to deliver the real living wage across the country, which has led to enormous benefits and has delivered tangible life-changing impacts for many people working in low-paid sectors of the economy, not least social care. But, as the gender principle and other sections of this submission make clear, wholesale change is required to affect how we view social care, the value we place in it, the investment we make in it, and the opportunities it offers to people who work to deliver care and who receive it.

There is a collective recognition and desire to improve pay and working conditions across the care sector in Scotland:

- The Coalition of Care Service Providers in Scotland has stated that there is a need for cross-sector parity of pay and conditions, improved career pathways, recognition of prior learning and consistent delivery of employees' training and development needs

- Engender argues that reforms to commissioning and procurement through a national commissioning model present an opportunity to drive up standards, reduce the prevalence of temporary and zero hours contracts, improve rates of pay, reduce long working hours, and remove unpaid overtime.

- Engender also highlights that recruiting more men to work in the sector is necessary and that there needs to be an economic imperative to do so. Without investment and action to tackle the undervaluation of care work they argue we will see women pressured to plug the gaps either on poor rates of pay or unpaid, perpetuating the negative cycle.

- Brexit is threatening to put enormous new pressures on the nation's social care workforce due to the sector's current reliance on migrant workers. With one in five care workers born outside the UK, the sector is likely to experience significant staffing pressures as many social care workers will be excluded by the UK Government's wage threshold requirements.

- Close the gap recommends increasing collective bargaining in the social care sector. They point to improvements this would help deliver in improving terms and conditions whilst highlighting the need for it to be carried out on a sectoral, rather than a workplace, basis.

- Unison Scotland have recommended a timetable to introduce a social care sectoral bargaining arrangement should be established as a priority, covering wage rates and terms and conditions across the sector.

- Marie Curie wants better palliative and end-of-life care training for social care staff, which is often not provided in spite of the fact the workforce is expected to deliver it for patients on a daily basis.

Principle 8: Participation and inclusion in co-produced design and delivery are essential, accommodating flexibility for individual needs and preferences, and reflecting local contexts

There is a strong feeling within the sector that inclusive co-production of design and delivery of care are essential. However, like universality, while the principle is easy to support, the major challenge is reconciling the principle with delivery in practice: it requires consistent standards of care regardless of diversities relating to individual needs and local contexts in each care scenario across the country.

Strong partnership working is crucial to successful delivery of co-produced models of care in different contexts and our consultation revealed strong support for structural changes to facilitate greater integration and collaboration between organisations supporting people with health and social care needs. There were calls for third sector organisations to be included equally as voting members on all integration authorities and requests for clearer engagement between third sector partners and Third Sector Interfaces to facilitate effective engagement with Integrated Joint Boards.

The introduction of a national care service has the potential both to improve or worsen flexible co-production depending on if and how such a model is implemented. Any such service would need to be designed to avoid the pitfalls of a homogenous one-size-fits-all structure, which would go against the principle of the model of self-directed support.

The Social Justice and Fairness Commission is keen to explore options to innovate within our system of social care. We have dedicated a section of this submission – 'A new dawn? Innovation in the delivery of care' – to envision some of the options to innovate, co-produce and think afresh about how we deliver care in Scotland in future.

Principle 9: Regulation and inspection should be strengthened to ensure rigour and oversight

The principle of regulation and inspection is a fundamental pillar of the care system to ensure it delivers and continues to deliver all of the social and economic goods it is designed to. Without it, with the best intentions in the world, the system will fail.

Our consultation revealed that third sector providers consistently receive ‘very good’ and ‘excellent’ gradings from the Care Inspectorate across most adult care services. However, they feel that the balance of regulation and inspection activity is too heavily oriented towards support provision. The Public Services Reform (Scotland) Act 2010 gives the Care Inspectorate the power to scrutinise commissioning, but there is a strong sense within the third sector that it has not been used as effectively as it might. They contest that aspects of the care system such as commissioning and procurement need to be more critically challenged, as well as the impacts they have on the workforce and the people being cared for.

A National Care Service?

The idea in principle

There has been much discussion in public and by different political parties and other groups about a national care service - a singular service for the provision of care across the country.

An integrated care service is a way of understanding that care services comprise adult social care, specialist residential care, eldercare and childcare, which should work to the same standards of quality across Scotland and be delivered in a way that meets the needs of individuals and specific local contexts.

There is increasing public awareness and use of the term a National Care Service, as the experience of Covid-19 has laid bare our reliance and dependence on care and how undervalued care and those working in care services and providing care at home have been. A National Care Service cannot simply be about bringing care provision back within state control, or an issue to be traded-off between political parties. Care and carer organisations, disabled people's organisations, political parties, feminist and other advocacy organisations have talked about a National Care Service for a long time. It is not the preserve or idea of any one organisation.

An Integrated National Care Service is an ambition to ensure universal quality, local flexibility, and transparency and accountability in the governance and finance arrangements, delivering care and support in appropriate forms to individuals in Scotland.

A National Care Service could have several advantages, such as the assurance of better quality and standardised terms and conditions. Such integration would also have to be coupled with better pay and conditions and opportunity for career progression and the commitment to the Scottish Living Wage will be an important part of this.

However, it would be important to recognise the need for local flexibility in the delivery of services in communities, given what works in parts of remote and rural Scotland may look different to that in urban parts of the country. What will be important is that all services form part of a trusted approach, where consistently high-quality services are provided no matter where the person lives. This could be a system which builds on the National Care Standards already in existence.

There are various options for developing this model, such as through the integrated joint boards, NHS, councils, third sector or a hybrid of these models. Central to any model is a need for transparency and accountability of decision making, and participation of service users and local people in decision-making.

Our consultation

We circulated a discussion paper to a broad range of people and organisations directly engaged in the provision of social care to gather perspectives and gain insights into their visions for future care in Scotland. This paper provided a list of three potential delivery model options for social care in Scotland:

- A national care system under the existing integrated health and social care partnerships
- More direct care provision by councils, building on the care services they already provide
- A national care system, sitting alongside and inter-related with the NHS

Our consultation work established that there is widespread support in principle for a national care service that offers the opportunity to better implement measurable national standards of care and to strengthen oversight and regulation of it. It was also noted that a national care service could become a recognised national symbol of quality, valued and trusted by the population to deliver excellent standards of care for everyone who needs it.

However, while that is an honourable aspiration, no one should be under the misapprehension that that would be an easy place to get to. In our consultation the Coalition of Care Support Providers in Scotland perhaps best articulated and highlighted the concerns that exist about the care a national service could and would deliver in practice:

- CCPS would welcome a more strategic, national approach to the agreement of cross-sector workforce terms and conditions. However, they are concerned that a national care service has the potential to bring a homogenous one size-fits-all approach, which would represent the antithesis of person-centred self-directed support.

- They also argue that although there is a perception in some quarters that a national care service would become a trusted national resource like the NHS, there is a risk that the opposite could be the case. They therefore make the case that trust will need to be earned rather than assumed. Indeed, they believe that without careful planning the move to a national care service could actually undermine trust and suggest that this would have to be carefully managed in the event of such a transition.

- Whatever flaws currently exist, local knowledge and expertise in service delivery are often a strength of care service provision at present and CCPS would seek assurances that this wouldn't be lost or subsumed in the transition to a national care service.

- CCPS members have expressed concerns that what constitutes good clinical practice may conflict with good social care practice. A national care service would need to avoid pitfalls of the medicalisation of social care.

- CCPS would seek more information on how a national care service model would procure social care from independent providers and suggest it would need to address the weaknesses of the current competitive tendering system. Without clear alternative models of commissioning that support better outcomes for people and enable them to live a good life, a national commissioning service runs the risk of making the same mistakes or worse at a national level. They argue that commissioning, wherever it occurs, should be collaborative and treat third sector providers as equal partners.

These are all legitimate concerns. Any move to a national care system should include specific provision to mitigate against such identifiable risks.

A new dawn? Innovation in the delivery of care

A blended care service: quality provision that reflects local needs and possibilities

A blended care system needs to be responsive to the changing needs of individuals across the life stages. That's why care needs to feature in our housing policy, our infrastructure planning, and as a core element of community participation and decision-making. Local community level decisions on care hubs and other settings of non-domiciliary care are an essential part of co-production of care services and funding pathways, as well as decisions on the use of space and facilities locally. Current mechanisms need to be more transparent and more inclusive of local people and particularly of service users, especially disabled people and others accessing care support whether to live independently or using care services to stay at home or be looked after in residential settings.

While reforming our care system requires us to look at who provides the care, even more importance should be placed on what care is provided and how that care is provided. We need to be bold and innovative in looking at new models of care delivery. One area we are keen to explore in this submission and in conversations around the reform of social care and future models of local provision is the idea of care hubs or care villages.

Care hubs/villages

A model based around care ‘hubs’ or ‘villages’ could provide a blend of the care provided. The hubs could be in one or several physical locations or could be virtual given the differing needs of more remote parts of Scotland where services would need to be delivered differently. Although having a focus on care, other intergenerational services could also be provided in the hub such as nursery provision. There have been some good examples of this with co-location enabling older citizens the opportunity to interact with some of the youngest, providing a stimulating environment for service users, and local sharing of resources and facilities such as kitchens and transport.

A care hub or village could include a sheltered or very sheltered housing complex that has care provided on a scale that can increase or decrease as the needs of the person changes. It could also include permanent care and/or nursing home beds for those with more complex needs. Respite provision could provide much needed breaks for those people still living within their own homes and their carers who need regular breaks to continue to live independently. Day care services could also be located within the hub, which would provide much needed social contact for people who are socially isolated and lonely and suffering poor mental health. The care village could provide much needed social interaction for many, improving their quality of life while enabling people to live independently for longer.

Those providing care at home services could also be co-located within the care village ensuring that services are joined up and staff working within each care setting are interacting and working closely together. This model would also provide a variety of career opportunities and richness of experience in different settings for those working in the care sector.

The concept of the ‘20-minute neighbourhood’ has attracted huge global interest, whereby people in any part of a town or city should be able to find shops, public services, leisure facilities, green space and employment opportunities within a 20-minute walk of a good affordable home. Care should be a core part of this vision and the care hub or village would fit in well to this concept.

Integrating unpaid care and carers in a vision for social care

Locally accessible facilities such as a care hub, that combines social activity, opportunities for socialising and combating isolation for carers and people accessing care services, as well as access to health and other support, potentially offer greater support to unpaid carers. Our reliance on unpaid care by partners and family members is consistently overlooked and undervalued. The economic, social, and personal costs to individuals – predominantly women – who reduce or give up paid employment to care for family members or friends are hugely significant to the individual, to our economy, and to our systems of social care and support which have come to rely hugely on unpaid care.

Any future vision of care in Scotland must integrate the experience of unpaid carers and their contribution to the wellbeing of others and must protect the wellbeing and economic security of carers. There have been some recent developments to support carers in Scotland through additional social security payments, something which could be expanded upon to provide greater support. There is still much work to do to ensure carers feel valued and are genuinely listened to – despite legislation intended to support them, and the engagement and advocacy of individual carers and highly effective carers organisations.

A future integrated care system must be based on the inclusive participation of service users, carers, and providers in developing a range of social care services and delivery mechanisms that ensure the dignity and respect of all recipients and providers.

Our findings and recommendations

A National Care Service

Informed by our consultation work, the Social Justice and Fairness Commission has concluded that:

- We support the introduction of a national care service in principle, and believe that, implemented properly to sit alongside and interlink with the NHS where appropriate, it can help society to value social care like it values the NHS. We believe a national care service can play an important role in supporting each of the core principles detailed in this submission and which underpin our vision of ethical social care in Scotland.

A careful and considered transition to a national care service, sitting alongside and interlinked with the NHS, has the potential to:

- Expand the existing national system with the benefit of establishing consistency of terms and conditions and of approach

- Create a single streamlined system that would help to eradicate issues such as delayed discharge and deliver a better focus on social aspects of care beyond healthcare services

- Benefit both health and social care without privilege or hierarchy whilst relieving recruitment and retention problems

- Offer staff the ability to enter a joint health and care service and to progress and develop their careers across care, community and acute settings

- Provide care through a well-known and trusted brand – the National Care Service or Integrated National Care Service – providing important assurance to those being cared for and their families

It must, however, include provision to ensure:

- There is local flexibility at the point of delivery of services. This should include consideration about ways in which third sector organisations can operate as equal partners within the system.

- An NCS model avoids the medicalisation of social care. What constitutes good clinical practice may conflict with good social care practice and a national care service must avoid loss of local knowledge and expertise in service delivery.

- Self-directed support is at the heart of any NCS system so all service users – whatever their particular circumstances – can properly exercise choice and control.

- Unpaid carers should be formally recognised and treated as equal partners in the decision-making process.

- A national commissioning model can be explored as a potential avenue through which third sector providers can offer care under the national care service brand, rather like GPs and community pharmacists currently deliver NHS services as independent contractors

Reforming care within a national care service

Within any national care service model, choices will need to be made about the ways in which care services are delivered locally. The Social Justice and Fairness Commission is attracted to excellent examples of innovative care that can and should become mainstream under a national care service. One such concept we are keen to see explored and tested is that of care hubs or villages.

The Social Justice and Fairness Commission believes that:

- We should move towards a blended care system that is responsive to the changing needs of individuals across the life stages. Care needs to feature in our housing policy, infrastructure planning and as a core element of community participation and decision-making.

- Local community level decision-making on care hubs and other forms of non-domiciliary care, space and facilities are essential features of co-production of care services and funding pathways.

- Current mechanisms should be more transparent and include service users and local people to enable those receiving care to choose the support they need.

- From an early stage we should seek to develop and test innovative blended care models such as care hubs or villages. Whilst focused on care, they should follow best practice examples and include other intergenerational services such as nursery provision. Co-location of this kind enables older and younger citizens to meet and interact, providing a stimulating environment for all service users and making effective shared use of resources and facilities such as kitchens and transport.

- Social care has the potential to fit perfectly within the ‘20-minute neighbourhood’ concept – whereby people in any part of a town or city can find shops, public services, leisure facilities, green space and employment opportunities within a 20-minute walk from a good affordable home – and we should aspire to try, test, deliver and upscale it in practice.

Integrating unpaid care and carers in our vision for social care

Any future vision of care in Scotland must integrate the experience of unpaid carers into the fabric of the care system and recognise and value their contribution in supporting the wellbeing of others. Further, it should protect the wellbeing and economic security of carers.

The Commission supports inclusive participation of service users, carers and providers as equal partners across the range of social care services and delivery mechanisms.

Supporting the workforce

A National Care Service brings opportunities to improve and standardise pay and conditions and facilitate career progression opportunities. The commitment to the Scottish living wage provides a firm foundation and starting point from which to drive improvements.

Recruitment and retention issues have presented an ongoing challenge for the sector, which has a poor reputation for pay and status. Despite the commitment to the Scottish living wage, it is often viewed as a physically and emotionally demanding career with limited progression opportunities, challenging work and long and unsociable hours.

The Social Justice and Fairness Commission recommends:

- Greater acknowledgement of and clear action to tackle the gender dimension of poor pay and conditions, progression opportunities and access to professional development and training

- Strategies are employed quickly to address undervaluation of the workforce. Aside from the urgent need to tackle the root causes of gender inequality, this work is pressing due to serious workforce challenges stemming from Brexit impacts on migrant workers as well as from changing population demographics.

- Moves are made to increase sector-wide collective bargaining in social care sector through greater trade unionisation in the workforce.

- Greater standardisation in aspects of social care such as training and education are applied to ensure consistency and quality of care.

- Robust mechanisms for job evaluation are established to address the sector-wide economic undervaluation.

Investing in care

In response to the questions on additional funding, there has been a general call for more resources but little in the way of specific detail of how that should be achieved.

The Social Justice and Fairness Commission calls for further detailed work to be carried out on all funding options to investigate what measures can be taken now using devolved powers to fund a national care service, and which would require the full tax and benefit powers of independence.

Most of the detailed responses focussed on the current structures around commissioning, procurement and funding decisions with strong recommendations for these to be overhauled.

On the basis of our research and consultation work, the Social Justice and Fairness Commission supports:

- Future funding decisions being primarily informed by a sharp focus on social care outcomes performance (i.e. quality of care and support for service users and families) and not outputs (e.g. numbers of social care staff or hours spent with a patient)

- Recognition of social care as a key growth sector with the potential to generate economic as well as social returns on investment

- Prioritisation of investment in social care as a key contributor to the challenge of rebalancing gender inequality for the social care workforce and service users. Due consideration of gender impacts should always be given when making funding decisions.

- Reforms to commissioning and procurement through a national commissioning model to drive up standards. Aims should include tackling the prevalence of temporary and zero hours contracts, low rates of overnight pay, long working hours and unpaid overtime.

- Removal of 12-month fixed-term funding contracts to deliver palliative and end-of-life care and their replacement with three-year or longer rolling contracts.

- Exploration of models requiring reinvestment of surpluses back into the social care system, causing discomfort for any organisation that values shareholder profit over reinvestment.

The issue of future private sector involvement in a new national care service model requires further discussion. We are of the view that it has an important role to play in maximising choice for care service users, but that a significant shift away from private sector dominance of the care home sector is required. The Social Justice and Fairness Commission therefore recommends a detailed analysis and review is undertaken to set out a route map towards a better sector balance and investigate potential mechanisms for controlling and reinvesting surpluses and profits within the sector.

Regulation and inspection

The need to strengthen regulation and inspection is widely supported. The Social Justice and Fairness Commission therefore recommends that the Care Inspectorate should have the same enforcement powers to require change and improvement in commissioning and procurement as it currently has for service provision.

Digital working

The Social Justice and Fairness Commission recommends that investment and training should be allocated to social care to equip workforces with the digital skills to support patients. This will enable them to view and use their own records to help them secure the care they want and need.

Support for people with autism and learning disabilities

Representations have been made by a number of individuals, groups and organisations to better address the needs of people with autism and learning disabilities. They are concerned that many are effectively excluded from society because they don’t get the respect or support that they should as equal citizens.

They are concerned that the human rights of people with autism and learning disabilities – as well as the legal duties placed on agencies – are routinely ignored, leaving individuals and their families fighting to get the support they are legally entitled to.

They want the voices of people with autism and learning disabilities to be heard at every level of policy development within central and local government and for services to work better so that people get support without having to battle the system. They want a system that cares enough to get it right.

They are calling for an Autism and Learning Disability Commissioner – the first of its kind in the world – to be established in law to champion the human rights of people with autism and learning disabilities.

The Commissioner’s role would be to strive for better outcomes, introducing accountability in public services and promoting the rights of people with autism and learning disabilities. This would enable them and their families to exercise choice and control and live good lives free from discrimination.

The Commissioner’s role would also help ensure that people with autism and learning disabilities receive the services and support they are entitled to and have an equal stake in Scotland’s future.

There is a broad coalition of support from across the third sector – including Enable, National Autistic Society Scotland and Scottish Autism – to establish such a commissioner, which has helped scope out the role, powers and the difference that such an office could make.

The Social Justice and Fairness Commission supports the establishment in law of an Autism and Learning Disability Commissioner to champion the human rights of people with autism and learning disabilities.

SOLACE

National Care Model

Summary of Issues

Introduction

The Scottish Government announced the establishment of the Independent Review of Adult Social Care in Scotland on 1st September with a target reporting date of January 2021. The Review Group whilst engaging with a broad range of stakeholders does not have representation from local government, SOLACE, COSLA, Social Work Scotland (SWS) or Health and Social Care Scotland (HSCS).

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.

The Review will consider and make recommendations on:

- The needs, rights and preferences of people who use services, their carers and families;
- The experience of people who work in social care, including their employment arrangements, opportunities for training and progression, and relationships with other professions across health and social care;
- Arrangements for funding, governance, ownership, administration and delivery of 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;
- Regulation, scrutiny, quality assessment and quality improvement capacity and capability;
- The role of local communities in providing capacity and assets to support people to live as well and as independently as possible and to enjoy the same facilities, universal services and opportunities as other citizens;
- The role and contribution of local and system level leadership:

- Future policy developments that should be a focus for the Scottish Government and any recommendations regarding the legislation that currently underpins social care provision and regulation; and

- Opportunities to redesign the overall system of social care to improve people's experience of care.

The Programme for Government that announced the setting up of the Review explicitly references consideration being given to a national care service. The following section considers a range of key issues to assist consideration of the implications of setting up a national service.

Key Issues

There is a broad range of models that could inform / guide the establishment of a national care service ranging from the compulsory purchase and transfer of private and third sector assets and businesses into public sector control (effectively sectoral nationalisation) to changes in local governance arrangements for existing services within a mixed economy delivery model to relate to a national service that is governed like the current NHS model.

Until there is clarity on the policy intent it is difficult to respond in precise terms however the following points are listed as relevant and should be addressed:

- The complexity of compulsory purchase of property and other assets from private and third sector businesses would be hugely significant, and a lengthy process undoubtedly further complicated by anticipated legal challenge. The matter is further complicated by the complex lease interrelationships between care operating companies and asset owners who often have no role in the business and a broad range of contractual arrangements those businesses and operators will have with 3rd parties and service users.

- The costs of asset acquisition would be an enormous and unnecessary strain on the public purse. Often the assets in question may represent a model of service that we would wish to move away from and the public sector may end up owning assets that are not in line with future asset requirements and/ or represent future maintenance and investment liabilities.

- Non asset-based businesses (e, g. housing support; care at home services, and other forms of visiting care and support) would also require to be valued and compensation paid to owners for the loss of their business. The same complexities will exist with existing contract arrangements. Despite those compensation payments to buy those companies out, the only tangible asset is the transfer of the staff resource. Following TUPE transfer the matching of terms and conditions with the current public sector workforce will also significantly add to the current cost of service.

- A number of providers represent a level of specialism in model of care, service users supported or in terms of facilities. These specialisms have built up over a long period of time and will be difficult to replicate or given sufficient focus in order to retain this capacity within a nationalised model.

It is important to also consider adult social care within a wider health and social care system and in particular the drivers of social care demand. There is no point in focussing only on how social care is commissioned, organised or delivered if the demand tap is turned on and the flow increased through decisions made outwith the adult social care sector. The following bullet points expand on this point.

- Adult social care cannot be reviewed within a silo – adult social care is one part of a wider health and social care system and is directly impacted by decisions, policy and clinical behaviour in a range of health settings. The drivers of social care demand often come through acute and primary health care settings. “Whole system” consideration of the drivers must be about more than the perspective of the end user – providing a one door access to health and social care should be relatively straightforward however making the whole system operate efficiently is more complex.

- There is a fundamental recognition that there has been little progress in changing other drivers of demand in terms of poverty, lifestyle, education that combine to produce health inequalities. Similarly we have seen inadequate progress in the implementation of realistic medicine; social prescribing and anticipatory care planning – and ultimately, despite talking about it for a long duration, little progress in shifting the balance of care.

- Rising public and political expectations are also influential factors and would benefit from a more open public discussion on what the public can expect from a health and social care system of the future. Also what the system should expect the public to do in relation to lifestyle, payment, taxation, unpaid care etc.

- The movement of resource within the system hasn’t kept pace with policy development creating resource pressures that accounts for too great a proportion of management capacity to manage to the detriment of innovation and service improvement. For example set aside budgets have not had the intended effect and have failed to facilitate either the quantum or pace of resource to move.

- The result has been to continue to increase the resource demand and proportion of public spending which ironically rewards the status quo/ clinical behaviours, inhibits innovation and drives social care demands.

In considering the wider health and social care context, inevitably this draws attention to the current model of governance and accountability and in particular the effect of the Public Bodies (Joint Working) Scotland Act in establishing Health and Social Care Partnerships with governing Integrated Joint Boards/ Lead Agencies.

- Whilst there is universal support for improved integration of health and social care, either the body corporate nor the lead agency model works consistently or in truth particularly effectively. The role of the Chief Officers within this accountability structure is increasingly difficult and had led to a high attrition rate amongst a group of very capable officers.

- The extent of integration is variable in different areas with adult services only models predominant – there are however areas where children and families social work or justice services are included. For the most part acute services are retained functions by the local Health Board yet, as noted above, are drivers of community based services demand.

- The extent of delegated powers to IJBs are not consistently understood by either local government or health boards which makes effective decision making and in particular, step changes in policy or service delivery models, more challenging to deliver. The twin reporting on performance, planning and finance to local authorities and to Ministers via Health Boards illustrates the challenges experienced by Health and Social Care Partnerships and the balancing act for senior staff. This has contributed to slow implementation of change in both health and in social care.

- The need for local service responsiveness is clear nonetheless – Scotland is a greatly diverse country and HSCPs has provided a mechanism for that local perspective. NHS Highland’s area extends from the far north of Scotland to the Kintyre peninsula at the southern end of Argyll and Bute. It is around 195 miles from Inverness to Campeltown with no patient pathways going north from Argyll and Bute. Whilst this may be an extreme example, the importance of locally responsive and accountable services is a key consideration in every HSCP area.

- Some focussed consideration is needed to address the governance and accountability issues noted above.

The distinction between social work and social care needs to be clearly understood and maintained. Both are parts of the wider system, and both professions require distinct consideration in terms of resourcing and workforce planning/ career development.

- Social Work professions hold key statutory responsibility for the assessment and management of risk, protection and importantly areas where judgements have to be made about the deprivation of liberty.

- Across Health and Social Work and Care the tolerance of risk is an underdeveloped consideration - our risk thresholds have changed over time with, in particular, older people now living in community settings with fairly high end complex needs. But to control risk in these settings costs a significant amount of resource – there is a balance between the three pillars of personal choice, affordability and levels of risk that needs to be reconciled. Dependency and complexity are not well recognised or understood – the IoRN (Indicator of Relative Need) is good work but does not sufficiently cover mental health.

- In terms of the person centred care – more explicit consideration should be given to the inconsistent implementation of Self Directed Support (SDS) and what needs to change to make it a more viable option (including a recognition that SDS may often lead to double running costs for asset based services running under capacity).

- Some further reflection on whether the Adults With Incapacity (AWI) legislation is fit for purpose. Whilst acknowledging there is a rights issue here, a great deal of delays in appropriate care placements are in reality delays in legal processes to obtain the rights to make professional judgments on care placement. Some of these delays are damagingly lengthy, the legislative basis for social work to make interim placements once no further medical need is established and whilst the legal process is pursued for guardianship would substantially reduce bed days lost and not compromise individual rights.

The Food Train

Hello Ian,

Hope you are well.

I wanted to take the opportunity to contact you as a member of the Review of Adult Social Care expert panel. I appreciate the review will be looking at all aspects of how care is procured and delivered, but I'd like to raise two issues in particular; the legislation itself and food within social care as an area of deep neglect over 20 years of Free Personal & Nursing Care at Home legislation, and ask that during the review the panel could consider the legislation and the importance of food to wellbeing, recovery, avoidable malnutrition, falls, frailty and avoidable hospital admissions.

Our Eat Well Age Well project has spent 2 years gathering data about older adults food needs and found higher prevalence of malnutrition than previously thought. https://ilcuk.org.uk/a-review-and-summary-of-the-impact-of-malnutrition-in-older-people-and-the-reported-costs-and-benefits-of-interventions/ cited 1 in 10 older adults at risk or being malnourished with 93% of those living at home. We found approx. 12% of older people living at home without care/support were at risk or already malnourished, but for older people living at home in receipt of domiciliary care this rose to 32% at risk or already malnourished. https://www.eatwellagewell.org.uk/callstoaction

There are countless pieces of research that chart the demise of community meals provision, the loss of lunch clubs and day centre closures. All these provided older people with support needs to have hot meals every week, and with clubs/centres came the opportunity to each socially with others. We know from countless shopping lists written by our members, their daily food intake is severely impacted by the time available to the carers e.g. for some we must only provide microwave meals that take 5 minutes or less otherwise the carer cannot leave lunch or dinner, some live purely on tinned food, some live purely on frozen meals depending on their care visits. We know many had a meal visit cut and carer now leaves a sandwich in place of that visit. Older people getting care have become more and more isolated at home, eating alone, not eating what they'd like and not getting enough calories per day which leads to weight loss and a long list of health implications. We have launched research this week in partnership with Glasgow University which evidences all this, but also highlights the simple solutions – essentially all the food based supports that have been cut, are part of the solution alongside community screening and training https://osf.io/preprints/socarxiv/6fwm8/

Timely research today also evidences how Covid19 has exacerbated a system that is disabling rather than enabling https://www.scottishhumanrights.com/media/2102/covid-19-social-care-monitoring-report-vfinal.pdf

It all brings me back to the point we illustrated in the attached letter from 2016, the legislation that underpins the delivery is not fit for purpose. It is a medical model that has no scope for approaches that are assets and rights based and it is a tool being used to ration care. It has created a postcode lottery for older people across the country that is unacceptable. The grey area around food within the legislation was highlighted as far back as 2007/2008 when Lord Sutherland led a review. His findings highlighted that Councils (as it was back then) would need to provide food access to enable the delivery of the food preparation/help with eating elements of the legislation – that simply hasn't happened. The legislation needs hauled out by the roots and replaced with a set of statutory social care rights and standards that encompass all parts of the persons wellbeing, enables a life lived well and actively promote dignity and choice. In addition a shift of power and resources from the public sector to people and communities will allow a radical overhaul of how social care is delivered and by whom, driving it away from toxic procurement and competition and towards people and place.

I hope the review will be bold and ambitious, but I appreciate the time is short and the scope is large, and I hope you don’t mind me contacting you with my thoughts.

Best wishes to you (and all the Welsh family)

Michelle

Michelle Carruthers MBE, Chief Executive
2015 Clore Social Fellow

First Minister
St. Andrew's House
Regent Road
Edinburgh
EH1 3DG

2nd March 2016

Dear First Minister,

It was very nice to meet you again recently at The Gathering. The warmth with which you spoke of the voluntary sector and your Government's commitment to honest and open relationships was welcomed by everyone in the room. When we spoke briefly after the Q & A panel, I asked your thoughts on whether Free Personal and Nursing Care (FPNC) in terms of the Community Care and Health (Scotland) Act 2002[1] is delivering the outcomes in adult social care which the policy was intended to achieve, and whether you would support a review. You indicated the matter required consideration and asked for my thoughts. I now write to follow up on our conversation, setting out my thoughts and those of other sector colleagues on the timely need for a review.

It is now 17 years since the publication of the report of the Sutherland Commission,[2] almost 14 years since the Act came into effect, and eight years since Lord Sutherland's initial review of FPNC.[3] There is no doubting the provision of Free Personal Care is regarded as one of the Scottish Parliament's foremost

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[1] See www.legislation.gov.uk/asp/2002/5/contents

[2] See http://webarchive.nationalarchives.gov.uk/20140131031506/http://www.archive.official-documents.co.uk/document/cm41/4192/4192.htm

[3] See www.gov.scot/Publications/2008/04/25105036/0

achievements. By embodying a system in which responsibility for care costs is shared between the state and the individual in a fair, equitable and transparent way, it has successfully brought security and dignity to many older people, ignited our aspirations to enhance independence, and helped to shift the balance of care by increasing the number of older people cared for at home.

As the devolved institutions wrestle with ongoing problems of constrained public funding, we think it is important to re-state the principle that FPNC makes a vital contribution to ensuring that older people enjoy the security that marks a civilised society. Nonetheless, there are a range of contextual, demographic and policy changes in the years since which all point towards the need for a further review.

Firstly, we wish to see that the policy remains financially sustainable, and copes with changing demand. Although the Sutherland Commission considered that increases in demand due to introducing the policy of FPC were likely, they did not seek to quantify them. However, the then-Scottish Executive's Care Development Group[4] did, but they also accepted that predicting this would necessarily be difficult and might require further review. By way of example, they anticipated a Scottish population of 5.016m by 2026, whereas projections now place this at 5.547m, some 10.6% higher. Long-term projections[5] now predict the Scottish population will reach 5.7 million by 2039 (a 6.6% increase since 2014). Increases among the oldest age groups are not only the largest – for instance, those aged 75+ will rise by over 85% – they also account for the *entire* predicted rise in the overall population.

The increasing and ageing population impacts on the numbers of people living in Scotland with one or more long-term health condition(s). Almost half of adults have one or more long-term condition(s), with around a quarter experiencing multiple conditions. Older people are three times more likely than younger people to have such a condition, and two-thirds of these conditions limit the abilities of those who have them.[6] These factors suggest a very different demographic profile compared to the one present when the Act came into force, and that some re-forecasting of the costs of FPNC would be prudent.

A review could also consider ongoing concerns about FPC's impact on contractual routes for funding care home places, and significant reported delays in the receipt of FPC despite eligibility being clearly established, often being much longer than the timescales set by the National Eligibility Criteria for FPNC.[7]

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[4] See "Fair Care for Older People": www.gov.scot/Publications/2001/09/10069/File-1

[5] See www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/population-projections-scotland/2014-based

[6] See Scottish Health Survey 2014: www.gov.scot/Publications/2015/09/6648/318742

[7] See www.gov.scot/resource/doc/924/0088325.doc

On a related note, Lord Sutherland's initial review also addressed the issue of the loss of entitlement to Attendance Allowance (AA) for FPC recipients who were care home residents – worth £23 million in 2002/03, but now over £40 million annually. The Smith Commission report and Scotland Bill envisage that AA will be devolved, alongside other disability benefits such as Disability Living Allowance and Personal Independence Payment. The Scottish Parliament and Government will therefore gain the ability to consider financial provision for care needs in a more comprehensive way, which enhances independence, choice and control.

We recognise and welcome the additional resources for social care which the Government identified in its recent budget. However, we also note that there are many demands on these resources, with half of the £250m identified to be directly used in helping raise the wages of care workers – an important step, but not one which will necessarily improve the extent or change the model of care provision.

The National Eligibility Criteria are applied in different ways in each of the 32 local authorities, each of which also has varying charging policies for non-residential care. Divergent implementation may also hinder the achievement of FPNC's objectives and the national health and wellbeing outcomes, creating geographic inequalities for older people. A review of FPNC could explore ways in which the taking of an equalities and human rights-based approach to health and social care integration would establish a more common standard across the country.

The second broad rationale for a wider review relates to the models of social care provision and care packages financed by FPNC. The Christie Commission called for, and the Government indicated agreement with, a "decisive shift to prevention" in public service delivery. Some moves toward personalisation have been made through the enactment of self-directed support legislation. But the basic models of care provision do not yet reflect this intended shift, nor the opportunities afforded by health and social care integration.

Assessments of the need for care are based on specific tasks, designated on a nursing model as "activities of daily living" (ADLs) (and also "instrumental" ADLs), which individuals may be unable to perform for themselves and with which they require assistance. This is embodied in the statutory definition of "personal care" in the 2002 Act, and in the National Eligibility Criteria. It also informs the budgets for care determined within self-directed support (SDS). By its nature, this is a deficit model, built on an assessment by health and social care professionals of what is wrong. It is geared towards substituting for lack of function, not generating improvements in health and wellbeing. Since poor health has been posited to have a negative impact on social resources and participation, furthering loneliness[8] and decreasing capacity for self-management,[9] this may also be counter-productive, by

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[8] http://psychsocgerontology.oxfordjournals.org/content/69/2/311

[9] http://heb.sagepub.com/content/30/2/170.short

normalising or even exacerbating functional decline. This model, especially when combined with budget and time pressures upon care providers, may also contribute towards greater malnourishment. And perhaps worst of all, by focusing on a person's needs rather than their abilities, it reinforces the damaging notion that older people are not valued as citizens, but thought to be costly, burdensome and inconvenient.

These are exactly opposite to the ambitions of Free Personal and Nursing Care, which as well as achieving financial fairness, is designed to encourage more people to be able to retain their independence and live well at home or in their communities.

An asset-based approach that is based on achieving positive outcomes; which is person-centred (taking into account complete health, care and support needs); and which therefore prioritises preventative and anticipatory care and early intervention, would be far superior. If that approach also emphasised individual involvement, self-management and augmenting personal capacity, it would be better still. We believe a review would enable a fuller examination of how these objectives could be put into practice, considering ways in which innovative planning and practice of social care contributes to not only the best possible outcomes but also allows the prioritising and allocation of public resources in the most effective way.

The Community Empowerment (Scotland) Act 2015 explicitly states a welcome intention to tackle disadvantage and inequality. Therefore, the policy of FPNC may require refreshment to reflect the changing nature of public health issues and acknowledge the so-called 'fifth wave of public health'[10] where solutions to potential public health crises are cultural – addressing the social determinants of health; our physical, social and economic environments – and multi-sectoral in nature[11]. Unpaid carers would also be an important voice in articulating the ways in which contextual and environmental factors affect wellbeing, and what forms of support are needed for a holistic rather than a deficit approach.

Other recent policy developments, including the publication of the National Clinical Strategy, the passing of the Carers (Scotland) Act 2016 into law and the creation of a network of treatment centres across the country all serve to add further context for the need for greater consideration of the FPNC policy. We would also point towards learning from emerging models of primary care, including the National Links Worker Programme and the House of Care pilots, as further context for change.

Together, our three organisations work alongside a large number of people who come into contact with FPNC provision, as recipients of care as well as formal and informal carers. We also believe that a review of FPNC would also create an opportunity to consider the widening role and contribution of third and independent

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[10] http://www.ncbi.nlm.nih.gov/pubmed/21256366

[11] http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(13)62341-7.pdf

sectors to this policy area. Significant positive steps taken towards integrating health and social care could also be further enhanced by a review, bringing together a large and diverse voice to these discussions.

We welcome your consideration of a FPNC review and look forward to hearing from you in due course.

Yours faithfully,

Michelle McCrindle, Chief Executive, Food Train

Ian Welsh, Chief Executive, Health and Social Care Alliance Scotland (the ALLIANCE)

Brian Sloan, Chief Executive, Age Scotland

The Usual Place

THE USUAL PLACE

I'm sorry for the delay in forwarding these films of our OT Students talking about their experience in The Usual Place. We have been caught up in organising developments for young people further to the physical closure of The Usual Place till it is safe for us to reopen.

Both students have advised that they would be happy to discuss their experience and the impact having a placement in an employability service for young people with additional support needs has had on their thinking and presumptions about what is possible and individual potential. I've also attached a film about one of our young people who has a visual impairment, a learning disability and physical impairment. His mother told us that she was advised that the most this young man could expect is supported living and social support. He is now saving for his own home, training to be a head chef and has a life not a service. Importantly his success has had a huge impact on the wellbeing of the family who have moved from being carers, and in his twin sisters case, prospective carers to being equally supportive members of the family.

Morgan won the SCLD Learning Award and recently talked about his achievements so that other young people with additional support needs can have hope for a life of contribution rather than dependency on health and Social Care Services.

Our original film was made by a BBC Camera person whose daughter worked for us. We simply asked him to talk to people about what was important to them. It features young people, customers and families. Two of the young people featured have their own business, others are employed in retail and delivering care. 2 people in this video are particularly proud that they are Key workers and have worked through the pandemic, one in a shop and the other delivering care to 4 disabled men in a group living arrangement.

Happy to offer any further info we have and have attached some social accounting case studies looking at outcomes for young people and cost savings with investment in employability rather than health and social care support.

Katie's Video: https://www.youtube.com/watch?v=v5Q_zZwJr6o
Kate's Video: https://www.youtube.com/watch?v=DnAvDurtzNo

Morgan YouTube: https://youtu.be/IjO73W3QH54

Morgan SCDL: https://vimeo.com/485975538?fbclid=IwAR3E-xjMz3TYaMCkYJ5YUt5zaCITUAGtN4_lnltgcu-IzKbJTmQ57u8-odQ

Original Film : The Usual Place - The Full Story - YouTube

Kindest regards

Heather Hall
Chief Executive Officer
The Usual Place

The Usual Place

Craig's Journey

Craig is a young person who has a learning disability and severe sight impairment. Craig came to TUP on a placement from school. Craig lacked confidence, demonstrated limited communication skills, had very poor self-esteem and no self-belief.

Craig had additional support for learning in school however Craig told TUP staff that he watched the school careers advisors and teachers help his peers make plans for work, modern apprenticeships, college and university and none spoke with him about his ambitions. Craig said this made him very angry, upset and hopeless. Craig lacked any hope for the future.

Craig's family's expectations for his future were also very low and his family expected either to admit Craig into institutional day care services or have to look after him at home.

Craig joined TUP as a School placement 1 day per week for a term. Craig attended a rural school and learned to travel independently to work.

Craig really enjoyed his time in the TUP kitchen, Craig said he had always wanted to learn to cook but had not been allowed to attend the Home Economics class at school because the teacher was worried he might hurt himself or others. Beginning with 1:1 support, Craig worked with mentors to test his skills and establish any adjustments that might need to be made whilst navigating the kitchen, essential self-care, daily processes and in learning professional knife skills. Craig showed his mentors what adjustments to practice made sense for him and, in turn, improved practice for all. These included, all equipment and food having a permanent location. E.g. white and brown bread always kept in the same place and designated shelves for products with clear labels which he could read. TUP also invested in "talking" scales and timers.

With this support in place Craig was able to fully and independently access and use the kitchen facilities, in particular, learning how to chop vegetables like a professional.

While at TUP, Craig showed potential in his ability to work with sharp professional knives and while initially he required a great deal of 1:1 support during his first 10 weeks at TUP to enable these skills to develop this also gave Craig confidence to move from being exceptionally quiet and struggling to speak to staff and other trainees within TUP to active social and professional participation with a positive outlook.

Craig worked hard with the team over the 10-week period learning key skills through which he developed confidence, skills and independence.

Costs incurred working with The Usual Place (Hourly rates include NI, Pensions and core costs)

- Mentor 780 hours @ £11.16 = £8704.80
- SVQ Mentor 140 hours @ £11.16 = £1160.64
- Manager supervision 12 hours @ £19.80 = £237.60
- Set up and work placement meetings 12@ £19.80 = £237.60
- Specialist equipment £250
  Total £10,590.64

Potential costs avoided through work of the Usual Place

- 4 Additional GP appointments @£90 = £360
- Potential 3 CPN appointments @ £35 =£105
- Potential 6 Multi agency meetings est. @ £1400 = £8400
- 2 attendances per week at day-care 52 @ £72 = £7488
- 52 weeks in supported accommodation @ £1552 = £80,704
- 52 weeks Universal Credit min @ £14924
  Total £111,981

Excludes option of parent's loss of income @£36,611 (average national salary) and consequential effects

Estimated potential net costs avoided through working with the Usual Place **£101,390.36**

Sources Early Intervention Foundation – Making an Early Intervention Business Case Evidence and Resources, PSSRU Unit Costs of Health and Social Care

Evidence of progress

On leaving school Craig joined TUP SVQ Professional Cookery Programme directly. Craig moved from 1 day per week to 2 days per week to meet SQA requirements

Craig's skills and confidence grew, Craig took 'work' home with him and honed his cookery skills practising at home too, increasing his independent living skills and demonstrating to his family that he could live and work independently with the right enablement and skills investment.

Craig's family grew in confidence and their outlook changed. This family turnaround in hope and optimism further fanned the flames of Craig's ambitions and he successfully applied for a part time job as a kitchen porter whilst continuing his training in TUP. This earning assisted the families overall income and wellbeing

Such was Craig's ability in professional knife skills that Craig started to train other TUP trainees, new volunteers and mentors further enhancing his confidence. Craig completed his SVQ successfully.

Successful outcomes

Just as Craig completed his SVQ a Kitchen Assistant post became vacant in TUP. This was openly advertised. Craig used the support of the Employability Partnership to independently apply for the post and prepare for the interview. Craig did exceptionally well and got the job

Craig has gone from strength to strength in this post and can now run the kitchen independently. Craig demonstrates emerging leadership skills and we hope that Craig will be able to join the Leadership Development programme soon in Inspiring Scotland

Importantly Craig has made friends at work and as his skills have increased Craig has worked with Dumfries and Galloway Chef Assessor delivering professional public cookery demonstrations

Demonstrating impact of successful outcomes via Social Values

Improvement in confidence – Youth £9283

Vocational Training - £1124

Member of a social group - £1850

Moving from unemployment to full time employment - £14443

Feeling in control of life - £15894

Source - Housing Association Charitable Trust 2018

The values can provide a basic assessment of social impact, provide evidence of value for money, and compare the impact of different programmes**.**

The Usual Place

Jenny's Journey

Jenny was a young person, who in her early thirties, was somewhat outside the age range of our usual service delivery. Jenny was a foreign national who had a learning disability and speech and language impairment. Jenny had no experience of choice and control in her life. She had experienced many losses in her life and was traumatised by what she had witnessed in her home country. Jenny's home country had not provided her with any care or support services. Jenny was alone in a foreign country, isolated, frightened and did not trust anyone. Jenny had had very limited education and had never worked or had much experience of life outside of her accommodation.

On arrival in this country Jenny was settled with the family of a distant relation who did not know about her and had never met her but had been happy to provide a home. The relatives were elderly and infirm but knew of The Usual Place and visited TUP to discuss the potential of Jenny volunteering to help Jenny get used to being around people, develop her language and help her feel less fearful and alone.

AS soon as Jenny had Home Office leave to volunteer, the TUP Team met with her and agreed that she could volunteer with TUP. (TUP had previously agreed with funders that 10% of all beneficiaries could come from outside core delivery age groups)

When she first came to TUP, Jenny was fearful and mistrusted people, saying little and clinging to the familiar. Mentors turned this need for familiarity into a strength, building on small gains in confidence and achievement. E.g, the dishwasher process is simple to learn visually, and though repetitive, provides an important part of the overall food service delivery. It therefore provided a quick win in terms of competence which in turn built confidence and a feeling of achievement.

Jenny needed lots of encouragement and support in the early days to try anything new and move from one activity to another. Mentors worked 1:1 with Jenny for over 6 months enabling her to develop skills in communication and relationship building. Gradually, Jenny's personality started to emerge as she became more trusting and less fearful. Jenny developed the ability to build rapport and join in the conversations with people around her, gradually being able to work more independently.

Jenny decided that she wanted to join the SVQ Professional Cookery Programme. This was a huge step forward and evidence of emerging self-worth and ambition. She was also keen to strengthen her academic abilities and said she wanted to learn to read and write. An adult education worker engaged with TUP to use real-life literacy requirements to develop a programme of learning which dovetailed with the SQA requirements creating optimal learning and an early sense of achievement as Jenny had much less need for a scribe.

As Jenny's practical and social skills increased, including her language and communication skills, she happily conversed with team members and grew in confidence. Jenny started to volunteer two days per week, in the kitchen at the local older people's day centre, further expanding her cooking skills and making new friends.

Costs incurred working with The Usual Place

- Mentor 975 hours @ £11.16 = £10,881
- SVQ Mentor 156 hours @ £11.16 = £1740.96
- Manager supervision 24 hours @ £19.80 = £475.20
- Set up and work placement meetings 12@ £19.80 = £237.60
- English lessons @ £31.50 per hour = £2457

  Total £15791.76

Potential costs avoided through work of the Usual Place

- Potential 24 Additional GP appointments @£90 =£2160
- Potential for deterioration in mental health 52 CPN appointments @ £1820
- Potential 52 additional social work meetings @£35 = £1820
- Potential 8 Multi agency meetings est. @ £1400 = £11,200
- Day care place 2 x per week 156 @ £72 = £22,464
- 78 weeks in supported accommodation @ £1552 = £121,056
- 78 weeks Universal Credit min @ £287 per week = £22,386

  Total £182,906

Estimated potential net costs avoided through working with the Usual Place **£167,114.24**

Sources Early Intervention Foundation – Making an Early Intervention Business Case Evidence and Resources, PSSRU Unit Costs of Health and Social Care.

Evidence of progress

Jenny achieved her SVQ in professional cookery, a source of great pride in her achievements. Jenny wanted to build on her practical skills by completing the SVQ in Hospitality Services. Jenny felt that this additional qualification would help her feel more confident in a public facing hospitality setting.

Jenny continued to develop her communication and language skills developing confidence in a public facing role. Jenny successfully completed her qualification whilst starting to explore next steps. Jenny enjoyed the sense of contribution helping her elderly relatives provided her. As Jenny grew in confidence and competence, she offered peer support to new volunteers and trainees. Jenny told us that she got a lot out of giving back and helping others and was considering a caring role

Jenny attended an NHS open day with other Trainees to explore the opportunities. Jenny was really taken with the hospitality service and housekeeping service departments and wanted to explore the opportunities further.

Successful outcomes

TUP arranged for Jenny to explore her ambitions in a 12-week placement in a local care home. This was really successful Jenny travelled independently and worked for 2 days per week, with a one day keeping in touch at TUP

Following Jenny's work experience in the care home, the care home managers were so impressed that they offered Jenny a job in the laundry, which she had really enjoyed.

Jenny now has a job as a Laundry Assistant and does all the laundry for residents, taking clean laundry to each resident's room and enjoying the social time with them whilst hanging up clothes and putting them away in the drawers etc. as directed by the individuals.

Jenny has ambition now to move out of her current living arrangements to her own accommodation. Jenny has developed all the life skills required to live independently, is continuing to volunteer 2 days per week and has told us that she never expected to feel so happy or to have qualifications and a paid job she loves

Demonstrating impact of successful outcomes via Social Values

Improvement in confidence – Adult £13080

Vocational Training - £1124

Moving from unemployment to full time employment - £14443

Feeling in control of life - £15894

Relief from anxiety and depression – Adult £36766

Source - Housing Association Charitable Trust 2018

The values can provide a basic assessment of social impact, provide evidence of value for money, and compare the impact of different programmes.

The Usual Place

Jim’s Journey

Jim is a vulnerable young man with learning disabilities, aged 20. He left school with no qualifications and very low expectations for himself and his career prospects. His parents had little hope for Jim having an independent future life.

Jim experienced regular bullying at school which caused Jim great distress and in turn resulted in challenging behaviour at home. Additionally, he has several health conditions including asthma, poor muscle tone and generalised exhaustion.

Jim’s learning disability means Jim needs more time to learn things and to behave appropriately in different situations and circumstances.

Jim attended a number of college and work experience placements after leaving school which were unsuitable and inadequately supported, leading Jim to become withdrawn, depressed and isolated. He was dependent on family members taking time off work to be with him. This had an impact on the family income and wellbeing

Jim found out about The Usual Place and, following a great deal of encouragement in exploratory meetings with TUP staff, Jim joined the early enablement programme which provided for 1:1 Support in a step-down approach to enablement and increased confidence and personal agency.

Jim initially volunteered 1 day per week, building confidence, self-worth and skills .This development was enabled through 1:1 Mentor Support. After 6 weeks Jim increased this to 2 days and with further support and encouragement Jim chose to join the SVQ Hospitality Programme. The Usual Place worked with Jim and his family to enable independent travel from home to work.

Costs incurred working with The Usual Place (Hourly rates include NI, Pensions and core costs)

- Mentor 780 hours @ £11.16 = £8704.80
- SVQ Mentor 140 hours @ £11.16 = £1160.64
- Manager supervision 12 hours @ £19.80 = £237.60
- Set up and work placement meetings 12@ £19.80 = £237.60

Total £10,340.64

Potential costs avoided through work of the Usual Place

- 24 Additional GP appointments @£90 = £2160
- Potential 52 CPN appointments @ £35= £1820
- Potential 8 additional social work meetings @£35 = £280
- Potential 4 Multi agency meetings est. @ £1400 = £5600
- 2 attendances per week at day-care 52 @ £72 = £7488
- 52 weeks in supported accommodation @ £1552 = £80,704
- 52 weeks Universal Credit min @ £14,924

Total £112,976

Excludes option of parent's loss of income @£23,000 and consequential effects

Estimated potential net costs avoided through working with the Usual Place **£102,635**

Sources Early Intervention Foundation – Making an Early Intervention Business Case Evidence and Resources, PSSRU Unit Costs of Health and Social Care.

Evidence of progress

Jim grew in confidence and skills, learning to work well as part of a staff team and communicate effectively with customers, Jim required less and less support as his confidence grew reporting much greater overall wellbeing and a sense of purpose and hope.

Jim's family were delighted and reported that Jim now travelled independently around their small town, to the shops and to run errands and out to meet friends. Jim had also started driving lessons.

Successful outcomes

As Jim’s confidence grew, he decided to apply to volunteer with NHS D&G and now volunteers 1 day per week showing patients around the hospital and greeting people at the welcome desk. Jim has learned to drive and is confident to drive locally and is independent in transport. Jim has elderly grandparents and now takes them shopping during the week and helps at home. Jim’s family say the change in Jim is transformational and they can now work full time with no concerns about Jim at home.

Jim is about to start a work placement with a view to full time employment in 12 weeks at a local care home

Jim is happy, enjoying his volunteering and has made good friends in The Usual Place who he socialises with Jim says his health is now good and relationships at home are very good. Jim is also able to travel now and helps 3 elderly relatives stay at home by taking them shopping and using the skills he has learned in The Usual Place to help them around the house

Demonstrating impact of successful outcomes via Social Values

Improvement in confidence – Youth £9283

Relief from anxiety and depression – Youth £11819

Vocational Training - £1124

Regular volunteering - £3249

Member of a social group - £1850

Source - Housing Association Charitable Trust 2018

The values can provide a basic assessment of social impact, provide evidence of value for money, and compare the impact of different programmes**.**

The Usual Place

Sam's Journey

Sam was an Autistic young man in his final year at school. He lived in 24 hr supported accommodation and was a care leaver. Sam had spent the last few years in a variety of care facilities and arrangements meaning that Sam had experienced a very unsettled home and school life. Sam had been exposed to adverse childhood experiences from a very early age and was deeply troubled by the trauma in his life. Sam had no real family support and was isolated, lonely and increasingly fearful for the future. Sam had a great deal of support from Psychological and Psychiatric Services to enable him to learn to cope. Although Sam did reasonably well in his mathematics and computing exams, he did not see himself as being able to cope at College or at University.

Sam was introduced to The Usual Place by Support Staff from his supported accommodation who knew about the Usual Place. TUP staff met with Sam over a few weeks to find out about Sam's strengths and interests and to learn about Sam's communication preferences and career ambitions. It became clear that Sam had no interest in hospitality but did have interest in Admin and Finance and said he had once considered a career in business finance. Sam worked with the TUP team to develop a work experience programme that would enable him to gain confidence and self-worth, alongside the communication skills he wanted to achieve to help him in his home and future work life.

Sam showed excellent skills with the till in both the café and the shop. Using the till enabled Sam to build up confidence with people and communicating in a safe and predictable way, gradually increasing his comfort in 1:1 interactions with people he did not know. Sam also worked alongside TUP Admin Staff, assisting with administration and finance tasks. Sam quickly demonstrated a gift for finance and administration, and it was clear that this is where his ambitions lay.

Whilst in TUP Sam's mental wellbeing improved exponentially. He told TUP staff that he enjoyed the company, had made new friends and was growing in confidence in meeting new people and communicating. Sam stated that now his ambitions were to get a job, have his own home and learn to drive.

A local business leader was in the TUP and talking about their need for an Admin/finance Assistant and creating a Modern Apprenticeship opportunity. TUP asked if they would consider an Autistic young person with a real gift for Admin and Finance. They confessed fears in taking on an Autistic person in case their team could not provide the support needed.

TUP CEO explained the challenges that Autistic people can face, despite their gifts and value to the workplace. Low expectations, discrimination and negative attitudes lead to an impoverished life and poor mental wellbeing. She highlighted the differences positive employment can make to the life of an Autistic person

The Business leader reconsidered their position and asked to meet Sam and for TUP to assist the business should it be agreed to look at Sam's potential to take on a Modern Apprenticeship.

Costs incurred working with The Usual Place (Hourly rates include NI, Pensions and core costs)

- Mentor 780 hours @ £11.16 = £8704.80
- SVQ Mentor 140 hours @ £11.16 = £1160.64
- Manager supervision 12 hours @ £19.80 = £237.60
- Set up and work placement meetings 4 @ £19.80 = £79.20
  Total £10,182.24

Potential costs avoided through work of the Usual Place

- Potential for 6 Additional GP appointments @£90 = £540
- Potential 52 CPN appointments @ £35= £1820
- Potential 8 additional social work meetings @£35 = £280
- Potential 4 Multi agency meetings est. @ £1400 = £5600
- 2 attendance per week at day-care 52 @ £72 = £7488
- 52 weeks in supported accommodation @ £1552 = £80,704
- 52 weeks Universal Credit min @ £14,924
- **Total £111,356**

Estimated potential net costs avoided through working with the Usual Place **£101,174.**

Sources Early Intervention Foundation – Making an Early Intervention Business Case Evidence and Resources, PSSRU Unit Costs of Health and Social Care.

Evidence of progress

The Business Leader met with Sam on several occasions with TUP staff. Both Sam and the Business Leader had some anxieties but decided together on a trial work placement in the business.

The Business Leader asked TUP to provide some training to their staff team to enable the team to provide the best possible start for Sam.

TUP provided an enablement workshop developed to demonstrate that the staff team could all relate to being new to a workplace and remember what had helped them settle in. Sam had agreed that the CEO could share some information about Sam's gifts and what would enable Sam to best settle in. The workshop helped identify some of the additional challenges and solutions for an Autistic team member. The outcome was that the staff realised that they already had all the skills they needed to ensure that they could welcome an Autistic team member and enable their contribution and inclusion.

Sam joined the Business for work experience, which was a huge success for Sam and the staff team.

Successful outcomes

The Business team worked hard to make Sam welcome and to include him in the work of the organisation. Sam was quickly able to take on an independent workload, completing all tasks to a very high standard. Sam reported never having felt happier and the staff team told TUP CEO that they felt confident in employing and working with Autistic people in the future

Sam attended TUP 1 day per week to continue to build his social skills. Sam started driving lessons and moved to less supported accommodation in line with his ambition to achieve full independence.

Sam is now employed by the Business full time and volunteers for TUP where Sam will support the development of a new project designed to enable organisations to employ Autistic people with confidence.

Demonstrating impact of successful outcomes via Social Values

Improvement in confidence – Youth £9283

Moving from unemployment to full time employment - £14443

Feeling in control of life - £15894

Member of a social group - £1850

Relief from anxiety and depression – Youth £11819

Source - Housing Association Charitable Trust 2018

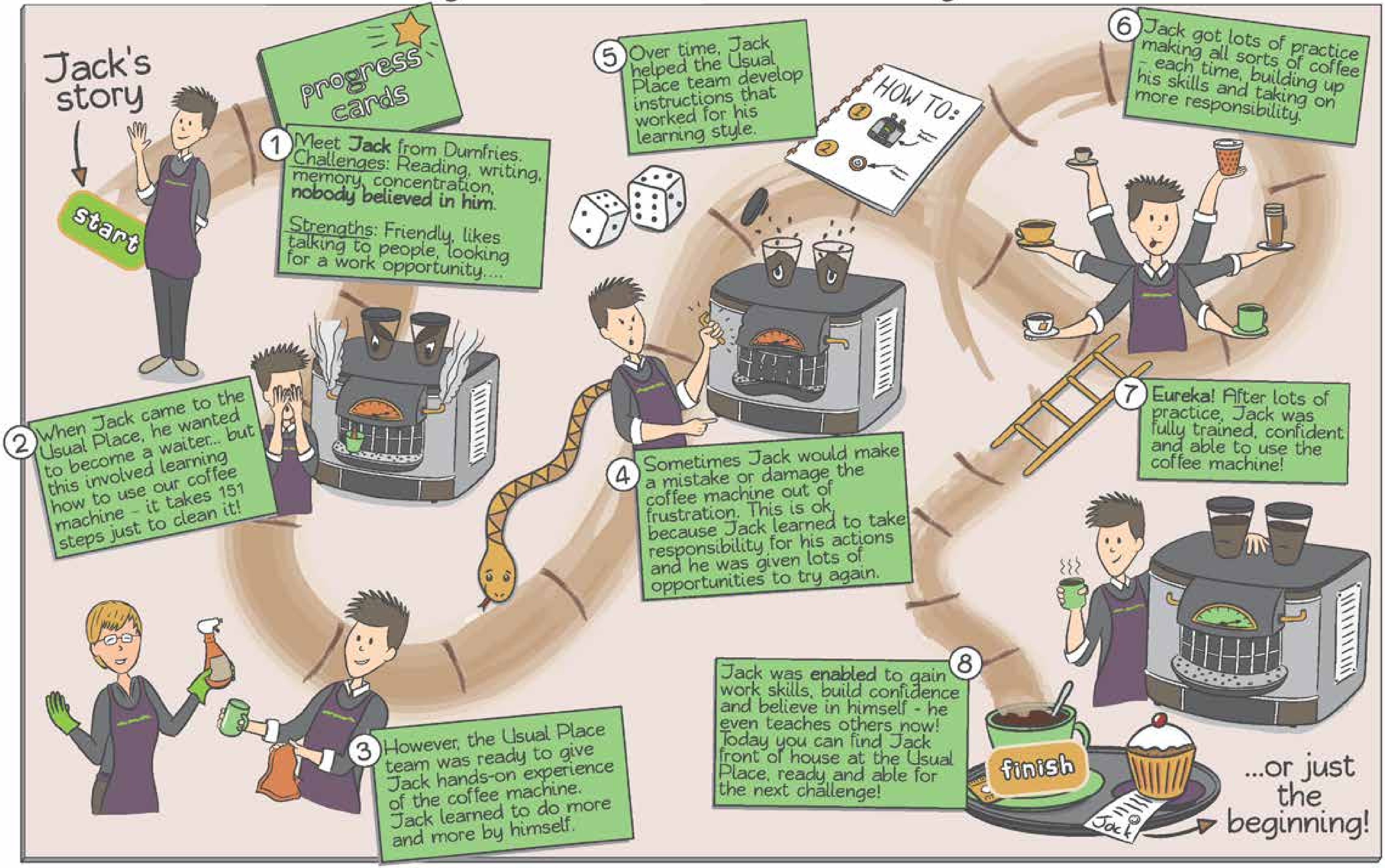
The values can provide a basic assessment of social impact, provide evidence of value for money, and compare the impact of different programmes**.**

The Usual Place

What is 'enablement'?

Building the confidence to do it yourself!

The keys to life



① Meet **Jack** from Dumfries.
Challenges: Reading, writing, memory, concentration, **nobody believed in him**.

Strengths: Friendly, likes talking to people, looking for a work opportunity....

② When Jack came to the Usual Place, he wanted to become a waiter... but this involved learning how to use our coffee machine - it takes 151 steps just to clean it!

③ However, the Usual Place team was ready to give Jack hands-on experience of the coffee machine. Jack learned to do more and more by himself.

④ Sometimes Jack would make a mistake or damage the coffee machine out of frustration. This is ok because Jack learned to take responsibility for his actions and he was given lots of opportunities to try again.

⑤ Over time, Jack helped the Usual Place team develop instructions that worked for his learning style.

⑥ Jack got lots of practice making all sorts of coffee - each time, building up his skills and taking on more responsibility.

⑦ **Eureka!** After lots of practice, Jack was fully trained, confident and able to use the coffee machine!

⑧ Jack was **enabled** to gain work skills, build confidence and believe in himself - he even teaches others now! Today you can find Jack front of house at the Usual Place, ready and able for the next challenge!

The Usual Place and Dumfries Theatre Royal

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The Dumfries Arts Award Project: towards building a programme theory of innovation transfer across two social organisations

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Abstract

Purpose – The purpose of this paper is to critically understand a programme theory of the "transfer" of work in one social organisation and sector (an innovative and successful social enterprise community café, The Usual Place that seeks to enhance the employability of young people with additional support needs in "hospitality") to another (Dumfries Theatre Royal, a regional theatre and registered charity, specifically the "Dumfries Arts Award Project" and more generally, "the arts").

Design/methodology/approach – By means of gaining insight into the complexity of the transfer of innovative practices between two socially oriented organisations and theoretical insights into associated conducive contexts and optimal processes, the work used realist evaluation resources within a longitudinal ethnographic approach. Within this, a series of specific methods were deployed, including semi structured key stakeholder interviews, non-participant observation and "walking" and "paired" interviews with service users in each organisation.

Findings – The principle finding is that with attention being paid to the context and intervention processes associated with transfer processes and having sufficient capacity and strong partnership working, it is possible to take an innovative idea from one context, transfer it to another setting and have relatively immediate "success" in terms of achieving a degree of sustainability. The authors propose a provisional programme theory that illuminates this transfer. They were also able to show that, whilst working with the potentially conservative concept of "employability"; both organisations were able to maintain a progressive ethos associated with social innovation.

Originality/value – The work offers theoretical and methodological originality. The significance of "scaling up" social innovation is recognised as under-researched and under-theorised and the use of a realistic evaluation approach and the associated development of provisional programme theory address this.

Keywords Social innovation, Realistic evaluation, Policy transfer and translation

Paper type Research paper

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Introduction

Many have conceived of shifts in the direction of social policy since the 1990s as transformative "turns" (UNRISD, 2016). Such ground has expressed various aspirations including, seeking social justice, promoting universalist and rights-based approaches and pursuing more inclusive and participative policy processes (Koehler, 2017). In this context, this paper reports on a project drawing on some of these resources – a desire for "social innovation" (Ayob *et al.*, 2016), the role of "social enterprise" (Monroe-White and Zook, 2018) and the potential of "inter-organisational transfer" (Battistella *et al.*, 2016).

Funded by the European Social Fund/Scottish Government's "Social Innovation Fund" (SIF) and The Holywood Trust and undertaken between February 2018 and June 2019 by a practice/academic partnership in Dumfries and Galloway (D&G), south-west Scotland, the project involved an exploration of the potential inter-organisational "transfer" of values and practices for a particular group [young people with additional support needs (ASN)] in an innovative social enterprise to another socially oriented organisation. This "source" organisation, who acted in a mentoring role throughout the project was *The Usual Place* (TUP), an established community café that seeks to enhance their trainees employability, remove barriers to attaining paid employment and promote social inclusion. This is achieved through a nuanced mix of café work placements, intensive needs-led support and externally accredited vocational qualification ("Scottish Vocational Qualifications" - SVQs).

The "target" organisation was Dumfries Theatre Royal (DTR), a regional theatre and registered charity chosen because of an existing informal relationship between TUP and DTR and a belief that there was both congruence in ethos and the possibility of extending the remit of TUP's employability work to young people with ASN interested in the arts. This was branded the "*Dumfries Arts Award Project*" (DAAP) and was enacted by a SIF-funded "Project Manager" (responsible for administration) and "Project Officer" (responsible for delivery). The project was undertaken using the Trinity College, London/Arts Council England "Arts Award" qualification. An appraisal of this process was undertaken by researchers from the University of Glasgow (UoG).

Central to the significance of this project is the problematic social status of people with ASN (Quarmby, 2011). Their life expectancy is 15–20 years shorter than the general population (University of Bristol, 2017), their physical health significantly poorer (IHE, 2018) and they are more likely to experience psychological problems (Hatton *et al.*, 2017). It is also recognised that people with ASN disproportionately experience exclusionary forces (IHE, 2018, p. 13). Of specific interest, the employment status of people with ASN is particularly disadvantageous; the employment rate of people with disabilities at 50.7% compared to 81.1% for the general population with those aged 16–24 experiencing an even lower rate of 38.2% (House of Commons Library, 2018).

In keeping with the "transformative" turn established above, these circumstances have prompted calls for actions directed at what are perceived to be non-universalist, low rights circumstances and the injustices that follow (Scior and Werner, 2015). A series of measures have been proposed, ranging from enhancing access to health services (for example, an annual health check) through to more profound "anti-poverty" strategies that address the structural roots of social exclusion (IHE, 2018). Enhancing employability is seen as particularly effective in achieving these latter goals (Lindsay, 2011), gaining recognition within Scottish policy (SCLD, 2016). The Government's strategy for learning disabilities, *Keys to Life* (Scottish Government, 2013) has four strategic outcomes: "a healthy life", "choice and control", "independence", and "active citizenship" – including "facilitating employment opportunities" (Smith, 2018, p. 1). In line with fostering inclusive participation, this ground suggests approaches that: promote what people *can* do (not what they cannot); deliver needs-led, tailored training opportunities with 1–1 support in *various* workplaces; and nurture a wider "joined up" system, populated by a *range* of employability-related organisations (Scottish Government, 2013).

Located in the increasingly prominent "Work-Integration Social Enterprises" (WISE) context that suggests the particular suitability of social enterprise models (Vidal, 2005) and social innovation (Roy *et al.*, 2014) in promoting employability, over the past five years and with employability as its founding *raison d'être*, TUP has aligned itself with these principles, creating a place that Power and Bartlett (2018; 337) see as a "bespoke space" and "welcoming community" for young people with ASN. So, in summary, the project sought to explore the potential for complex innovative work in one socially oriented organisation to be successfully transferred and sustained to another novel socially oriented organisation.

Exploration of this ground was initially based on the localised foundational research questions:

RQ1. What core features within TUP are significant and necessary for transfer?

RQ2. What CMO configurations are significant in the transfer of these features?

Insights from these grounded observations informed two broader questions:

RQ3. To what extent can transfer of innovative practice be achieved between two socially oriented organisations?

RQ4. To what extent can the progressive orientation of these organisations be maintained in this transfer?

Empirical work was constructed around three components: a capturing of the nature of the work being undertaken in TUP and an assessment of initial perceptions of the nature and feasibility of any TUP/DAAP transfer; grounded observations of the implementation of DAAP in DTR; and a concluding synthesis of these insights.

The observations reported here have value and originality in two respects. First, they exist in a context described by Monroe-White and Zook (2018, p. 506) as often "anemic", lacking critical scrutiny of the theoretical and empirical basis of social enterprise as inherently "innovative". As such, Jessop *et al.* (2013, p. 111) note a narrow "reductive interpretation" of social innovation, with a tendency to rely on affirmative "wisdom of practice" perspectives (Sinclair and Baglioni, 2014; 472). Our exploratory work addressed this by adopting a theory informed, longitudinal and interpretative approach (Ayob *et al.*, 2016). Second, whilst the social innovation/enterprise literature occasionally alludes to notions of practice "transfer" (Moulaert *et al.*, 2013), some point to the difficulties of actually achieving this in "non-market" and complex circumstances that involve "a new process, or a new way of organising production activities" (Borzaga and Bodini, 2012, p. 8). Others also suggest that little attention has been paid to this matter (Phillips *et al.*, 2019). As such, our use of resources from the "inter-organisational transfer" literature (Battistella *et al.*, 2016) provides novel insights. Given these deficiencies and the complexity inherent in both the delivery of innovative practice *and* its transfer, we felt that a realist evaluation approach (Pawson and Tilley, 1997) would be most suited to these circumstances, allowing us to develop a programme theory of the multiple interactions taking place within and between the social organisations.

The paper outlines various conceptual resources relevant to our project, describes the methodology that was used, sets out and reflects on our key empirical findings and explores wider implications that flow from these insights.

Conceptual resources

In its instigation, three related conceptual bases were important to the project and formed an explicitly "theoretically informed" approach (ICEBeRG, 2006). These were "social enterprise" (in relation to the socially oriented nature of our two case organisations); "social innovation" (in relation to our SIF research), and the potential within these contexts for "inter-organisational" transfer (the basis of our SIF proposal). These themes informed practical project work, shaped the various forms of data collection undertaken and ultimately, influenced the way this data was analysed and understood.

Primarily, we saw "social innovation" as our over-arching aspiration, whose fulfilment can potentially be optimally achieved by "social enterprise" models (Phillips *et al.*, 2015). The core normative notion of "originality" within "social innovation" literature is naturally prominent; for example, Ayob *et al.* (2016, p. 637) see it as offering the possibility of "generating *new* ideas and in delivering *new* solutions". The simple ability of "meeting a social need" has been one way of characterising innovation (Mulgan, 2006, p. 146), the products of it being only *one* element in an existing market economy. Furthermore, some see social innovation as a defensive means of patching over various health and social "crises", filling gaps from the withdrawal of "the State" and/or offering cheaper alternatives (Moulaert *et al.*, 2013).

Alternatively, others see a desire for innovation as arising from a fundamentally different set of values (Jessop *et al.*, 2013), antithetical to the above conservative expediency (Sinclair and Baglioni, 2014). For example, the *process* by which innovation occurs is made central (Sinclair and Baglioni, 2014) and shaped by the view that certain features are essential, including that they: are underpinned by "collectivist" and "mutual" principles (Ayob *et al.*, 2016); offer the potential to challenge prevailing service delivery systems (Montgomery, 2016); potentially re-orientate existing power relations, (Ayob *et al.*, 2016); ultimately resulting in 'transformational' social change (Sinclair and Baglioni, 2014). These aspirations have been located in a "democratic" frame and a contention that, "the satisfaction of basic needs cannot be guaranteed through either market al.location mechanisms, or free-market democracy" (Moulaert and Nussbaumer, 2005, p. 50). As such and of most significance to this paper, some see social innovation as being a particularly relevant model in meeting, "alienated needs [. . .] raising participation levels [. . .]. of marginalised groups" (Montgomery, 2016, 1991).

The related concept of 'social enterprise' and its central feature of the "primacy of social aims" via "trading" (Teasdale, 2011, p. 101) is seen as *one* way of achieving "social innovation" (Sinclair and Baglioni, 2014) and conceptually it displays variability along similar lines (Teasdale, 2011). Some suggest that social enterprise is inherently innovative (Chell, 2010), this contention being supported by both theoretical (Phillips *et al.*, 2019) and some empirical (Monroe-White and Zook, 2018) evidence. In this sense, social enterprise *can* have the potential to fulfil the progressive ambitions outlined above. Again, the potential for progressive social entrepreneurship to drift towards conservatism is however noted (Dey and Steyaert, 2012).

Beyond these bases, the notion of inter-organisational "transfer" was a central concern that can be seen as, "an active process during which the technology (and the knowledge related to it) is transferred between two distinct entities" (Battistella, *et al.*, 2016, p. 1196). Practically, various "objects" of transfer are suggested, including: policy goals; structure and content; administrative techniques; institutional arrangements; and various values and attitudes (Dolowitz and Marsh, 1996, pp. 349-350). Mavra (2011, p. 5) establishes various rationales for seeking "replication", spanning the pragmatism of looking to "scale up", diversify and increase income to wider aspirations of spreading socially innovative practices and "message(s) of the social enterprise movement" (Mavra, 2011, p. 5). Mavra (2011) goes on to posit a range of degrees of "replication", from "franchising" and "licensing", to a softer "collaboration", involving "informal partnerships and resource pooling" (Mavra, 2011, p. 5). Some see this process as being made up of two phases (Nicholls and Murdock, 2012). First, a creative "ideational" one, emphasising the mobilisation of knowledge from a range of stakeholders (Phillips *et al.*, 2019) as part of a "communicative process" (Park *et al.*, 2017, p. 6). Second, an "implementation" phase is suggested, where innovative ideas are enacted with a view to, "embedding effective and sustainable social enterprise and social innovation" (Sinclair *et al.*, 2018, p. 1317). In this context, Hartley and Benington (2006) propose variables that can facilitate or impede translation, including: features in the "originating" organisation that will suggest whether it *can* communicate knowledge; the quality of the articulation process itself; and an ability to recognise and *use* knowledge in the recipient organisation. This territory suggests the significance of relational and potentially transformational interactions (Hartley and Benington, 2006, p. 103). Significantly, some have pointed to the tendency for transfer processes to be relatively functional and driven by rudimentary transactional models of change (Park *et al.*, 2017).

Methodology

In order to establish a strong ontological foundation and as suggested above, our research approach was informed by the use of "realistic" approaches (Pawson and Tilley, 1997) as an analytical tool and a desire to ultimately build a provisional programme theory of the transfer. This theorises the outcomes of interventions being one manifestation of "CMO configurations" involving, interplay between "context" (policies and priorities related to employability and young people with ASN) and "mechanisms" (both the "stand-alone" internal workings of TUP and DTR *and* the specific dynamics of the transfer processes). Koenig (2009, p. 10) sees this resource as particularly compatible with the subtleties of case studies and "the capacity of a "critical" case study to sustain theory building" – here, not simply asking *has* transfer happened, but *how* it has been done (or not).

The nature of the organisational circumstances then suggested the use of an ethnographic approach (Hammersley and Atkinson, 2007). This orientation was felt particularly suited to our study research questions in that it allowed data collection to be guided by conceptual resources, whilst acknowledging the importance of the grounded cultural features within TUP and DTR. Furthermore, this ethnography drew on "critical realist" resources (Porter, 1993) that allowed us to recognise the potentially complex and contested nature of "reality" in TUP and DTR whilst also arriving at pragmatically useable end points (Barron, 2013). Hartley and Benington (2006, p. 107) see this as being particularly useful in understanding processes of *translation* – with, "close participant observation and engagement by the researcher, within organizations and networks [. . .]. illuminat(ing) the subtle factors which explain why knowledge transplants". This was enacted by having a UoG researcher located in both TUP and DTR, undertaking data collection in various forms (see below). Furthermore, the work was structured as a "locality" case study (Aaltio and Heilmann, 2009), allowing the possibility that insights might be "telling" beyond this particular case (Mitchell, 1984).

Data collection was undertaken in 2 phases and sought to develop comprehensive perspectives by accessing insights from a wide range of informants (internal staff within TUP and DTR, the young people working in TUP and DAAP and various external stakeholders). Phase 1 was concerned predominantly with TUP in order to build up an in-depth picture of their model and understand the means by which they have been seen to successfully promote trainee employability and social inclusion (Table 1).

Method	Participants	Details
'Walking' Interviews	17 trainees from TUP	Walking interviews are a form of a participant observational method whereby the researcher walks and interacts with participants during an interview in a natural location. This work helped to build rapport with young people at TUP and gain deep insights into the grounded experiences trainees had in TUP Offered particular insights into 'mechanisms' and 'outcomes'
'Paired' Interviews	9 trainees from TUP	Trainees from TUP attended a training session in which the basic principles of conducting interviews were explained and the young people also devised the questions that were asked Trainees interviewed each other about their experience at TUP, with support from the research team (2 interviewers – 1 interviewee). Offered particular insights into 'mechanisms' and 'outcomes'
Semi-Structured Interviews	17 Stakeholders (6 Internal and 11 External) Interview schedule structured around resources pertaining to CMO configurations and theories of 'transfer'. Internal stakeholders included senior members of staff at TUP (CEO, COO, Chairperson); key individuals within DAAP (DTR Director, Project Manager and Project Officer); various external stakeholders (SVQ assessor, a parent of a trainee, local MSPs, employees from D&G Council and disability organisations)	Used to gain an understanding of TUP's position within the community and its strengths and weaknesses. Insights into early expectations for DAAP and early transfer were also sought Offered insights into 'contexts', 'mechanisms' and 'outcomes'

Table 1.
Research conducted which focused predominantly on TUP (June–Sept 2018)

Phase 2 involved further stakeholder interviews and grounded observations of the implementation of DAAP within DTR (Table 2).

Different aspects of this data offered insights into different parts of our CMO configuration: perceptions of "context" came particularly from historical recollections from stakeholder interviews; insights into delivery and transfer "mechanisms" also came from these interviews but were strongly complemented by trainee's grounded experiences gleaned from walking and paired interviews; and perceived 'outcomes' were drawn from all aspects of data collection (as well as routine TUP and DTR data sources).

Analysis was undertaken within each of these strands throughout the project using a form of "thematic analysis" (Braun and Clarke, 2006) where data was classified into categories, reduced and arranged into manageable forms and patterns developed and substantiated. Using guidance offered by Morse *et al.* (2012) on the notion of achieving "verification" via a series of phases that progress from data confirmation to theory building, a form of analysis was particularly prominent in the concluding part of the work that involved a series of knowledge exchange workshops between researchers, TUP and DTR participants, the young people and wider stakeholders. Here, provisional reflections were interrogated and eventually amended in

Method	Participants	Details
Semi-Structured Interviews	5 internal stakeholders and 1 external stakeholder Interview schedule structured around resources pertaining to CMO configurations and theories of 'transfer' Stakeholders included: the Chief Executive Officer and the Chairperson of TUP, the Project Manager and Project Officer on the DAAP, and the Director of DTR. A parent of a young person attending DAAP was also interviewed	Conducted almost a year on from the creation of DAAP, this work reflected on the pilot year by exploring the nature of this transfer to date, reviewing its implementation and analysing the success and difficulties of the programme Offered insights into 'contexts', 'mechanisms' and 'outcomes'
Outcome star and accompanying notes	Trainees on the DAAP	Trainees' outcome stars and accompanying notes were used to gain an insight into their experience on the first 12 weeks of the programme from their own perspective. Areas explored included: transferrable skills, theatre knowledge, confidence, inclusion, hope for the future and feeling that their work is helping DTR Offered insights into 'outcomes'

Table 2.
Research conducted which focused on the DAAP (Oct-Dec 2018)

an inclusive way. Subsequent finalisation of empirical themes in relation to our theoretical bases was again done collaboratively within the core project team.

Key findings

The following section addresses the first two of our research questions; a grounded review of the key CMO features within TUP and DTR relevant to transfer.

Context: conducive policy and empowered communities

As the "source" organisation, two contextual features within TUP were particularly significant. The first was what John Kingdon terms a "policy window of opportunity" (Kingdon, 1995); the generalised recognition in formal policies such as "Keys to Life" of a "social need" for opportunities to enhance the employability prospects of young people with ASN – a perspective that could be considered as having been traditionally unheeded. Many stakeholders within both TUP and DTR highlighted the generally hostile economic climate that this work was being undertaken in and a paucity of such opportunities for young people with ASN in D&G a parent of a young person with ASN who is now a TUP trainee highlighted the social isolation their child had experienced when leaving school and that *employability support was almost non-existent*. Whilst this might suggest the very *need* for a response, some within TUP and DTR acknowledged these difficult circumstances as making "employment-related" interventions practically challenging and possibly insubstantial given the hostility of the environment.

The second was a local articulation of this "need" within D&G. The specific origins of TUP lay in a conference in 2011 ("Youth Matters: what needs to happen for me to reach my full potential"), where frustration over these circumstances was expressed by young people and a desire for innovative and equitable employability approaches articulated; for example, a health professional delegate felt:

> [. . .] at the end of that conference [. . .]. What they told us was they wanted exactly the same as any other young person [. . .]. a career [. . .]. jobs [. . .]. To be able to go to college [. . .] a future [. . .] but they just couldn't access it as easily as anybody else.

With respect to CMO configurations within DTR, informants were clear that the founding of DAAP within DTR was facilitated by drawing upon the same conducive contextual policy resources described above that TUP had originally exploited; for example, a DTR informant suggesting, "in many ways [. . .] TUP had made the case for this type of work that we could use".

Mechanisms: strong leadership and supportive organisational values and culture

Returning to TUP as the 'source' organisation in the transfer, three 'mechanisms' were identified as being crucial to the successful establishment of TUP and its ultimate sustainability. First, determined leadership was considered to have been a significant driving force across all informants. Those from outside TUP (local politicians and local authority officers) cited various attributes such as "belief", "ambition" and "determination" to 'sell' the innovation; one of these stakeholders (a politician) suggested, "I don't think I've ever met a more determined group of individuals in all my life". This resolve was also recognised within TUP, a senior worker suggesting, "we just went to people and said we want your help [. . .] . this is the situation [. . .] [. . .] we know we can make a difference here". Additionally, a more critical ethos towards what was perceived to be a prevailing disinterest in the needs of young people with ASN was also evident, an internal TUP stakeholder stating:

> [. . .] we feel quite able to challenge [. . .] we did get turned down for some funding from the Scottish Government and we invited them to come down and speak to us [. . .]. we're not happy about this [. . .] tell our young people that you're not going to fund this [. . .]. and when they came down they reversed their decision.

This willingness to act as wider advocates was thus identified as an increasingly prominent feature of the work done by TUP, linking the grounded experiences of their employability concerns to the general status of young people with ASN in society.

Another feature of TUP leadership often cited was their 'reflexivity' – an ability to accept feedback and willingness to adopt new ideas. An external stakeholder (local politician) talked of how TUP leaders were constantly reviewing their systems, "at both micro and macro levels" and this leadership approach was confirmed by an internal TUP stakeholder stating, "we're not precious about anything [. . .]. we're happy to take comment [. . .]. to learn from anyone [. . .] we can work with imperfectness".

This ground leads on to a second mechanism -that of an organisational "ethos" and associated "values". TUP was founded on three such tenets: "everyone can contribute", "everyone is of equal worth" and "everyone should be treated with dignity and respect" and they find continual expression in both the strategic direction of the organisation and its day-to-day work; for example, an internal TUP stakeholder suggested, "we really believe as an organisation that if you keep your core values at the heart of everything you do [. . .] you're not going to stray too far from that". Many also expressed a belief that this was a "whole organisational approach" (a TUP informant) articulated across paid staff, volunteers and trainees alike; for example, an internal TUP informant felt, "I would expect every member of staff [. . .] for that to be tripping off their tongues [. . .]. not as words [. . .]. it's what we do [. . .] creating a value-based culture".

The final mechanism was what participants described as the fact that TUP "is a real café" (a DTR informant). Many expressed that the "social purpose" basis of the café was not explicitly conveyed to customers, one DTR informant feeling that TUP "don't go for the sympathy vote". This "authentic" orientation was considered central to creating "true to life" experiences for trainees, expressed by a TUP internal informant as:

> [. . .] they're having to interact with the public [. . .] these people who have been shied away for however many years and stuck in a separate classroom at school or in college [. . .]. They're now having to work in a public domain [. . .] (and) because it's happening in a natural way [. . .]. I think both attitudes are changing for the better.

As well as these productive features, a series of issues related to mechanisms were highlighted as significant to potential transfer. First, as with many social enterprises, funding was cited as an ongoing challenge. Although the café does make some profit, external funding is still required to sustain the organisation and allow its social goals to be achieved; this being in the words of a senior TUP informant, "a constant fight". The variety of funding sources and associated demands for evidence was also seen as challenging, an internal TUP informant suggesting, "we have to fit into people's funding guidelines [. . .] so sometimes we've had to change aspects of what we do [. . .] to get the funding we need to carry on".

Second, some highlighted the delicate balance that exists within TUP between sustainability based on some external funding and the possibility of it moving towards being a more "free-standing" (TUP informant) business. Accepting this tension between ambitions to grow as a business and the effect this may have on maintaining its social goals, a range of suggestions from across all informant groups were made on how TUP might enhance its status as a commercial business, including: extending opening times and utilising weekends; widening the range of functions undertaken to include events such as weddings; and offering paid consultancy to other Third Sector organisations.

Third, despite acknowledgment that the exposure the local community has had to young people with ASN in TUP had resulted in positive changes in attitudes towards this group (as a form of 'inclusion'), it was felt that some societal orientations were still challenging. One TUP participant reflected on this, "I think attitudinal stuff is a challenge [. . .] our young people say that it's the biggest challenge [. . .] attitudes towards them". The views of some local employers were considered particular problematic in terms of employing young people leaving TUP, one internal TUP informant suggesting, "getting businesses on board was very hard [. . .] a lot of businesses were probably scared by what it could entail".

Our exploration of the transfer of 'mechanisms' was conducted at two points: an early 'concept testing' appraisal, followed by a deeper review later in the transfer process. In the foundational work, most stakeholders within TUP and DTR expressed confidence for the *potential* of transfer. The notion was seen as a fundamentally robust one, many expressing the potential the 'arts' sector has in fostering the same developmental outcomes achieved in TUP; a DTR informant believing, "all drama is very good for young people [. . .] it builds confidence [. . .] encourages empathy by putting yourself in someone else's shoes". It was also felt that the 'public-facing' asset of TUP was one that was replicable within DTR, a DTR stakeholder suggesting, "it offers people an opportunity [. . .] to be part of something in the community". In a wider sense, the creation of DAAP was seen as an opportunity for mutually beneficial partnership working between the DTR and TUP. This had been instigated by means of an 8 week induction placement that the DAAP Project Manager and Project Officer undertook within TUP with the aim of immersing and familiarising them with the practices and cultures of TUP.

At the same time, a series of potential challenges were identified. Most immediately, the short-term nature of the SIF funding suggested the need for project initiation and embedding to be done relatively quickly. Practical concerns over having the basic capacity to deliver this complex programme were also expressed. It was felt that having only two staff members might limit the scope of the project in terms of how many young people could actually enrol; for example, a DTR stakeholder suggested, "we feel that we should have two project workers on the project [. . .] . should always be present with the young people".

It was also recognised that DAAP was being implemented in an established organisation with historical, structural and cultural features that would not necessarily be compatible with DAAP innovation. Potential resistance was felt to be possible due to a lack of experience of working with people with ASN [from a TUP informant, "the main barrier is the people that they'll be working with in the theatre [. . .] not being used to working with young people with additional support needs"] and organisational traditionalism [again from a TUP informant, "the biggest challenge is overcoming the inertia of an existing place [. . .]. having its own way of doing things [. . .] doing things differently"]. The need to quickly build support for the project across the whole of DTR was therefore seen as crucial, particularly using the local reputational 'capital' that TUP had in fostering the required cultural re-orientations. A TUP stakeholder saw this DTR scenario as requiring "leadership [. . .] to take the theatre with them".

Beyond these pragmatic concerns, two broader themes were reflected on in this preliminary context. The crux of the 'transfer-translate' relationship expressed in the academic literature was articulated. The notion of simply 'transferring' the TUP model was universally seen as inappropriate; for example, an informant from within DTR felt:

> [. . .] what we got from The Usual Place was a framework [. . .] [. . .] they're not so precious that we can't adapt it and tweak it as the theatre approach would need" and "they've been great really [. . .] of saying to us [. . .]. This is what we do [. . .]. But now it's all very much about you [. . .] learning what works for you in the theatre.

However, there was also a consensus that the one feature that *should* be transferred was the TUP *culture* and associated *values* (from TUP sources). A TUP informant captured this as, *I suppose it's about value transfer [. . .] what I hope is that the Arts Programme will be able to pick up our values and culture [. . .] in a way that works within that organisation.*

In the second part of the review conducted 6 months later, at a point when significant DAAP development had occurred, a number of actual 'mechanisms' from the TUP model were considered to have been directly transferred to the DAAP. The most prominent consisted of the more intangible aspects of the model that can be seen to align with TUP values. For example, it was felt that an accommodating approach, in which individual capabilities of the young people are not pre-determined had been directly incorporated into DAAP practice, a DTR informant suggesting, *that's been transferred [. . .] that sense of [. . .] let's not make any assumptions about what people can do.* Similarly, the TUP leadership style, based on inclusion and equality was also seen to have been integrated within DAAP, again a DTR informant expressing, *there's been a collaborative leadership approach [. . .] everything that we've done we've said to the young people [. . .] you must tell us if this is working for you [. . .] not working for you.* On a more practical basis, TUP had provided various hands-on insights and materials on for example, fostering volunteering, health and safety and safeguarding policies.

The grounded 'front facing' TUP mechanism was also transferred, the tasks undertaken by DAAP trainees being both firmly pragmatic [a DTR informant suggesting, *everything the young people do is real [. . .] they haven't done anything pretendey*] and integrative [a DTR informant stating, *we've managed to get 8 trainees embedded in the organisation [. . .] they really are doing the jobs everybody else does*]. This engagement was considered to have had a positive effect on the wider organisation, acting as a prompt for making DTR more inclusive; for instance, during the implementation period, DTR held its first ever 'relaxed performance' pantomime. A DTR informant attributed this innovation to the DAAP, stating, *that would never have been done if it wasn't for the arts award.* Two specific transfer 'processes' were seen as underpinning such success. First, a number of informants identified the extended induction time the DAAP project staff spent in TUP at the onset of the project (seen by a DTR informant as an "immersed experience") as crucial in fostering this part of the transfer, particularly intangible service values; a DTR informant cited, "I think that that was an invaluable experience [. . .] I learnt a lot in those 8 weeks [. . .]. The way that the Usual Place work with young people and I brought a lot of that with me". Second, particularly in the early 'ideational' phase of the work, the monthly steering group meetings with project partners were universally commended for fostering trusting relationships and enabling effective communication; a TUP informant suggesting, "[. . .]. I think bringing everybody together has been really effective".

At the same time, many recognised that a number of aspects of the TUP model had more precisely been "*adapted*" in DAAP (DTR informant) to fit the existing organisational context of DTR. Three examples were pertinent. In relation to values, whilst as a discrete initiative, DAAP aligned itself to many TUP principles, these values were accommodated *alongside* DTR's existing codes of conduct and organisational values. DAAP trainees were expected to conform to *both* of these sets of principles. Some of the practicalities of project delivery were also modified. For example, the length and format of the TUP induction process where trainees experience different aspects of the theatre was felt to be inappropriate to the circumstances within DTR and was significantly shortened and simplified. Finally, DAAP's engagement with external partners was also different. For example, whilst TUP has significant links with D&G's 'Totally Access Point' (DGTaP) - a public/private/third sector partnership that fosters access to employment and had helped trainees transition from TUP to mainstream employment - the more complex and profound needs that DAAP trainees had meant that this aspiration was not so immediate and as such, this link was not so significant. So, although DAAP does have a strong focus on building employability skills, it was quickly recognised that the needs of some individuals on DAAP differed from those at TUP and efforts were made to signpost trainees to more appropriate goals, such as internal DTR workshops.

Related to some of the "mechanisms" issues identified above that TUP had faced, two fundamental challenges to transition were identified. The most significant was an organisational one – the fact that the TUP informed DAAP model was being introduced into an *existing* establishment, captured by a TUP informant, *we started from new [. . .] they're having to go in and change the old.* The second was a more practical one based on the nature of support actually given to the young people. Whilst the size and multi-faceted nature of TUP resulted in support being extensive and varied, it was felt that the more focussed scope of DAAP meant that assistance came from a relatively limited group – predominantly the two project workers and captured by a DTR informant as, "they'll certainly see the two support workers doing all the tasks all the time [. . .] but they may not get to be working alongside everybody on all trades".

One of the main consequences of such circumstances was that some problems emerged in relation to the integration between DTR staff/volunteers and the young people. Some felt that DTR staff could have been more clearly informed about DAAP; for example, a DTR informant felt, "if we had done more communication [. . .] people would have been quicker to be more comfortable working with people" and as such, one DTR participant talked of "a hidden separation". Furthermore, a range of operational barriers to sustainability were identifiable within DTR, including: problems in quickly recruiting trainees [“it took us a little bit of time in the initial stages just to recruit and get the word out there” (DTR comment)]; concerns over adequate staffing levels and subsequent programme capacity [if both project staff were absent at the same time the programme would “run into the ground quickly” (DTR comment)]; the notion of programme activity straying into mainstream DTR work, [couched as “project drift” (DTR comment]; and concerns over longer-term funding sustainability [“I would be concerned about there being enough funding available to do this kind of this high level support” (DTR comment].

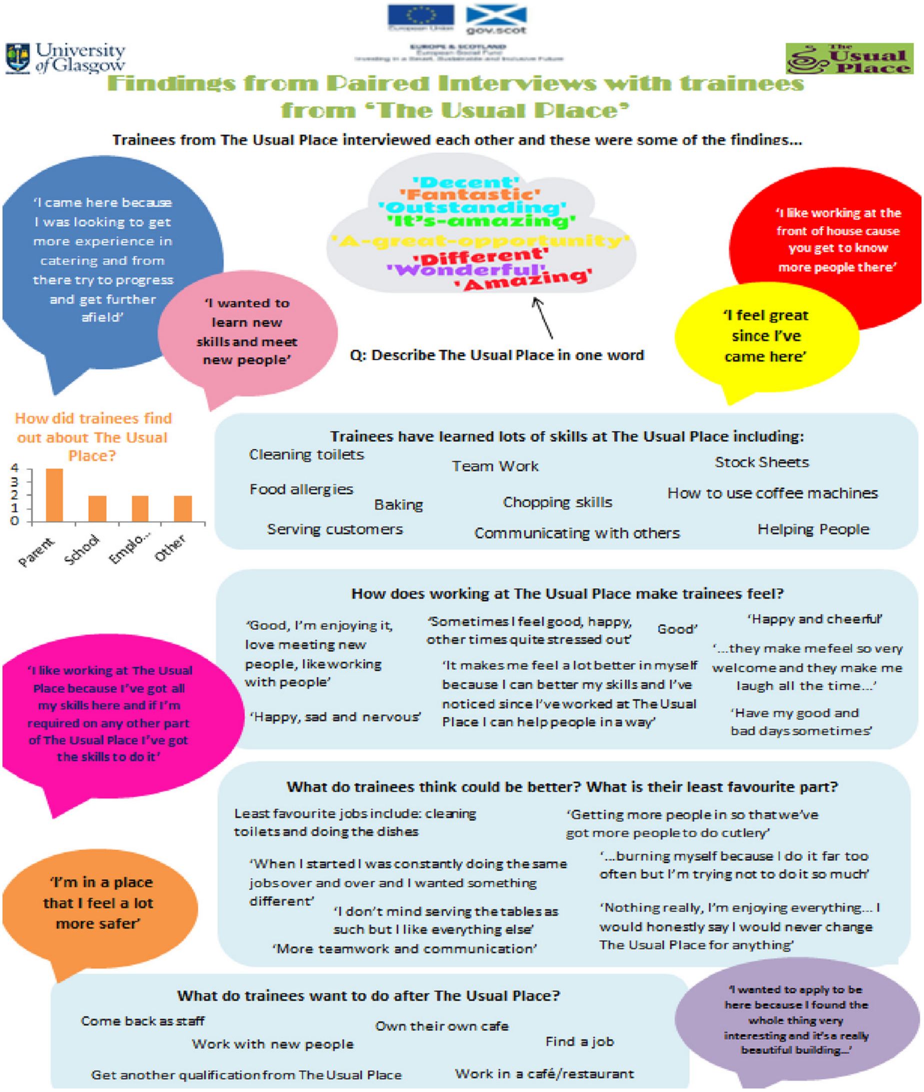
Outcomes: individual and collective

The final element of the realist model involves understanding the outcomes that arise from the interaction of contexts and mechanisms in each organisation. In relation to TUP, a series of tangible achievements were visible, for example: the numbers gaining SVQ and associated awards (such as first aid and food safety qualifications); those leaving TUP and gaining employment in other organisations (including becoming self-employed); and those going into modern apprenticeships and further education. A range of more complex outcomes were also cited; for example, enhancing wellbeing and promoting social inclusion. Here, TUP informants highlighted growth in the notion of “confidence” in the trainees, associated with the conducive social environment described above; and this was confirmed by an external DTR stakeholder who felt, “it’s great to see the work that they are doing with the young people [. . .] their confidence has just grown because of the work they do”.

The interactive aspect of the work involving ‘walking’ and ‘paired’ interviews also provided rich insights into the experiences and outcomes of the young people. This work highlighted the wide variety of tasks and related learning that was on offer spanning, the kitchen, front of house, shop/retail and general facilities management. Conducive features of the TUP environment not identified by stakeholders were also highlighted, including: the general ‘calming’ nature of the café setting; the ethos of ‘equality’ and involvement; the ability for there to be flexibility over the types of tasks being required of them; and the accessibility of the building. Similar themes arose within the ‘paired’ interviews, which we presented as an accessible infographic (Figure 1).

Outcomes were also felt to extend beyond trainees. As discussed above, many felt that the “*front facing”* nature of TUP (TUP informant) and its “real café” status (DTR informant), created an environment in which constructive interactions between those with ASN and the public that otherwise would not have been possible. This was linked to both creating a situation where ‘enablement’ was prominent (a TUP front line worker suggesting, “the trainees are more capable than traditional expectations believe”) and ‘normalised’ (an external political stakeholder concluding, “the Usual Place has become a normal part of the landscape”). This impact extended even further. As a ‘shining bright light’ (external political stakeholder) of good practice, informants across all groups identified a ‘trickle-down effect’ to other forms of community action – for example, the creation of an accessible park adjacent to TUP was frequently cited. As previously mentioned, an ‘upward’ dynamic was also recognised, where TUP had been able to act as advocates for young people with ASN regionally and nationally; a TUP informant suggesting, “people in key decision-making position [. . .] are seeing that young people can do it”.

In relation to DAAP, a range of positive outcomes from the transfer was also seen to arise within the trainees. In general terms, a collection of broad insights on DAAP related outcomes was gleaned from our participant observation work and expressed in the infographic below (Figure 2).



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The Usual Place

Findings from Paired Interviews with trainees from 'The Usual Place'

Trainees from The Usual Place interviewed each other and these were some of the findings…

'I came here because I was looking to get more experience in catering and from there try to progress and get further afield'

'I wanted to learn new skills and meet new people'

'Decent'
'Fantastic'
'Outstanding'
'It's-amazing'
'A-great-opportunity'
'Different'
'Wonderful'
'Amazing'

Q: Describe The Usual Place in one word

'I like working at the front of house cause you get to know more people there'

'I feel great since I've came here'

How did trainees find out about The Usual Place?

Trainees have learned lots of skills at The Usual Place including:

Cleaning toilets
Team Work
Stock Sheets
Food allergies
Baking
Chopping skills
How to use coffee machines
Serving customers
Communicating with others
Helping People

How does working at The Usual Place make trainees feel?

'Good, I'm enjoying it, love meeting new people, like working with people'

'Happy, sad and nervous'

'Sometimes I feel good, happy, other times quite stressed out'

Good'

'It makes me feel a lot better in myself because I can better my skills and I've noticed since I've worked at The Usual Place I can help people in a way'

'Happy and cheerful'

'…they make me feel so very welcome and they make me laugh all the time…'

'Have my good and bad days sometimes'

'I like working at The Usual Place because I've got all my skills here and if I'm required on any other part of The Usual Place I've got the skills to do it'

What do trainees think could be better? What is their least favourite part?

Least favourite jobs include: cleaning toilets and doing the dishes

'When I started I was constantly doing the same jobs over and over and I wanted something different'

'I don't mind serving the tables as such but I like everything else'

'More teamwork and communication'

'Getting more people in so that we've got more people to do cutlery'

'…burning myself because I do it far too often but I'm trying not to do it so much'

'Nothing really, I'm enjoying everything… I would honestly say I would never change The Usual Place for anything'

'I'm in a place that I feel a lot more safer'

What do trainees want to do after The Usual Place?

Come back as staff
Own their own cafe
Work with new people
Find a job
Get another qualification from The Usual Place
Work in a café/restaurant

'I wanted to apply to be here because I found the whole thing very interesting and it's a really beautiful building…'

Figure 1.
TUP insights

Despite the programme being in its early stages, informants stated that they were already seeing detectable changes within individuals, including increased personal confidence and self-belief as well as gaining sector specific knowledge of the theatre. One parent informant provided an emotive portrayal of the effects of DAAP on their daughter noting that, *"she is now saying 'my friends' for the first time"*. Individuals had also attained a series of tangible achievements: 11 young trainees had been awarded their Bronze Arts Award and 4 have gone on to the Silver Arts Award; 5 had demonstrated practical employability skills by organising a performance as part of an arts festival; 9 had demonstrated increased

THEATRE ROYAL DUMFRIES

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Dumfries Arts Award Programme

The findings below are derived from data from the 'Outcome Stars' and the accompanying review notes of three interns on the 'Dumfries Arts Award Programme'. The Outcome star is a flexible tool used to discuss personal and career development and is a way of mapping an individual's progress in relation to key variables. In this case, the variables mapped were: transferrable skills, theatre knowledge, confidence, inclusion, hope for the future and feeling that their work is helping the Theatre Royal. The interns give each variable a score between 1 and 5.5 with 5.5 being the most positive. By reviewing the scores given to these variables at 3 regular intervals during the first 12 weeks, the progress of individuals can be mapped. The review notes looked at similar themes and complement this data by allowing more descriptive information to be collected.

In the first 12 weeks, 3/3 young increased their hope for the future

3/3 young people felt they had increased their theatre knowledge

Interns on the Arts Award Programme have increased their knowledge and learnt various skills including things like:

Working on Front of House and showing people to their seats

Dancing

Painting Scenery

Working with others

Watching and reviewing performances

3/3 young people gave positive scores (5 or 5.5/5.5) for feeling included on the programme

2/3 young people felt they had increased their transferable skills on the programme over the first 12 weeks

The interns feel they are helping the Theatre Royal by:

Making props for shows

Sorting tickets

Helping to do scenery for productions

Helping other people on the programme

Handing out leaflets

Being friendly to other people in the theatre

2/3 of the young people's stars showed an increase in confidence over the first 12 weeks.

Interns on the programme hope to get closer to their ambitions by:

Working towards the Arts Award

Doing more performing and dancing in front of people

Getting more skills

Working with other people in the theatre

Improving their singing

Working on front of house and selling tickets

Young people said they enjoy being at the theatre, working with others, and being part of the team

Figure 2.
DAAP insights

knowledge of different art forms and development of their own creative practice; and 4 had demonstrate their increased independence by working independently alongside DTR staff.

Discussion

We now move on to our final two research questions – how these localised insights might be understood theoretically and potentially extrapolated to wider circumstances. Earlier, we established a series of conceptual resources that informed the project. In light of the empirical observations above, we return to this ground to reflect on the articulation between TUP and DAAP within DTR and more broadly, from one socially oriented organisation to another. Our observations are structured around two concerns reflected in our latter research questions:; the extent to which socially oriented organisations can achieve transfer of such potentially innovative practice; and the degree to which social organisations can maintain a 'progressive' purpose in this 'employability' context.

Our work hypothesises a provisional "CMO configuration":

> [. . .] the existence of a national level 'policy window' creates an opportunity for a localised expression of the needs young people with ASN that in turn fosters the creation of a series of organisational mechanism within TUP and DTR that result in the achievement of a wide range of individual, social and political outcomes.

Figure 3 summarises this CMO Programme Theory.

In relation to the second theme, work in both organisations can be considered progressive in that they met the 'social needs' of groups that have traditionally been marginalised and in a way that exhibited a social purpose and collective organisational orientation. In keeping with Power and Bartlett's (2018) notion of 'bespoke spaces' and 'welcoming communities', this was practically expressed in relation to trainees finding TUP and DTR both "safe" (TUP informant) and "supportive" (DTR informant) and suggests the potential for these organisations to be seen as providing what Vlot-van Anrooij *et al.* (2020) have recently termed, a holistic 'setting' for meeting the needs of people with intellectual disabilities. Here, a 'setting' comprises a multitude of features – conducive policies, pleasant structural environments and collaborative communication and participation. Significantly, the project context allowed all of these features to be expressed within TUP and DTR *in unison* and resulted in trainees attaining a series of achievements from these supportive bonds *within* the organisations, including gains in individual wellbeing, strong collective experiences and tangible employability skills. The latter theme of inclusive participation was also inherently associated with the ability within TUP and DTR to pursue a 'values-led' approach to leadership (Humble *et al.*, 1994) and as such achieve social advancement.

Beyond the organisations themselves, the robustness of these foundations gave TUP and DTR the assurance to foster wider bridging and linking into employment opportunities in destination workplaces *beyond* theirs. In TUP, partnerships have been formed with many agencies (e.g. D&G College and Local Authority employability support services) and trainees have gained employment in a range of sectors such as, hospitality, care and retail. As a result of the transfer process, the visibility and status of young people with ASN within DTR is much higher and constructive links have been made with other local arts initiatives. These actions suggest that broader 'ecologies of support' (Duclos and Sanchez Criado, 2019) with significant links with a range of associated agencies are possible.

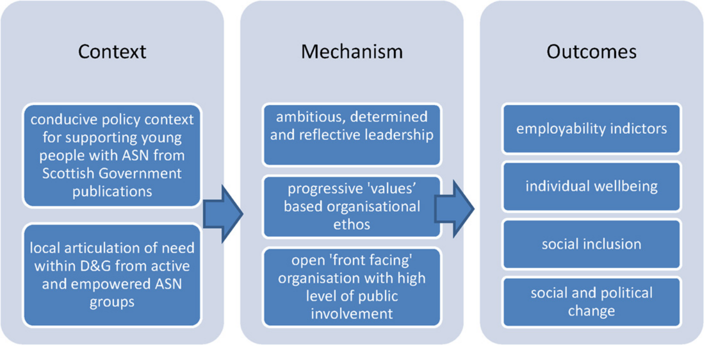

Figure 3.
CMO programme theory

As suggested above, the deployment of employability as an innovative means of promoting social inclusion is not however without its critics within the 'WISE' literature and the issue was alluded to in our fieldwork. Such critique exists in relation to a wholly "supply side" approach to employability (Peck and Theodore, 2000) and the particular suitability and effectiveness of a social enterprise model in this domain (Teasdale, 2010). Here, simply promoting *individual* employability is seen as a relatively conservative response to deeper failings in employment policies and as such, might not conform to the progressive aspirations of 'social innovation'.

In our context, this critique can however be qualified. Whilst employability was *the* central feature of the day-to-day work in TUP and DAAP, it can be seen as a *facilitatory* resource that informed a *wider* concern of promoting the wellbeing of young people with ASN as individuals, as well as elevating their visibility collectively in society. This coming together of mutually re-enforcing practice and political action can be seen as a form of "capabilities-focussed praxis" (Le Fanu, 2014; 70), recognised in the disability (Le Fanu, 2014) and human rights (Falcón, 2016) literatures as an effective way of mediating between "dominant" and "counter-public" positions (Falcón, 2016; 816), thus addressing, "educational exclusion and marginalisation prevent(ing) young people with disabilities from accumulating the various types of human capital" (Le Fanu, 2014, p. 69).

Both organisations were therefore acutely aware of the need to engage locally and nationally with various stakeholders to address *systemic* issues and this was effected via various channels; for example, building partnerships with local businesses and community groups and lobbying Scottish and UK Governments. Crucially, the basis and currency of this political engagement came from the real-world experiences that arose from employability work.

Finally, the dynamics of the actual transfer can also be seen in relation to the various theories of transfer established above. Contrary to simple technocratic transactional models, the mechanisms here were highly complex, social and essentially transformational. Again, the most striking feature of the transfer was its grounded nature – where relational and communicative "micro" interactions between TUP and DTR were prominent. From the onset, such mechanisms were embedded in the interaction; for example, the initial TUP placement undertaken by the DAAP project workers, the regular project team meetings and joint work that was subsequently undertaken. In this communicative context, it was clear that TUP as an "originating" innovative and entrepreneurially successful organisation was able to communicate their prior experiences and as recipients, DTR was willing and able to accept and use such insights. The relatively open-ended rationale and expectations underpinning this relationship – based on a "non-competitive" desire to spread socially innovative practice – was particularly conducive to this relationship.

Similarly, the "objects" of transfer were varied and often ephemeral. These spanned the intangible notion of organisational "culture" to tangible features like policies and procedures. This was not to say that transfer was always done on a simple 1–1 basis. Whilst some aspects were "replicated" within DAAP, there were some accommodations and divergences. This is suggestive of forms of "grafting" and "transplanting" rather than "copying" and "pasting" and an ongoing mutually beneficial relationship *between* the organisations rather than a unique one-off and one-way process.

Conclusion

At the start of the paper, we suggested that there has been relatively little exploration of the development and particularly transfer of innovative practice within the context of socially oriented organisations. In bringing together a nexus of features – two socially oriented organisations, complex and nuanced innovative practices, an explicit transfer goal and a multi-faceted research approach, we sought to address this gap.

In these complex circumstances, we have learned that with appropriate attention being paid to transfer processes, having sufficient change capacity (funded DAAP project officers) and strong partnership working, it is possible to take an innovative project from one context, broadly transfer it to another and have fairly immediate success. The mutually beneficial 3-way TUP-DTR-UoG project partnership provided an effective balance between learning, action and evaluative reflection. Most importantly, the theoretically informed, research driven and properly resourced context we were operating in allowed us to pursue a series of planned, incremental processes over the space of 18 months that created an environment where relatively subtle and intangible relationships could be nurtured and as such relatively profound "transformative" change achieved. These "trust-based" foundations became an indispensable basis for implementing more tangible actions later in the project.

We did naturally experience difficulties. The timescale was pressured in terms of bringing about and 'fixing' the change that was required. TUP is a complex organisation and formally mapping out the core features of it that acted as a basis of the "transfer" was in itself a major task. Relatedly, the initiation of DAAP was multifaceted and complicated. However, we achieved a series of successes, most specifically: securing follow up funding within the DTR allowed DAAP work to continue in the organisation at least in the medium term; the modified form of vocational arts based qualification ('The Arts Award') is now accessible to young people with ASN; and the project has created a strong partnership between TUP, DTR and UoG. Consequently, a series of successes and forms of learning are visible. For TUP, it has offered the chance to reflect on its own work and the way that it interacts with other 'start up' ventures. For DTR, as well as the DAAP specific impacts, it has raised the profile of work with those with ASN in the wider theatre; For UoG, it has presented opportunity to develop familiarity and capacity in evaluating complex interventions and transfer.

Finally, and returning to our research questions, both disciplinary and project specific reflections are possible. We have suggested the existence of contrasting paradigms within the social enterprise and social innovation domains that spans pragmatic, functional stances through to more radical possibilities where innovative social enterprise can foster genuine participation, engage politically and create social change. In relation to 'praxis', our work suggests that a productive interaction *between* these positions is possible and consequently, any simple dichotomy is theoretically and practically unhelpful. We also established a gap in 'transfer' research in this domain and our work sheds light on the mechanisms and resources that inform successful transfer. Additionally, we show that sensitive ethnographic approaches to research can successfully illuminate such processes.

In relation to the project, we are conscious that in further enhancing accessibility and inclusivity, the TUP and DTR nexus is still relatively narrow. We therefore see the need to engage with a wider system and associated assets in both civic communities (e.g. individuals, formal community groups, libraries, schools, etc.) and the agencies and organisations associated with promoting employability (e.g. employers, employability services, education, health and social care services). Additionally, our vocational focus has been fixed on "hospitality" and "arts". In being able to meet a range of employability preferences, we are aware of the need to explore the feasibility of working in other potential domains such as, leisure and sport and horticulture.

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Third Sector Interface for North Ayrshire - Arran Community and Voluntary Service

TACT
THE AYRSHIRE COMMUNITY TRUST
Strengthening Our Communities Together

Arran CVS
BUILDING SUPPORTIVE COMMUNITY NETWORKS

Response to Review of Adult Social Care

Third Sector Interface North Ayrshire

There needs to be a vibrant and varied marketplace of local providers within our communities in order to offer significant choice for individual's care and those utilising self-directed support. There are existing third sector organisations and groups who can provide such a local environment, who know their people well and the needs of their community. However, a greater national commitment to sustainability is required, an opportunity to build resilience and flexibility into these local resources, which empowers them to enable people closest to their homes, and meet with their aspirations of what quality care should look like.

Covid has demonstrated for us all, the power of local community networks and third sector organisations. Aileen Campbell, cabinet secretary for communities and local government, was particularly keen to highlight the sectors swift and effective response to Covid in collaboration with others. She referred to the value of third sector and how they are critical in helping people avoid access to A&E, around Mental Health and other health and wellbeing matters. A greater investment and further commitment to third sector and communities, to keep up the momentum, and, work locally with local people would improve outcomes and meet preferences for families and carers.

Covid has demonstrated there can be a reduction in the barriers of bureaucracy, the burden of complicated reporting and funding applications, some organisations may lack the resources/relevant skills for such returns, but are undoubtedly best placed in their community for response and delivery. They need adequate support, the creation of a level playing field in all aspects of funding and opportunities. Third sector deserve the same opportunity to source, train, fund and sustain a quality workforce exceeding or in line with conditions of statutory partners. Sustainable long term funding and commissioning for community organisations which allows them to respond, co design and deliver services locally with and for their communities.

In turn the sector will thrive and continue to support early intervention and prevention within a much improved social care system or model, working alongside statutory services whilst intrinsically linked with housing, a basic social need which impacts on all levels, and quality health care. The ask must be local, a national service will not meet with expectations on the ground or provide local solutions.

Vicki Yuill

Chief Executive Officer

Arran CVS partner in Third Sector Interface North Ayrshire

Thistle Foundation

Introduction

Thistle Foundation is a leading Scottish health and wellbeing organisation that supports people to live the life they want regardless of health condition, disability or life situation. We employ circa. 450 people.

Thistle provides a range of person centred health and wellbeing services and supports across Scotland for disabled adults and young people and those living with long-term health conditions. We work in partnership with local authorities, the NHS, other Third Sector organisations, the people we support, and their families to build capacity, resilience and coping skills so that people are better able to live a “good life”, whatever that means to them.

Approximately 380 employees work in our Supported Living services. Our support teams are individualised and provide personalised support for each supported person to live as independently as possible in their own home and community.

Through our Health and Wellbeing service, we also provide 1:1 and group self-management support to hundreds of people every year who either self-refer or are referred by health practitioners. We do this from our Centre of Wellbeing in Edinburgh and in all GP practices across Midlothian.

Thistle also provides training and consultancy support to NHS, Local Authority, Health and Social Care Partnerships and other 3rd Sector organisations to help them build competence and capacity to adopt approaches to working with people that are person centred, strengths based and focus on what matters to them.

We are delighted to contribute to the consultation on the independent review of adult social care and would like to thank the panel for considering our views. We have contributed to the submission made by the Coalition of Care and Support Providers Scotland (CCPS) and fully endorse the content of the CCPS submission. On that basis this document should be seen as complimentary to the CCPS document and both documents together should be taken as Thistle’s full submission. There are two aspects of the CCPS submission that we would like to build upon as follows.

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

The current social care system and practices within the system are deeply flawed in that they have an in-built bias towards ‘assessing’ people for existing scarce services which may already be too scarce or unavailable rather than focusing on what matters to people and what they want, need and already have in their lives first and foremost.

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The wider context of austerity measures and reduced services caused by the previous recession has also tended to encourage people to ask for and hold onto what they know is there, rather than having a more expansive view, which may enable a greater use of peoples own or community resources.

We believe that Self-Directed Support (SDS) should provide the fundamental underpinning for ensuring a focus on people's needs, rights and preferences. However, despite some successful piecemeal pilots and projects across the country that have provided important learning about how to practice SDS, it has not been consistently embedded and is not well understood by organisations or the people they serve. This means that much of the potential and promise of SDS to be used creatively remains unharnessed and people end up with one-size fits all services.

Our experience of working with health and social care professionals across Scotland indicates that much can be done to develop different practices by professionals to change this 'serviceland' focus of assessment. There is also still a need for more direct and tailored support to some families and individuals to enable them to think beyond what is available and come up with creative support solutions which enable their full citizenship and contribution to be harnessed.

We think there is a need for more investment in support for people and communities to:

- articulate what really matters to them;
- plan what kind of life they want; and,
- source the supports (possibly beyond health and social care) which would enable them to pursue their outcomes and what matters to them.

We would ask the review to consider how greater investment can be made in:

- The development of an improved collective understanding and capacity to put SDS into practice across health and social care organisations, people who use services and the public at large.

- The development and capacity of professional workers to have 'Good Conversations' with people and communities that focus on what matters to them and

- The development of brokerage models which enlist tools such as person centred planning, that have a relentless community focus and can enable individuals and families to make better decisions about services and the support available to them within their communities and the social care system.

2. The experience of staff working in the social care sector

We believe that person centred support provided by frontline social care workers to people and their families is a highly skilled craft. The work is very often complex and, as well as personal care tasks (which are often a smaller part of the role) involves supporting very diverse human beings with differing needs, preferences, communication styles, relationship challenges, social and family circumstances. The recipients of our support have the right to be supported by people with a good grasp of human development, up to date skills and practices as well as an understanding of the importance of wellbeing and citizenship.

For these reasons the value, reputation and standing of this role need to be raised in a number of ways including: training and develop of highly skilled workers; development of organisational models and cultures that support workers to be at their best; and the level of pay workers receive.

If this role is to be valued more, the quality of training and ongoing learning including reflective practice required is far greater than that currently paid for by commissioners. This needs to change. In addition, staff wellbeing is an often neglected sub-story to what happens in social care and workers' willingness to go the extra mile can often be very much at the expense of personal wellbeing. This needs to be addressed and integrated into staff training and ongoing practice and learning.

Through our self-organised teams programme we are pioneering a different model of organisational development which delegates autonomy and control closer to the person supported and empowers frontline staff to make decisions about how best to support someone within the various regulatory frameworks. Self-organised teams will, we believe, not only work better for individuals, they will also enable workers to express their skills and contribution to the full. We agree with colleagues in the Scottish Social Services Council (SSSC) that the Wellbeing Practitioner role that we are developing as part of this model is just that - a 'practitioner' rather than support worker. This kind of role expresses the kind of autonomy required of colleagues working in an individualised service, usually alone, usually in the community or person's home often 24/7.

We believe that the highly skilled and complex work of social care workers makes a significant contribution to the cohesion of families and communities and indeed supports others to make their own contributions. In a modern society these roles should not be paid at levels equivalent to or lower than sectors such as retail or even Health and Social Care Partnership peers. They should be paid at a level that recognises the value of the contribution they make and in line with fair and equitable cross sector benchmarks.

We would ask the review to consider:

- How greater investment can be made in the quality of training and development required to maintain and continue developing the highly skilled craft of providing person centred support for people.

- The development organisational models such as the self-organised teams model that recognise the contribution that workers make to people's lives and promotes the development of workers professional autonomy and higher quality roles in social care.

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- How the level of pay received by social care workers can be increased and set at a level that recognises the significant value and contribution that social care workers make in line with cross sector benchmarks.

Mark Hoolahan, CEO

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November 2020

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tide -Together in Dementia Everyday

"Making Carers Count"

A Response to the Adult Health and Social Care Review in Scotland

Contents

Introduction

Together in Dementia Everyday (tide) is a UK-wide charity supporting carers and former carers of people living with dementia. We focus exclusively on connecting carers together, providing a safe, non-judgemental space where they can share their experiences. We provide them with a variety of learning and training opportunities so that they can become involved in the network and the activities and events that we offer. This ensures that they have choice and flexibility in whichever way they want to express their feelings and take their real lived experiences to gain equal parity in the care of their loved ones and influence and inform real change.

Making Carers Count

Making carers count is the overwhelming ask from the members of tide. The UK's 700,000 unpaid carers of people living with dementia require urgent action to address the many challenges they face. Unpaid carers –usually family or friends of the person with dementia - are the largest "workforce" in dementia care, saving the economy at least £13.9 billion a year. Without the dedication, commitment and significant sacrifice of these carers the whole care economy would simply implode.

So it is vital that their contribution is recognised and respected and that they are treated as equal partners in care with professionals.

The reform of Adult Social Care in Scotland offers a welcome opportunity to answer their ask - make carers count!

Making Carers Count

Carers and former carers of people with dementia deserve three key actions from Adult Health and Social Care;

- Acknowledgement
- Recognition
- Validation

Acknowledgement – of the huge contribution and sacrifice they make on a daily basis in taking on their caring role and what that contribution means both in economic terms and terms of the provision of what is specialist, person centred care in its truest sense

Recognition – of the significant impact caring has on the carers physical, psychological and mental well being and the need for greater levels of support

Validation – that their experiences, feelings and thoughts are accepted, respected and valued

These three key actions are an incredibly powerful response to carers and can result in a wide reaching positive impact on all carers but must be done in a truly honest capacity and not in the current tokenistic manner which many carers experience.

Moving forward we would like to highlight to the review committee some key areas for consideration and offer recommendations from our carer members at tide on how the reform of Adult Health and Social Care can contribute to the realisation of these recommendations.

Carers (Scotland) Act

The Carers Act was introduced to give carers new rights and was intended to recognise the valuable role carers play in lives of those they care for. It championed real involvement of carers and was supposed to provide support that was individual to each carer and person centred

In a report released by the Coalition of Carers in Scotland in January 2019 based on a survey of carers about the Carers Act they reported the following;

Are Carers Aware of the Carers (Scotland) Act?

Only 16% of the carers who responded to the survey knew what the Carers (Scotland) Act was and the rights it offered to carers.

Around one third (33%) had heard of the Carers (Scotland) Act, but were not really sure what the legislation was about.

Around half of all carers (51%) who responded to the survey had never heard of the Carers (Scotland) Act.

Over 50% of all respondents to the survey were not aware of any of their rights afforded in the Act including their right to a Carers Assessment and support from their Local Authority

Carers (Scotland) Act

Despite the intentions of the Act, the implementation has been varied at a local level and open to the individual interpretation of each Local Authority

The eligibility criteria set by Local Authorities was more reactive rather than proactive – real support for carers only seems to be provided once they have reached a crisis point

Only 18% of the carers who responded to the survey understood their right to access support of they met the local eligibility criteria.

A further 21% of carers had heard of this right, but were not too sure what it meant.

Almost two-thirds of the carers (61%) who responded to the survey were unaware of their right to access support if they met the local eligibility criteria.

A number of carers were also critical of the decision to allow local authorities to set their own local eligibility criteria. The lack of carer involvement in developing the local eligibility criteria in some local authority areas has led carers to believe that the local eligibility criteria is there to prevent rather than support them from accessing support

Pre March 2020 many carers were reporting that they had still not had a Carers Assessment and the subsequent introduction of Covid-19 Legislation has resulted in many Local Authorities suspending the carrying out of Carers Assessments when this is arguably the time they are needed most

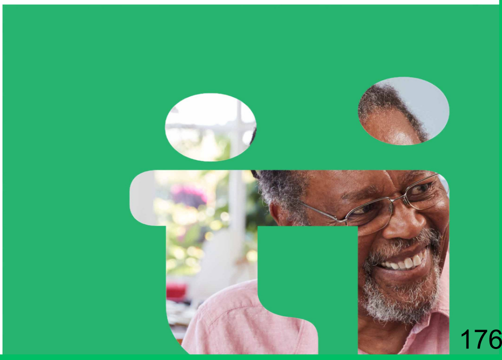
Recommendations for The Carers Act

- More investment to support the ongoing implementation of the Carers Act to enable a equitable application of the legislation regardless of what Local Authority you reside in

- Greater access to information on and advertisement of the Carers Act and the rights it affords carers. The advertisement of the Act should be more mainstream and on a variety of platforms e.g. Television, Radio and Social media so it reaches and informs a more diverse mix of carers in Scotland

- Review of eligibility criteria and how each Local Authority devised and implemented them. Our members would like to see the removal of all eligibility criteria and the only eligibility criteria that would be needed is that you are a carer for someone with dementia. The Carers Assessment should then be carried out and the support for each carer determined from that and the support should have a preventative focus as opposed to a reactive focus which id often only triggered by a crisis

- A transparent and widely accessible method of collecting and publishing data on how many carers assessments are carried out and how many carers are being supported in each Local Authority



Respite

The terminology respite, short break or break from caring minimises the importance of this support for carers. It suggests that carers only require a small amount of respite and that it is optional – this could not be further from the truth

The typical current provision for respite is either for the person with dementia to go away to a care home for 1 or 2 weeks or for paid staff to come into the house for befriending or the person with dementia may go to a day care centre.

If the respite is not appropriate and only causes further distress to the person with dementia or leads to providers telephoning carers to come back and collect the person or come home as the person is agitated and they are not able to settle them – then this is not respite for the carer. If they spend the whole time waiting for or, in many cases dreading a phone call, it is not worth doing it in the first place? This is why many carers decide not to bother with respite services and struggle on their own

Respite provided in the home is typically awarded in 2 or 3 hour a week slots and a paid carer will typically come into the house to stay with the person with dementia. 2 or 3 hours a week is nothing - when a carer gets such a short amount of free time then what you find generally is that during this time they do not choose to do something for themselves, they more often than not go shopping, attend appointments, go to the bank or the pharmacy and most of the tasks will still be for the person with dementia and so they do not get any quality time for themselves. Many carers tell us they feel like they are given these hours and it's like scraps off the table and they are expected to feel grateful because "at least they are getting something"

When a respite package is offered it is usually set up for a specific day and time each week and whilst a level of consistency is good for carers they are often left with no flexibility, if they want to change the date or time, the provider often can't meet the need of the carer and the carer is often expected to plan any changes weeks in advance – that is extremely difficult and adds more stress to carers

Respite

The impact of not having purposeful respite has huge physical and psychological ramifications for the carer and that has been highlighted during lockdown where carers are seeing services dramatically reduced or stopped altogether – carers are isolated, exhausted and under huge amounts of stress and strain and we must take this opportunity to learn and implement a new approach to respite and how it is offered and delivered for carers

If we don’t we will see more carers reach crisis point, more carers developing serious health issues and more carers being unable to cope with their caring responsibilities

All of which will add additional strain on the health and social care system, costing far more in the long run that real investment now in respite for carers

Recommendations for Respite

Respite should be recognised as an essential support for carers and as such it should be a **right** for every carer, it shouldn't be dependent on eligibility criteria or a post code lottery, there should be equity across the board. Respite for carers should have;

- Flexibility
- Choice
- Control

And be;

- Tailored for each individual carer and reflective of their individual circumstances
- Adaptable – it should grow and adapt with the carer as both their needs and the person with dementia's needs change

- Should not be provided by proxy of a support for the person with dementia i.e. Day care or Befriending – if they provider deem the person with dementia no longer suitable for that service they will inform the carer and begin a plan to withdraw the service many times without an appropriate replacement and so not only does the person with dementia lose their support, the carer also loses their respite and this often leads to many difficult and stressful conversations between the carer and the provider where the provider often end up maintaining the service longer than they should do. There is a distinct lack of services for people whose dementia is more on the advanced stage of the scale and it is the carers who are left to plug that gap with no additional support or respite

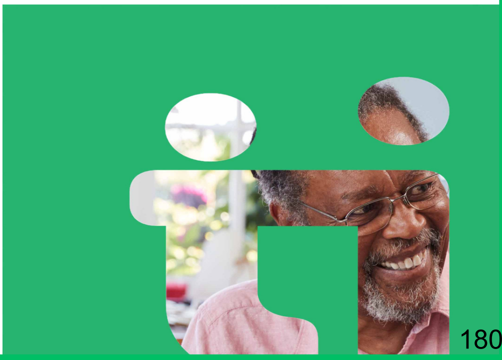
Recommendations for Respite

- Respite for carers should form part of their own post diagnostic support and should be **Self Directed** – not as part of the person with dementia's post diagnostic support or SDS – they should have their own

- Respite for carers should be essential and a right for carers and as such should be integral in any support given to carers. It should be part of that acknowledgement for everything that carers do and the support that they provide to the health and social care system – we all know that it couldn't be done without the contribution from unpaid carers

Respite services are often delivered with no real consideration for the person with dementia or the carer – respite services need to be;

- Age appropriate – distinct lack of appropriate respite for younger onset dementia
- Culturally appropriate – carers from BAME communities struggle to get respite due to the lack of culturally appropriate services provided
- Delivered by well trained, specialist staff – it takes a huge amount of faith and trust to leave the person with dementia in the care of others particularly if they are unable to give a verbal account of what has happened and in order for carers to feel comfortable the staff must have a sound understanding of dementia and how to support someone with dementia
- Staff providing respite should also be age appropriate and there should be a choice e.g. many males with dementia would prefer a male paid member of staff to support them and in many cases the person with dementia does not always feel comfortable with a younger person



Mental Health Support

Mental health support provision for carers is not sufficient enough to help them manage the complexities of caring for someone with dementia. A key area which lacks insight, acknowledgement and support is Living Grief and Bereavement.

Feelings and behaviours of grief and bereavement are very much permitted and accepted in society when there is loss of life. The common assumption is that they only occur when there has been a death. But when you are caring for someone with Dementia you can experience feelings of grief and bereavement whilst the person is still living

There is little awareness, acknowledgement or understanding about feelings of grief and bereavement when a person is still living – but when you care for someone with dementia, loss does not just mean loss of life

The carer straddles two different worlds. They have one foot in your world before Dementia – the one where they knew the person, lived and loved them, learned about all their hopes and dreams and experienced life with them. It was a world where they planned and mapped out the future and what they would do with that person.

Then they have their other foot in the world with Dementia which looks very different to the one they imagined, expected and planned for. They still exist in both worlds, and experience a constant pulling back and forth between the two – they may feel stuck at times as everything else around them moves forward and they may see other people experience the things and the parts of the life that they expected to.

They will be triggered into many cycles of grief and they may feel both a physical and emotional weight to memories of the life they were supposed to be living. It is a complex situation to manage and very difficult to explain to people who haven't experienced it

At tide we recognise and support our members with Living Grief and Bereavement including online sessions, a monthly focus group and booklets created by our members to help raise awareness and offer support to both carers and professionals in dealing with this very sensitive topic – you can access our booklets and more information about the support we provide here

https://www.tide.uk.net/resources/grief-bereavement/

Mental Health Support Tide Carer Member's Story of Living Grief and Bereavement

"I started to lose my husband, at least the husband I knew and recognised, the husband I loved, the husband I shared my life with, the husband I made memories with, the husband who had always been my friend and supporter, the husband who worked hard for our family, the husband who I laughed and cried with, the husband who I could chat to, the husband who made choices and decisions, the husband who was kind and loving, the husband I could share my worries with. That husband I lost and I continue to lose a little bit more of him each day.

Gone is the man who was thoughtful, funny, kind, helpful, caring, loving, respectful, a husband, father and papa.
That man has gone and will never return, and yes we grieve over losing him.

In his place is a stranger, someone who still lives with me and outwardly still in some ways looks like my husband, but a man whose personality and behaviour has changed so much that he is no longer recognisable to me as my husband.

I love but no longer recognise, a man who has no filter and will make inappropriate comments, a man who has tantrums, angry outbursts, a man who says the most hurtful things, tells lies, has periods of sulking or going in huff, a man who continually repeats words and phrases.

A man who can change from placid to angry in a split second in each and every one of these moments, I have to find the strength to have patience, I need skills for solving problems, finding solutions, listening and supporting most times day and night.

I know compared to some I am lucky that I can still have him at home but it feels like I have a stranger living with me, who no longer asks or cares if I am ok, no longer asks if he can help, no longer interested in our family life, or what we are doing, all these losses are so overwhelming when you still love that person but sometimes you cant stand to be in same room as them".

Former Carers
Tide Carer Member's Story
"When you are no longer a carer"

At tide we also support former carers of people with dementia and they are also lacking sufficient mental health support after the person dies. Here are the reflections of one of our tide member's;

Life is so full whilst caring for a loved one, no space for yourself, no thoughts for the future, no time, no you. Your life is filled with services; your home is shared with strangers daily. It is a busy difficult life. The death of your loved one is devastating, and you expect this, what you do not expect is to feel the following:

Abandonment: all services just leave. (You are no longer a carer)
Uselessness: you have no purpose, no value. (You are no longer a carer)
High level Anxiety: Who are you? What are you? (You are no longer a carer)
Post Traumatic Stress: Processing all the past events of your caring role, reliving the anguish, nightmares, sleeplessness, exhaustion, fear,
what is your future? (You are no longer a carer)
Guilt: Big powerful feeling, many people pray for the end of a loved one to come, life is unbearable for the cared for and the carer, you feel relief at first, then you feel guilt, even hatred towards yourself, selfishness (You are no longer a carer)

“No longer a carer” for me is very real following my husband’s death. I honestly believe that if there had been post carer support around me at this time, the deep self-destruct feelings I have would have been alleviated.
Someone who could have said “these feelings are normal”.
Someone who could have listened without judgment.
Someone you felt safe to admit your feelings too.

You can’t share these feelings with friends or family for fear that they think you are a selfish monster.
You need someone who allows you to talk about no longer being a carer.

Recommendations for Mental Health

- Acknowledgement and investment in support for “Living Grief and Bereavement”
- More Investment in counselling support and services so that carers have greater access
- Investment in good bereavement support for former carers (Sue Ryder, Marie Curie and Reform Scotland – Life After Death: Supporting Carers after Bereavement) is an excellent model for support
- Investment in different options of peer support for carers
- Bereavement policies and support from employers that doesn’t only apply when there has been a death

Employment and Caring

Dementia is something that disproportionately affects women due to their caring role

The scale of the impact of caring on women in phenomenal; they are the marginalised majority and no where more so than in the workplace.

Women are 2 to 3 times more likely to provide care for some with dementia for over 5 years

Women contribute 71% of the global hours of unpaid care

60 to 70% of carers of people with dementia are women

20% of female carers have gone from full time to part time as a result of their caring responsibilities

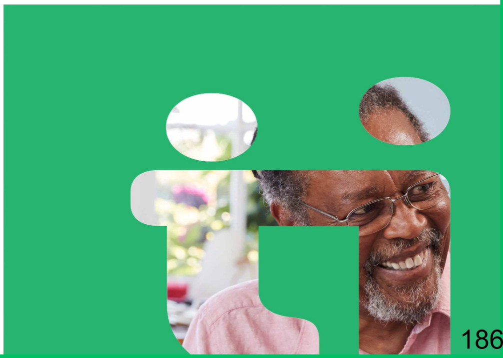
17% report feeling penalised at work

It is an essential adherence to their Human Rights that women receive fair and adequate support to maintain their right to employment, if that is their preferred choice (key word here being choice) and that their employers create carer friendly workplaces wherever is reasonably possible that support and enable women to continue being employed even if they have taken on caring responsibilities.

However as well as support from employers, carers also require a level of quality and consistency from the services provided through Health and Social care for the person with Dementia. The services should be flexible and varied enough that carers can maintain their employment and not forced into a situation where have to give up their employment and find themselves plunged into economic crisis and poverty unnecessarily due to their caring role

Recommendations for Employment and Caring

- Greater publicising to carers and carer organisations of the Carer Positive Scheme and more encouragement for organisations to apply to be part of the scheme
- Employment should be a key component of any Carers Assessment carried out
- More options for flexible working schemes where applicable for carers
- Increase in the options and choices of services provided to support and compliment carers employment and choices at work
- Carers must have a choice in whether they work or not – it should not be forced upon them in an effort by health and social care to plug service gap
- Former carers should be given adequate support to return back to employment when/if they choose to



Information and Advice

There are wide discrepancies across the board in terms of support and advice available to carers. The Carers (Scotland) Act requires local authorities to have a local information and advice service for carers. These services must provide information and advice about a number of things relevant to carers, including the carers' rights as set out in the Carers' charter.

This duty is more often than not commissioned through local carers centres and whilst many carers have received good information and support from their carers centre it is often not happening until a crisis point is reached. Local carers centres where not given enough investment to cope with the new onslaught of work created by the Act and many have had to struggle on with the same staff levels and a small increase in funding. Many carers centres were also given the responsibility of carrying out carers assessments and this combined with the increase in carers accessing carers centres have left many unable to cope.

Many carers are still not aware of their rights under the Act to information and advice and the majority of our carer members experience an imbalance when it comes to information. They are not given enough, given too much at the one time or not given it at the right time when they need it. It is often left to luck, chance or accident with regards to getting information and that needs to change

Recommendations for Information and Advice

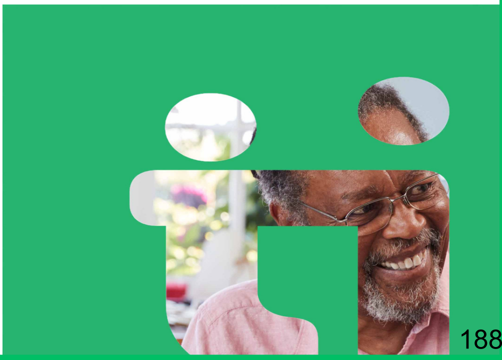
- Increase in the advertisement and publicising of carers rights, support available and relevant policy and legislation in a wider public health context. Just as we see just now with covid-19 public health announcements – information for carers on a wide variety of topics must be disseminated across general public platforms e.g. Television, Radio, Social Media, Education and Employment

- A central “hub” online that has all the relevant information and contacts for carers that is widely publicised and accessible

- Increased investment in BSL interpreters and signed videos giving deaf carers of people with dementia equal access to communication

- Increased investment in translation services to engage a more diverse range of carers

- Increased awareness of reducing jargon and ensuring materials are easy read and accessible to all



Human Rights

Many pieces of current legislation and policy begin with an aspiration of maintain the human rights of carers and most claim to be underpinned by Human Rights approaches. We have illustrated that the gap between policy and practice results in breaches of carers human rights in many different ways.

They are not support to recognise their own rights, the rights the legislation or policy affords them or how to exercise them. They are also not given a clear method or process by which to report when those rights are not upheld and this cannot continue.

Carers must be treated as equal partners in the care of the person with dementia and benefit from professionals, organisations and the Health and Social Care system as a whole recognising and acknowledging that parity – that their contribution, expert knowledge, expertise and experience of caring for the person with dementia is held in equal regard

Tide work in partnership with About Dementia Policy and Practice Forum hosted by Age Scotland and co-facilitate the Human Rights of Unpaid Carers Sub Group and are happy to consult with the review committee on our work to date

Recommendations for Human Rights

- Increased information and support and training to explain carers rights to them and how to exercise them – making them applicable to everyday life
- A central system where carers can report any incidences where their Human Rights or the Human Rights of the person with dementia are breached the data collated and reported on a regular basis to inform and influence change
- More training for professionals working with or supporting carers on human rights and how they apply to carers and their individual situations
- More transparency and accountability from Local Authorities as to how they are maintaining Human Rights of Carers through the implementation of the Carers Act and commissioning of services and support

Impact of Covid-19

The issues highlight in this report existed for carers long before Covid-19 but the restrictions enforced have not only served to increase the pressure and strain on carers they have shone a stark light on the frightening reality of caring for someone with dementia in the current Health and Social Care System.

The majority of carers are now providing more care than before as a result of the need for self-isolation or shielding, withdrawal of local services and reduced support from social care providers. Many carers are reporting concerns about home care workers visiting without adequate Personal Protective Equipment (PPE) and the risk of spreading infection. This has resulted in some carers choosing to reduce the support they receive from paid services, placing yet more strain on them.

Many carers are also reporting faster deterioration of the dementia symptoms of the people they cared for with the result being an increased complexity and intensity of care that now have to provide.

“I’ve been unable to attend to my Mother’s personal care needs (as care calls ceased several weeks ago), unable to assist my Father to care for her. (I was) unable to offer the emotional support my Father needs or respite for him. My Mother has lost all motivation or direction since the day centre was the focal point of her week prior to this. She has rapidly declined.”

Carer burnout – it is acknowledged that 70% of carers of people with dementia report that caring has a negative impact on their physical and mental wellbeing. (This is an increase on the global figure of 50% highlighted in ADI’s World Alzheimer Report 2019). This is increasing as many carers worry about their ability to cope with their current demanding situation combined with the uncertainty that they are facing by not knowing when social support services will re-open again, and when these do, in what shape and form.

Impact of Covid-19

They are concerned that they may lose their right to paid carer support and would face significant barriers when re-applying for a care package once the lock down is over. Many carers are extremely concerned about being able to continue caring safely and effectively, whilst maintaining their health and well being at this time.

“We lost access to dementia day-care & family support due to lockdown restrictions”

“I had a phone call from the social worker saying my Mum’s case was being closed. I had such a struggle to get an appointed social worker. (I) couldn’t believe, especially in these circumstances, that support has been withdrawn.”

“When the need for support arose, it very quickly became apparent that there was NO emergency care or support available & we were left to fend for ourselves.”

Financial Burden - Adding to the incidence of carer burnout are also concerns about financial issues and sudden changes to their daily caring routines

Social Isolation and loneliness –Very few carers have access to continued social support networks. Some organisations have adapted and are providing remote support in the form of zoom internet meetings, regular phone calls, coffee mornings, and activities to try and keep carers connected.

However, only a small proportion of carers may be able to access this kind of virtual support and we are extremely concerned at the further impact coronavirus will have on the incidence of social isolation and loneliness. A carer who responded to our tide online survey just simply stated:

“It’s a very lonely life”.

Impact of Covid-19

Given the essential contribution that carers of people with dementia make to the care system, this Covid-19 crisis has to be the turning point in how as a society we recognise, acknowledge and validate the contribution of carers and former carers of people with dementia.

Carers feel invisible, that they are just left to "get on with it" and that no one cares or appreciates them. We can stop this now, now is the time to act and make carers count

It has never been more important that Government, Local Authorities as well as employers, policymakers and commissioners, take action to recognise that carers of people with dementia are individuals in their own right, and not simply an adjunct to the person they are caring for.

Tide will continue to work with carers of people with dementia so that they can collectively use their caring experience, assert and claim their rights now and in the future.

References

- Women and Dementia: A Marginalised Majority by Alzheimer’s Research UK - https://www.alzheimersresearchuk.org/about-us/our-influence/policy-work/reports/women-dementia/

- Awareness of the Carers (Scotland) Act: Experiences of Carers in Scotland by Coalition of Carers January 2019 https://www.carersnet.org/wp content/uploads/2019/01/Awareness-of-the-Carers-Act-January-2019.pdf

- Life After Death: Supporting Carers After Bereavement by Sue Ryder, Marie Curie and Reform Scotland July 2020- Life After Death: supporting carers after bereavement

ToRCH

The Vision for a Teaching/Research-based Care Home (ToRCH) Centre

Compelling issue

One of the most urgent and serious issues facing the people of Scotland over the next 20 years is the need to provide health and social care for the increasing cohort of older people living with frailty, multi-morbidity and dementia. The Scottish Government 2020 Vision recognises that care homes play an integral part in providing a home for those at greatest need, but they need to be supported to do this effectively. Difficulties in the care home sector with staffing, support and availability put a strain on Primary Care services, and increase inappropriate hospital admissions and contribute to delayed discharges. All of this impacts negatively on residents, families and wider society. COVID-19 pandemic has sadly highlighted the isolation of care homes from government policy. Thus, an innovative scalable solution is required.

Inspiring and developing the care home workforce

In the UK, even prior to COVID-19, care homes were often seen, both publically and professionally, as ‘places of last resort’ to live or work; this perception needs to be challenged. Care homes with effective leadership, committed and supported staff, can and do provide excellent care (and increasingly end-of-life care) for their residents and their families. However, there are extensive recruitment and retention challenges. To develop the care home workforce, the younger generation has to be inspired to make the care of frail older people in care homes and ‘care at home’ their career choice. International exemplars from Norway, the Netherlands and Australia demonstrate the value of intergenerational engagement and student placements through closer links with universities and policy.

Potential to build-on good practice

Where care homes have engaged with quality improvement initiatives they have managed to retain staff and drive up standards. Much work is being done across Scotland in relation to the quality of care and residents’ experience e.g. falls prevention, anticipatory care planning, pharmacy review and end-of-life care. There is some evidence that care homes who had embraced development and training in palliative and end of life care prior to the COVID-19 pandemic were more resilient when faced with multiple deaths. However, implementation science is highlighting that quality improvement initiatives rarely last more than 3 years because of lack of on-going funding once the initiative has been completed; the current high turnover of staff in care homes doesn’t help. There is a need for a Scottish-wide transformation in relation to care homes that is embedded in the system – one such vision we believe is for a teaching/research-focused care homes centre or even four or five centres across Scotland as Norway has done.

The ToRCH (teaching/research-focused care homes) Centre vision:

The vision for a ToRCH Centre for excellence and innovation (informed by practitioners, residents and families and a year’s feasibility study) takes its accumulated inspiration from a number of international centres of excellence. It incorporates aspects of design, student placements, volunteerism, education and research. The Scottish Government, Lothian health/social care IJBs, Lothian universities, + care home organisations have all shown an interest in this longer-term vision. Being closely aligned to government policy, local universities/colleges and care homes/care at home services within a region will mean closer collaboration and support at a number of different levels.

The ToRCH Centre will consist of an innovative design of up to six 10-bedded ‘households’ for people requiring 24hr care + extra care apartments. Student accommodation will be part of both builds where students will live at reduced costs in return for 20hrs/month volunteering. All designs will have extensive attention to dementia-friendly engaged environments. Other amenities will encourage the ToRCH Centre as a destination point for the local community i.e. restaurant/pizzeria, nursery, shop, hairdresser, exercise pool for those in the community over 70 years.

Discussions are currently being held with Queen Margaret University with an interest of having the first ToRCH Centre built on campus. to serve care homes within SE Scotland. Further Centres could be developed from existing care home facilities with existing strong relationships with local universities.

Scotland has led the way in recognising the benefits of an integrated health/social care system. In realising our vision, to deliver the ToRCH Centre for excellence and community engagement, would not only demonstrate commitment to the care of older people but be the first of its kind in the UK. The Centre would not be an ivory tower; its main purpose would be to support, empower and train staff in care homes across a region sustaining quality improvement initiatives/research and inspiring the next generation in this important field of care.

September 2019 (revised October 2020 for representation to the National Social Care Review)

University of Edinburgh:

Jo Hockley OBE PhD MSc RN, Macmillan Senior Research Fellow, The Usher Institute

Professor Scott Murray MBE MD MRCGP, Emeritus Professor, The Usher Institute

Dr Susan Shenkin MBChB, BSc(Hons), MSc, MD, FRCP (Edin), Consultant in Geriatric Medecine, Royal Infirmary Edinburgh; Reader, The Usher Institute

Queen Margaret University:

Sir Paul Grice FRSE, FAcSS, Principal

Professor Brendan McCormack D.Phil (Oxon.), BSc(Hons.), RGN, RMN, FRCN. Head of the Division of Nursing and also of Occupational and Arts Therapies and the Associate Director, Centre for Person-centred Practice Research.

Edinburgh Napier University:

Professor Alison Machin PhD MSc HV BSc(Hons), PCGE, Dean of Health & Social Care

tsiMORAY

Third Sector Interface Moray

Re: Independent Care Review: Adult Social Care

tsiMORAY connect people to create change.

MORAY'S HEALTH AND WELLBEING FORUM

Moray's Health and Wellbeing Forum members continued to connect, meeting regularly online throughout lockdown and the ongoing pandemic:

- To motivate, inspire, include and build trust.
- To share information, experience, learning, knowledge and any other relevant resources across boundaries and between sectors.
- To translate discussion into a formal action plan.
- To facilitate timely, targeted and responsive communication.
- To create opportunities and mechanisms for local partners to collaborate

tsiMORAY's Leadership team invited Elidh to submit a brief statement to this review.

Submission

Volunteers, community groups and third sector organisations working at a local level in Moray have worked outstandingly hard through the pandemic, seeking out innovative ways of working and staying connected, sharing resources and coordinating activities to support people, and support public services to reach people most in need or vulnerable.

Everyone involved in these efforts has been aware of the barriers to accessing health and social care as well as at times other key basic necessities of survival, due to issues caused or exacerbated by the pandemic.
Health and Wellbeing Forum members continue to embrace digital innovation, despite the challenges, and bring a hopeful and optimistic attitude to the benefits these can bring, whilst doing all they can to remove barriers and mitigate the impacts of the pandemic on health and wellbeing of people and communities in Moray.

I propose this review considers the following actions as vital to keep people living well in resilient and thriving communities through pandemic recovery and renewal.

1. Pay attention to and invest resources in communities (of place and interest), through locally based/active third sector and community anchor organisations. This is key to ensuring public services are resilient and can meet people's needs, aspirations and provide necessary supports to unpaid carers who contribute their own care and time to a value beyond measure.
2. Invest in TSIs to continue to support the third sector through pandemic recovery and renewal. TSIs play a crucial connecting role in creating inclusive environments and platforms where people can connect, feel welcome, be heard, and come together to work towards common goals at a local level.

Through four Health and Wellbeing Forum meetings and four Hopes for the Future events from April to September 2020, people and groups stayed connected, and fed back on the Health and Wellbeing issues that mattered most to them. For this full picture, we are happy to share copies of meeting notes with this review by request.

Currently, people are continuing to adapt and evolve their services, paid roles and volunteering opportunities to meet the challenges and opportunities ahead, having contributed to remobilisation plans, and continuing to contribute to major strategic priorities such as Home First, and to the wider community wellbeing role of keeping people well and out of hospital and/or supporting them at point of hospital discharge.

We would welcome a commitment to partnership working and investment at a local level to maximise and value the contribution that people, communities and the third sector make to health and wellbeing in Moray both in terms of prevention/early intervention, supporting people following hospital discharge, in recovery and in living independently yet in a connected way at home and as part of our communities.

Turning Point Scotland

1999 to 2019
20
TURNING POINT
SCOTLAND
BECAUSE PEOPLE MATTER

THANKS TO STAFF PAST AND PRESENT
FOR 20 YEARS OF SUCCESS

Independent Review of Adult Social Care
Submission from Turning Point Scotland

Turning Point Scotland (TPS) works with adults who are experiencing a range of support needs in relation to learning disability, autism or acquired brain injury, fluctuating mental health or physical disabilities, problematic alcohol and/or other drug use, involvement in the justice system and homelessness. We work from the belief that people matter, that they are the experts on their support needs and that it is for us to work creatively with them and with partners to ensure that those needs are met.

We welcome the opportunity to contribute to the Committee's inquiry. We have worked with Coalition of Care and Support Providers (CCPS) and the Drug Death Task Force (DDTF) on the development of their submissions, and we support the points that have been made. Rather than repeat what has already been said, this brief submission is intended to add Turning Point Scotland's particular perspective and some practice examples for your consideration.

A system built around people, not labels

People are complex and multi-faceted. We know it is not effective nor efficient to attempt to address on support need in isolation with others. We have accepted the need to integrate health and social care, and while we still have a long way to go before that integration is experienced consistently by the people using these services, we believe that we must go further still.

We aspire to an adult social care system that coordinates all support required to enable people to live full, healthy and meaningful lives. When we consider the parts of the system in which TPS works – learning disability, justice, alcohol and other drugs, homelessness – there is remarkable consistency in the outcomes people want to achieve, in the barriers that they identify as standing in the way and in the enablers that they believe would help. Maintaining such segregated structures is of no value – not for the people who need input from multiple agencies, not for the services whose impact is limited because they can only work with one piece of the puzzle, and not for the separate systems that are each working to develop their own answers to questions that are shared across the whole system. This structure is inefficient, ineffective and stands in the way of the prevention, early intervention and integration demanded by Christie and promised by every government since.

This interrelation of support needs is clear from our own experience of service delivery and is supported by the evidence, particularly the Hard Edges Scotland report (2019) on severe and multiple deprivation. Operating as partners with, but independently of the public service system, we have had the freedom to find ways to adapt and build our support and our expertise around the needs of the people we support. Consequently, we have developed services that make connections across 'types' of support need that are kept quite siloed in the wider public service system – adult care and support at home that connects to social enterprise, justice services that connect to alcohol and other drug services, homelessness services that connect to adult care and support.

We acknowledge that we are calling for a fundamental shift in the way in which our adult social care system operates, but this review should be the opportunity to make such an ambitious call. We acknowledge that this is a big ship to turn around, but we in the third sector have been making these changes at the service delivery level, often with public sector partners. We have some of the answers, and we ask those responsible for the systems around these services to acknowledge us and the expertise we can bring to this challenge.

This discussion needs to move forward

So many of the elements we would prioritise for the future of adult social care have already been accepted and prioritised. We've accepted that people must have choice and control over their support, and we have the Self Directed Support Strategy and underpinning legislation. We know that support is most effective when it is built on collaboration and communication between agencies and around the needs of the person, and we have committed to facilitating these connections through the Health & Social Care Integration agenda. The report from the Christie Commission set out the elements needed for effective public services that are equipped to respond to future demands. Yet, in 2020, we still need a wholescale review of the adult social care system in order to work out our way forward.

We hope that in establishing this review, and in its wider thinking, the Scottish Government has learned from the reasons why the Adult Social Care Reform Programme, the Health & Sport Committee Social Care inquiry and all other preceding efforts to grasp this nettle in recent years have failed to deliver the desired impact. We hope that the contributions made, the evidence gathered and the ideas generated by these efforts have not been lost, and that this review and the Government's planning will build on this foundation. Most importantly, we hope that real and honest consideration will be given to understanding and removing the barriers that have got in the way of progress over the years; barriers that have prevented the kind of innovation and radical thinking that we need.

We are confident that the evidence you receive will illustrate the many barriers that prevent the existing social care system from operating as we would wish, and from driving the change that we know is needed – commissioning and procurement, short term funding, a vulnerability to cost saving measures, a lack of resources across the system – so we will not repeat them here. However, it is clear that this is no time for defensiveness or protectionism. There remains a significant gap between policy aims and commitments and the reality experienced by people using and working in adult social care services. We do not believe that we need new answers, rather we need to understand and be honest about what is standing the way of us delivering what we have committed to. This is where we believe this review must deliver.

Structures must support innovation

While we might not need new answers, we do need to find new ways to deliver the answers we've agreed, because what we've tried hasn't worked. We must look at each stage of the process – understanding need, demand and best practice, assessment and resource allocation, service design, commissioning, monitoring and evaluation – and consider what we can do differently.

The change we need can only come through innovation, so our systems must support and not hinder that innovation. It is clear that if we want a different outcome, this review must do something that has not been done, or at least has not been followed through, before.

We must be open to radical thinking. CCPS have developed a suite of 'Big Ideas', distilled from conversations with third sector care and support providers, to guide conversations around how we can change, what a new system could look like, how it could be structured. We hope that this review will engage in and encourage such conversations, and that these Big Ideas will be used to stimulate thinking around how we build supportive and enabling systems that allow us to innovate.

The third sector are leaders in innovation

Turning Point Scotland is built on values. The sole reason we came in to being was to deliver the best possible support to the people we work with and to make a positive contribution to our communities. We are here because the people we support matter, and we know this to be true across the sector.

Engaging with and learning from the people we support is fundamental to what we do. They are the voices that shape our services, that tell us what is needed and where the gaps are in our own practice and in wider public service provision. Our values drive us to continuously improve, to question and consider how we can do this better, to explore and invest in new approaches. These two elements add up to the ability to find answers to the kind of intractable problems being considered by the review, and it is this approach, and our experience of putting it in to practice, that we believe can support the development of a more effective, more sustainable adult social care system.

Example: Near Fatal Overdose Response – TPS are leading on a test of change in Glasgow, commissioned through the DDTF, to challenge the way in which we respond to near-fatal overdoses. This was identified in the evidence as an indicator of high risk of a future drug related death, and by people with lived and living experience of problematic drug use and by the staff who support them, as one of the key opportunities to intervene and prevent a future death. Working with people and staff teams we have developed a new approach that removes the barriers that previously prevented a more rapid response, to strengthen our response and ensure that people access the right support at the earliest possible opportunity to reduce their risk of a drug related death.

Example: Housing First – Over 10 years ago TPS invested in the UK's first Housing First pilot project. This was in response to the clear evidence that there was a small highly visible population who were being failed – and worse, increasingly traumatised – by the homelessness system that was supposed to help them. We undertook a scoping exercise to explore ways in which other countries responded to people who faced multiple and enduring support needs, and reviewed the evidence on what makes an effective homelessness intervention for people who need so much more than a home. And we learned that this is exactly where we have to start – with a home.

Over the course of the last 10 years we have seen awareness of and belief in the Housing First model grow across the country, and we have seen it adopted as the standard response in Scotland to people who are homeless and experiencing multiple and enduring support needs. To see the model embraced in this way has been remarkable, a real validation of the vision and the gamble we took in trying it out. But the real proof of this pudding is seen in the people we support. The Housing First approach finally allowed the system to adapt and respond to what this group of people really needed, people who had spent years stuck in a revolving door of rough sleeping, hospital admissions, hostels, prison, attempts to help that failed to see or understand what they were asking for; people who are now safe, secure and flourishing in their own home.

Example: Forensic Learning Disability support – TPS forensic learning disability services support people who present considerable risk to themselves and to others to live safely and independently within their community. Many people we support will have offended in the past and be involved in the criminal justice system, and the risk they present is often routed in a learning disability, a mental health condition and/or in trauma they themselves have experienced. The level of support required to manage risk, and the level of the risk presented, has meant that these people were among the last to leave secure hospital accommodation as their peers were supported to establish their homes within their community. They have often been supported in specialist out of area placements at considerable cost to the individual, their family and to the local authority responsible for their care and support. Dr. McDonald's 'Coming Home' report (2018) illustrates the scale of demand for this kind of support and clarifies the Government's commitment that no-one should be excluded from the outcomes delivered by the Keys to Life strategy.

Turning Point Scotland have developed an exceptional reputation among public sector colleagues in this area, working in partnership with them to develop service models that meet the needs of the person – they have the independence that they are entitled to, in their community and close to their family, with the support that they need to stay safe – and the needs of the wide range of agencies involved in that person's care – including social work, psychologists and law enforcement.

These needs seem to be diametrically opposed – the person being supported wants freedom, independence and autonomy, the agencies involved are largely focused on preventing harm to the person or to the wider community. However, we know that we are all working towards the same goal – safe, secure and sustainable support that minimises risk and enables the person receiving support to live a full life as part of their community.

TPS has learned how to deliver this goal, we have developed an approach that delivers for all involved. It is based on values of respect and empathy and developing trust and strong communication between partners, and it is successful. People are living safely and securely in their community, risk is managed and support is proportionate and sustainable.

In this field we have demonstrated our ability to work from a values base to find solutions that seemed to be out of reach. We are demonstrating the kind of partnership, respect and trust between the various agencies playing a part in this support, built on strong and honest communication and sharing of information, that needs to be replicated across the adult social care system. It can be done, we have done it, and everyone involved is in a better place as a result. This experience can support our ambition.

Example: Citizenship – The success of any social care intervention is underpinned by a complex, multi-faceted and hard to pin down resource that is variously described as mental wellbeing, community connection, resilience, recovery capital and social inclusion. It is hard to distil into an easily grasped concept, and so it does not fit neatly into any one area of responsibility, but we see its importance across our services. People are much more able to prevent homelessness if they feel connected to their community. People are in a much stronger position to make progress in their recovery from problematic alcohol and drug use if they have a sense of purpose and value. People's physical and mental health is improved when they have a clear sense of themselves and meaningful relationships with others.

Again, facing the challenge of seeing something as important but having no clear approach available to act, we invested in creating that approach. Through a partnership with the University of Strathclyde and Yale University we are developing a Citizenship approach, based on a model and philosophy originating in America. Defined as 'an innovative and holistic model for community integration and social inclusion' this approach considers the strength of an individual's connection to the elements that define citizenship - rights, responsibilities, roles, resources, and relationships (the 5 R's). Alongside these elements our approach also considers a sense of belonging and feeling part of your community, and is designed to address disconnection.

We have integrated this concept into every element of our support at every stage of a person's journey with us. It is not aftercare, nor is it another type of intervention; it is designed to enhance the work that we do and support people to redefine themselves and build an identify away from the reasons that brought them into services and realise that they have a life beyond those issues.

We are able to share our experience of innovation and of problem solving with the review as you develop your recommendations, and with the Government and other decision makers as those recommendations are delivered. Importantly, we have strong engagement networks with the people we support, through TPS Connects, and with our staff teams through the People Matter forum – two groups of people whose experiences and ideas are essential to the future of our adult social care system. These networks are available, alongside our wider experience of service design and innovation, to support thinking, planning and action as we move forward.

UNISON

National Care After Covid

UNISON's sector wide conversation about the future of social care

UNISON's Care After Covid seminars invited a range of participants to help shape a better future for adult social care. Discussions captured long standing concerns and the experience of the pandemic before focusing on the agenda for system reform. This paper records the key recommendations for future change.

A Rights-Based Response to Failed Care

There is a major rights deficit in social care. This was a major factor in avoidable infections, deaths, poverty and adverse mental health outcomes during the pandemic. The equality, human rights and Fair Work failings in social care are systemic. They exist in institutional structures, commissioning and run from delivery through to outcomes.

Duty bearers escape scrutiny and challenge. The absence of enforcement or effective remedy severely affects service users and workers. Arrangements for effective voice are equally ineffective. This leaves funders, commissioners and providers with unfettered power to perpetuate unfair work, discrimination and human rights failings.

Priority Actions

All care related organisations must engage with a rights-based approach. The weight attached to fundamental rights must be increased through Ethical Commissioning. Scrutiny and accountability require that FOI powers are extended to all care settings. A sectoral bargaining forum is needed to set equality, human rights and Fair Work standards. These standards should then be embedded in National Care Standards to enhance regulation of care.

Scotland must incorporate the ECHR and other international human rights norms.

All social care providers and statutory agencies should be reviewed to include arrangements for employee and service user voice in the co-design, co-production and governance of social care.

Above all, social care needs a charter of employee voice measures to empower workers in the workplace and underpin sectoral bargaining with robust workplace democracy.

Sectoral Bargaining

Agreement and joint action on chronic sector challenges is preferable to regulation, enforcement and litigation. Consistent improvement across social care needs national arrangements for sector-wide dialogue, agreement and implementation underpinned by employee voice arrangements in every workplace. As in health and local government, sectoral bargaining of this type will deliver consistent or common standards that drive sector improvements.

The bargaining agenda is broader than common standards for pay and working conditions. For example, Scotland needs to deliver better training in a way that addresses the needs of a sector in transformation and rewards workers as they progress through career pathways.

In that context, sectoral bargaining offers a mechanism to deliver tangible progress on existing National Performance indicators where progress is needed.

These include employee voice through collective bargaining; skills profile; skills shortages; skill utilization; gender pay gap; in-work poverty; contractually secure work; quality of care experience; dignity, trust and respect in public services; and, influence over local decisions.

Priority Actions

Agree the constitution, remit and resources required to establish sectoral collective bargaining. Embed criteria related to observance of sectoral bargaining arrangements and outcomes in commissioning, procurement, service contracts, monitoring, enforcement and the employment contracts of social care workers. Implement a charter of employee voice measures to underpin sectoral bargaining with robust workplace democracy.

Ethical Commissioning

Commissioning on capacity and price in a fragmented market is a major barrier to consistent progress on Fair Work and the quality and consistency of care. UNISON proposes a decisive shift to Ethical Commissioning using standards for Ethical Care agreed jointly through sectoral bargaining.

Priority Actions

Services should only be contracted externally when consistent application of National Standards can be guaranteed. Before commissioning, potential providers should be screened for strict compliance with ethical standards, possibly by Scotland Excel. Bids should then be evaluated, awarded, monitored and enforced against those ethical standards.

The standards should be agreed nationally through sectoral bargaining. Required standards should include inclusive governance, corporate transparency, equality, human rights, Fair Work and sustainable working.

Government should act on the learning from the pandemic and retain National Procurement Frameworks to ensure quality, security of supply and resilience.

People Before Profit

Scotland can neither afford nor tolerate the social care investment lost to the opaque and complex corporate structures of many private providers. The loss of care investment is substantial. In addition to the harm arising from financial “leakage”, experience links these providers with a history of instability, corporate collapse, unfair work, poor care standards and tragic public health outcomes. Ethical Commissioning should be used to put people before profit.

Priority Actions

Extend full Freedom of Information reporting obligations to all care providers receiving public funds. Embed robust transparency obligations in service contracts. Apply ethical commissioning processes and ensure strict monitoring and enforcement of tax, transparency, equality, fair work, safety and human rights obligations.

Integration Review

It should not be controversial to ask the simple question – is integration working? The key objectives of quality, effectiveness, efficiency and a person-centred approach are all at risk if IJBs are just a veneer of cooperation in governance and HSCPs become a third operational partner alongside health and local government.

Better Regulation

Scotland's regulators have succeeded in securing public protection across a diverse range of settings and occupations despite the fragmented nature of the out-sourced social care "market". With revised powers and additional resources these agencies are well placed to engage with a broader purpose – the promotion of quality care delivered by highly skilled workers employed in Fair Work settings.

Priority Actions

Review the remit, powers and resources of the SSSC and the Care Inspectorate to reflect a national commitment to stronger Fair Work outcomes. Task the SSSC with supporting the national transformation of learning, skills and workforce development as determined through sectoral bargaining.

Conduct a Human Rights audit of Fitness to Practice processes to retain existing standards public protection standards with greater efficiency, effectiveness and greater regard for the ECHR rights of registrants.

Revise all relevant care standards and Quality Frameworks to include equality, human rights and Fair Work criteria to ensure that service inspections address where care quality is undermined by unfair work. Empower inspectors to conduct more holistic scrutiny of contracted providers where individual service-based inspections indicate systemic Fair Work shortcomings.

Fair Work

The actions recommended above mirror the recommendations of the Convention's 2019 report, Fair Work in Scotland's Social Care Sector. The pandemic has simply highlighted the systemic problems recorded in that report. There is one crucial action that underpins all the improvements proposed above – a decisive intervention to strengthen employee voice in care. Employee voice must be strengthened in the workplace, at the company level, in commissioning processes, and, at a national level. Only national level conversations can bring consistency and quality to learning, skills, qualifications, workforce development and service delivery as well as the core aim of decent pay and working conditions.

Priority Actions

There must be a National Care Service which, as a minimum, must have the powers to oversee and ensure consistent delivery of Fair Work standards based on common terms and conditions as determined by sectoral collective bargaining.

Direct funders, commissioners, employers and regulators to take such steps as are necessary to guarantee Fair Work in Care.

University of Glasgow - School of Social and Political Sciences

University of Glasgow | School of Social & Political Sciences

Social Care Review: Submission of Evidence

Dr Charlotte Pearson

Professor Nick Watson

Centre for Disability Research, School of Social & Political Sciences/Institute of Health and Well Being, University of Glasgow

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In presenting this evidence we draw on over 25 years' experience in researching social care in Scotland and beyond. Our work began in the mid-1990s when we started examining the campaigns and drive to secure direct payments by the disability movement and the eventual development of Self-Directed Support (SDS) in Scotland. Our research has focused primarily on the experiences of those who receive care and has located this within a framework that promotes the rights and needs of disabled people within the social care system. We have also worked with service providers, local and national governments as well as third party organisations.

In our current work, a UKRI funded research project examining the impact of COVID-19 on disabled people, it is clear that the social care system in Scotland is not meeting the needs of disabled people. This failure has been exposed by the pandemic, but it also reflects a long term, systematic failure in the delivery of social care in Scotland. As part of this research we have spoken to 20 organisations of and for disabled people in Scotland and all stated that social care was not meeting the needs of their client group before the pandemic. There are very grave concerns that any post-Covid-19 settlement should not be based on a return to the 'normal' but that new approaches are required.

Our recent work on SDS (Pearson and Ridley 2017, Pearson et al 2018) and on health and social care integration in Scotland (Pearson and Watson 2018) all suggest that the values that underpin the legislation are sound, the problem has been in its implementation. Over the past 5 years, we have submitted a freedom of information request to all 32 local authorities requesting the breakdown of SDS users in each area. We are currently analysing the final tranche of data, but findings to date indicate that there has been little movement across the 4 SDS options. For example, the number of people receiving social through Option 1 (direct payment) has remained at roughly 10%, with little change over the last five years and the number of people receiving care funded through Option 3 (directly provided service) has remained at about 75%. There are provisions within the legislation to provide alternative models of support (Option 2 and 4), but at the moment these appear to be under-used.

The role of austerity in this cannot be ignored, but it is not the sole cause. There are fundamental structural problems within the social care system and that unless and until these are resolved social care in Scotland is unlikely to change. These problems are not unique to

Scotland and are reflected across OECD countries where personalisation has been implemented (Pearson 2019). Personalisation has often been accompanied by a worsening in the working conditions of care workers, including a growth in zero-hours contracts, loss of holiday and sick pay and pension entitlement.

Research suggests that Option 1 (direct payment) can be life changing for those who choose it. They are however very demanding and have not proved to be universally popular and SDS has not been able to improve their uptake. SDS is framed within a discourse of empowerment, inclusion, and participation. However, it appears that in practice this is not being enacted, and the hoped-for partnerships between those who use the services and those who fund, design, and deliver them is not being achieved. There is also evidence towards a shift towards increased marketisation in the delivery of social support and that personalisation has not improved disabled people's participation.

What is needed is an approach that allows for the benefits of Option 1 and the peer support it provides with the security of Option 3. The legislation itself provides for this through option 2, and there has been a gradual increase in the use of this option. However much of this provision comes through large, third sector organisations, with limited involvement from either those who receive the care or of the disabled people's movement. There is a danger that we will be replacing one large service provider, the state, with another. Full and effective participation of disabled people in the design and delivery of services is essential, a point reiterated by Article 3 of the UNCRPD.

We would suggest that the review look towards lessons from Norway and Sweden and also the recently enacted Welsh legislation and the move towards care and support delivered through co-operatives run and controlled by disabled people (Pearson et al 2020). The Welsh Government's drive for care to be delivered via not=for-profit organisations should also be examined. This will require a major cultural shift in service provision and sustained government investment.

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University of the West of Scotland - School of Health and Life Science

Response to Independent review of Adult Social Care Review November 2020

School of Health and Life Sciences, University of the West of Scotland

Within the Independent Review of Adult Social Care in Scotland a key component of the relates specifically *to the experience of people who work in social care, including their employment arrangements, opportunities for training and progression, and relationships with other professions across health and social care*. The School of Health and Life Sciences at the University of the West of Scotland (UWS) believe that in order for the social care sector to develop, education of the workforce is crucial. Through our experiences of delivering higher education programmes specifically for the wider health and social care workforce we would like to take this opportunity to share these reflections.

The School of Health and Life Sciences at UWS have responded to the changing landscape of health and social care by developing undergraduate and post graduate programmes on the integration of health and social care. These programmes address the Scottish Government (2011) recommendations of moving towards services that are preventative, anticipatory and focussed on improving the quality of life and outcomes for people through 'using all available resources'. These programmes have been developed to address the educational needs of a cross-sectoral health and social care workforce in cultural transformation focusing on educating for enablement and empowerment through co-production and an asset based approach.

The programmes we deliver are the BA (Hons) Integrated Health and Social Care and the MSc Leading People-centred Integrated Care. These programmes are reflective of 3 stages of education as identified by Frenk et al (2010):

- Informative education – the acquisition of knowledge
- Formative education – socialisation into work / profession
- Transformative education – preparing to be leaders and mobilising knowledge positive values.

The undergraduate BA (Hons) Integrated Health and Social Care programme develop the graduate skills required for the changing landscape of the sector and is focused on informative education. The postgraduate MSc Leading People-centred Integrated Care is designed to provide a progressive pathway for staff working in the cross-sectoral field of health and social care and focused on transformative education. The ethos behind both is to enable and empower the students to deliver, develop and lead integrated services across health and social care in order to promote and enhance quality, effective and efficient people-centred services.

A key feature of the programmes that can build and support the social care workforce is through the multi-professional and multi-sectoral nature of shared co-productive learning. This allows students to explore the complexities and challenges of delivering and leading system integration. This is advocated as a way of breaking down professional boundaries and in developing a more cohesive approach to professional practice. Shared and asset based learning takes place between the diverse roles of the students and staff. Additionally, it has a positive impact on cultural appreciation and shifts that are required to ensure the delivery of integrated, person-centred services from a confident and component workforce.

These programmes within the School of Health and Life Sciences have been built to provide opportunities for training and progression and develop relationships with other professions across health and social care through shared, cross sectoral learning. We have done this working in partnership with International Centre for Integrated Care, The Health and Social Care Alliance Scotland, and International Foundation of Integrated Care. These partnerships expose out students to global, as well as national issues, actions, and agendas, influencing and shaping the integration of health and social care; and provide students with opportunities to actively engage in real-world practice-based research and quality improvement activities. Raising educational attainment is crucial in order to raise the professional identity and integrity of staff working within social care. To support the cultural shift and transformational change it is vital to develop not only an experienced reflective practitioner but also an enquiring and transformative graduate to ensure the delivery of authentic people-centred integrated care.

Thank you for the opportunity to submit this response. As part of your ongoing review process, and should these be of benefit to your review, the School of Health and Life Sciences at UWS can provide further details on the ‘student learning experience’, academic outputs and wider impact of these programmes of study.

School of Health and Life Sciences,
University of the West of Scotland

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Wheatley Care

Response to the Independent review of Adult Social Care

Submission of Wheatley Care – November 2020

1. About Wheatley Care

Wheatley Care is a sector-leading provider of care and support to people across Scotland. Previously known as Loretto Care and Barony, we were formed on 1 April 2020 as the Boards of these two organisations decided to come together. We're an integral part of the Wheatley Group, Scotland's largest leading housing, care and property-management group. As part of Wheatley Group we can access resources to continue us to develop the support we offer including new technologies and learning and development for staff and people we work for.

Wheatley Care works closely with 9 local authorities and health and social care partners across central Scotland. We provide care and support to a wide range of almost 7000 people, including:

- older people;
- young people;
- people and families experiencing, or at risk of, homelessness;
- people with learning disabilities; addictions, mental health issues or alcohol-related brain damage.

2. About our Submission

We wanted to submit our comments on the key areas being explored by the Review to capture the unique breadth and diversity of our staff and the People We Work for.

3. Responses to the Key Areas of the Review

Needs, rights and preferences of people using Care Services and Support.

What's working well	•As an organisation we empower our customers to make choices that suit their needs. •We promote choice and take into account each persons' needs before support plans are developed. •The people we work for have told us that the support they get is tailored to what they want and centred around their needs.
Where there are issues	•It can be difficult to get responses from some HSCPs and Social Work teams regarding assessments. This can delay putting support plans into action. • Funding does not take account of needs of individuals and varying levels of support they may need day to day to meet their goals.
What we would like to be considered by the review	•We would encourage the review to consider how best to strengthen the adoption and implementation of SDS. •We would ask the review to consider how to expand the scope of funded social care to be more flexible and include less "formal", currently non-commissioned support.

The experience of staff working in the social care sector

What's working well	•As part of the wider Wheatley Group, our staff feel they are supported and have a robust infrastructure to support them, both through staff benefits and access to training. •Staff feel valued by the organisation.
Where there are issues	• Staff reflected that their role is not always recognised in the wider environment, and there is not the awareness from NHS collegues as to the value of the role and qualifications required. • Pay levels can effect recruitment and can distract potential applicants from the career path Care can offer.
What we would like to be considered by the review	•We would encourage the review to consider how best to ensure that our professional aspirations are reflected in awareness, status, esteem and reward.

Regulation, scrutiny and improvement

What's working well

- We welcome the findings and feedback from the Care Inspectorate and have reflected this in our improvement plans.
- We have internal processes in place to drive improvemetn and involve the people we work for in these discussions.
- We now find interaction with the Care Inspectorate much more meaningful.

Where there are issues

- There remains a level of subjectivity in the regulation framework although it has improved,
- Scrutiny does not consider the funding of the service on the limits of resources and how services are designed to provide greatest value for money.

What we would like to be considered by the review

- Examine the need for Care Inspectorate to look at the whole system and the external factors that impact on service quality and delivery.
- Assurance that scrutiny continues to develop its focus on self-evaluation & improvement and considers how to measure performance & quality on the basis of experiences and outcomes for people, rather than provider compliance with policy and process.

Human Rights and ethics in social care

What's working well

- Our team recognise and respect that social care support is a human rights issue: without social care, people with support needs may be unable to access or exercise their human rights (eg. to work, to family life, to freedom of movement, to democracy)

Where there are issues

- There is a need for some people we work for to continue to have access to face to face advocacy to support them, particularly where they don't have access to IT.
- We are concerned about private care companies working in the market and seeking profit

What we would like to be considered by the review

- We would encourage the review to establish a clear line of sight between high ethical standards and the level of budget required to underpin them.
- We would like to see the voices of people using services to be considered when setting legislation.

Commissioning and Procurement

What's working well	•We have built strong relationships with comissioning officers in the areas we work in and they know the work we undertake to support people, particularly those with complex needs.
Where there are issues	•We have found procurement focuses on a 'race to the bottom', market forces are key consideration over what the funding is aiming to do. •The procurement process is expensive and resource intensive, and value for money not considered.
What we would like to be considered by the review	•A review of the principles of Procurement and Care so that it considers policy and processes are suitable to reach the outcomes of care. •Consideration of the needs of the people we work for in setting contract lengthens and budgets.

Finance

What's working well	•We continue to be innnovative, developing models of care and support to provide value for money and highlight to Local Authorities how additional funding can bring benefits.
Where there are issues	•Local Authorities offer different payment rates, but expect the same level of resource and outcomes. •Levels of scrutiny on providers creates a sense of mistrust (covid had been particularly difficult) while we understand the need to follow the public pound the scrutiny feels disproportionate •No consideration in financial planning of investment in services i.e technology •Continually asked for more for less – i.e. increase in training requirements and standards, technology, recording outcomes – but no recognition within budgets of costs here so providers bear the brunt.
What we would like to be considered by the review	•We would encourage the review to seek analysis of spend in terms of volume, efficiency and outcomes achieved, by sector, as well as addressing the matter of overall funding levels •We would ask the review to examine the balance of risk - both financial and to consistency of care - between purchasers and provicers.

Potential national aspects of a social care system

What's working well	•We have embraced the national frameworks that have been developed. • We build our improvement plan around the National Care Standards that have been developed for Scotland.
Where there are issues	•National frameworks have barriers to moving into new local authority areas, this restricts growth and building consistent services across Scotland •National initiatives,such as Housing First work on a local level, reducing the opportunity for consistent practice and value for money to develop.
What we would like to be considered by the review	• Partnerhip arrangements for Local Authorities to work together • Fair work and recognition of Care Staff alongside NHS. •The role of people we work for and staff in setting national agendas.

4. Conclusion

We thank our staff and people we work for, for sharing their views and contributing to this submission.

Thank you for reading this submission. We would be pleased to discuss it with the review Chair, panel and secretariat, in whatever way would be most convenient.

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

SAMH - Submission to the Independent Review of Adult Social Care

Scottish Association of Social Work (SASW) - Submission to the Independent Review of Adult Social Care

Scottish Hazards - Submission to the Independent Review of Adult Social Care

Scottish Social Services Council (SSSC) - Submission to the Independent Review of Adult Social Care

Scottish Women's Budget Group - Creating a Caring Economy: A Call to Action

SICCAR and Food Train - How SICCAR and Food Train support older people to live well at home

Social work Scotland - Main and supplementary submissions to the Independent Review of Adult Social Care

Socialist Health Association Scotland - The Reform of Social Care in Scotland

Sue Ryder - Human rights in end of life care - Scotland

Sue Ryder - The case for proactive neurological care

Sue Ryder - Rewrite the Future: A report on progress in improving specialist care for people with neurological conditions in Scotland

UNISON Scotland - Care After Covid: A UNISON Vision for Social Care

UNISON Scotland - Future of Social Care – Response to Health and Sport Committee call for views

University of Strathclyde - Emma Miller - Ethical dilemmas: balancing choice and risk with a duty of care in extending personalisation into the care home

University of the West of Scotland – Decent Work in Scotland's Care Homes: The impact of Covid-19 on the job quality of front line workers