

A National Care Service for Scotland: Consultation Response

Introduction

About Dementia is a five-year project, funded in 2019 by Life Changes Trust and hosted by Age Scotland. We bring together people affected by dementia with professionals in the public and third sectors to influence change around policy and practice in Scotland. We do this through the mechanism of thematic policy sub-groups. In our first year our sub-groups focused on Housing, Transport & Mobility, Human Rights of Unpaid Carers and Prevention & Living Well. We added Technology, Human Rights of People with Dementia, Sport & Physical Activity and Befriending & Peer Support to these in our second year. Throughout the project, we have focussed on the lived experiences of those with dementia and their unpaid carers. We also seek to use a human rights-based perspective, along with an understanding of related legislation, to empower the groups we work with.

How we have approached the response

In order to provide a comprehensive response to the National Care Service (NCS) consultation, About Dementia organised a number of engagement events with people living with dementia, unpaid carers of people living with dementia, and professionals involved in providing support to both groups. Whilst some members engaged with the larger 137-page consultation document, others found it difficult to allocate enough time or energy to digest the important points made. Therefore, we felt it was crucial to create a [shorter brief on the consultation](#), which may increase accessibility and support our members to engage as meaningfully as possible with the topic (NB this was published in advance of the Scottish Government's Easy Read version of the consultation). Our condensed briefing was praised by both carers and people living with dementia, who also distributed the briefing throughout their carer and dementia networks.

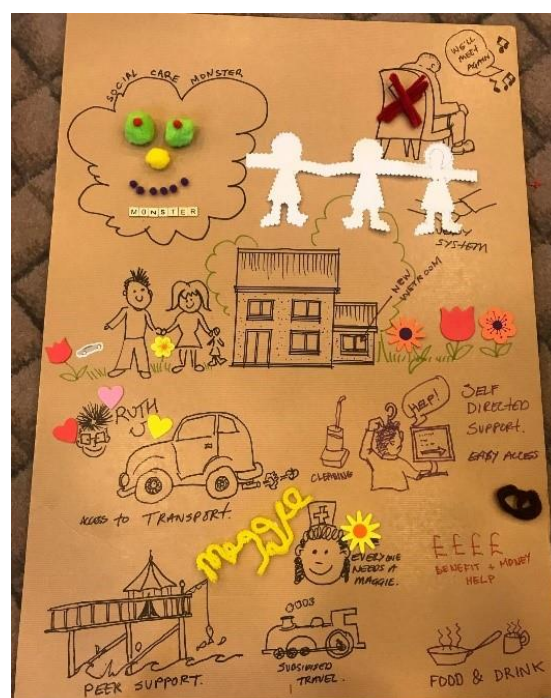
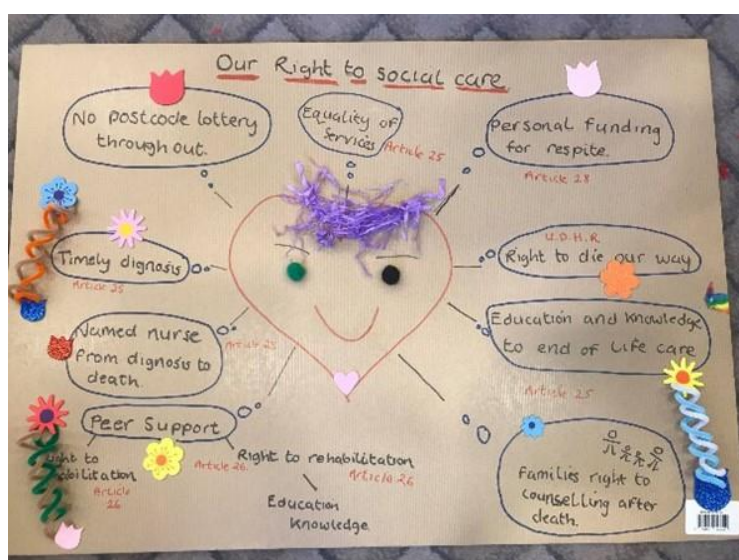
For many, this will be the biggest opportunity for public service reform in a generation, it was therefore key that we cast a wide net to ensure diverse engagement. For people living with dementia, two engagement events were held. Similarly, two events were held for unpaid carers, one of which was an evening session to allow greater flexibility for contribution. Finally, we held a single open engagement session which included About Dementia partners, facilitating contributions from organisations working to provide support to people with dementia and unpaid carers. In doing so, we also identified the areas we aligned on. At each of the events, we introduced the background to the consultation and provided a verbal summary of our briefing paper.

Conscious of the demands on many organisations and individuals at the present time, and aware that not everyone has the time or ability to take part in online meetings, we created an [online survey](#) to gauge responses from those unable to take part in our engagement sessions. The survey asked respondents to rate the

services they use on a scale of satisfaction, and also asked open-ended questions on the themes presented in the NCS consultation. To improve accessibility, we publicised that any interested parties could also request a telephone call to complete the survey.

We also used social media to generate interest in the NCS consultation among our followers and to encourage further engagement. Our “National Care Service Twitter Takeover” provided an excellent chance for further views to be expressed (you can view the thread by following the first post [here](#)). Over the course of the Twitter Takeover, our posts were seen by over 5000 people, with 300 direct interactions through likes, retweets and responses.

In addition, we make reference to discussions that took place as part of the Deepness 100/6000 Conference, Scotland’s first conference run by, for and about people living with dementia. We pay particular attention to a workshop in which people living with dementia were encouraged to ‘build’ their ideal National Care Service together, using creative materials.



Above and right: Examples from the creative workshop at the Deepness Conference.

Finally, we arranged a direct meeting on the NCS with the Minister for Mental Wellbeing and Social Care, Kevin Stewart MSP. All questions asked of the minister came from our invited activists, either people living with dementia or unpaid carers of those living with dementia.

We feel the extensive level of engagement organised by About Dementia was warranted given the expansive nature of the proposals. The willingness shown by our contributors to engage with the consultation response demonstrates their determination to see significant improvements made within social care for people living with dementia and unpaid carers. During our meeting with the Minister, we

were encouraged by his commitment to prioritising the voices of people with direct experience. We would hope that this is a sentiment shared by others responsible for the NCS's development. With rates of dementia diagnosis set to increase by over 50% in the next 15 years (ScotPHO, 2021), we ask that adequate thought for the unique circumstances of people living with dementia and unpaid carers is given when designing the new service. We hope this response will serve as a mouthpiece for the many experts-through-experience who were generous enough to contribute to it.

Given the breadth and depth of responses we received through engagement with our members, we have taken the decision not to respond directly to the questions contained within the consultation document. Instead, we present a narrative response that demonstrates the range of views expressed by our members, and allows their voices to be communicated directly through extensive quotations. For ease of inclusion within broader analysis of responses, we have themed our narrative around the key headings within the consultation document.

A Note on Our Sources

Nothing for us, without us. – **Person living with Dementia**

Any quotations provided within this response will be appropriately labelled with a source, although anonymity for all our activists, members and partners will be maintained. To demonstrate transparency and a commitment to direct-experience research, the following labels will be applied:

Person Living with Dementia

Current/Former Unpaid Carer of a Person Living with Dementia

Health/Care Professional

Third Sector Professional

Equally, throughout the response, sentiments expressed by broad groups will also be referred to on the above basis.

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The Consultation Process

*My concern about the consultation is that it's due to finish in November and not a lot of the experts know about it. ... I tried to get the word out to so many people, but even the NHS, the social care, they don't know about it. - **Current Unpaid Carer of a Person Living with Dementia***

Concerns were raised across all of our contributor groups about the design and promotion of the consultation process itself. One person living with dementia completed the response themselves and was unhappy with the overly structured, multiple-choice options provided for most of the questions. They suggested that there wasn't much of an opportunity to contribute more open answers highlighting best practice examples in Scotland. Ultimately, their opinion was that the outcome of the consultation was “*sort of predetermined*”.

Amongst professionals, there was equally a sense that the consultation could be considered intimidating, even exclusionary. The 137-page document was described by one professional as “*quite unwieldy, even for someone working in the field*”. Some professionals even brought the entire consultation process into question, stating that it was “*tokenistic*” and that service designers needed to “*get out and see people face-to-face*”.

About Dementia was privileged to attend the Deepness 100/6000 Conference, held in Dundee in September, as a silent observer. Conference speakers, all of whom were living with dementia, also spoke of feeling alienated by the consultation. By contrast, in introducing a workshop designed to encourage attendees to ‘build’ their ideal National Care Service, the conference organiser stated:

Governments confuse people by giving them information. You get so much information, you can't make heads or tails of it. So, I only have one question: What should a National Care Service look like for people living with Dementia? – [Person Living with Dementia at Deepness 100/6000 Conference](#)

We include this example to firstly demonstrate how overwhelming it felt for some to engage with the larger document, leading some to infer that the inaccessibility was intentional. Secondly, we wish to highlight to those involved in the consultation design that it is possible to [develop alternative and creative ways](#) to engage with people living with dementia and other cognitive impairments while involving people with lived experience meaningfully in policy development.

Finally, there were concerns raised by both people living with dementia and unpaid carers that the publicising of the consultation had been inadequate given the huge reforms being proposed. It was suggested that an advertising campaign could have been run to coincide with the consultations launch, which may have

encouraged a wider response from people with lived experience and professionals alike.

Sadly, for one long-term activist living with dementia, the manner in which this and previous consultations have been conducted has shaken their faith in the prospect of meaningful change occurring as a result of such processes: *“What we’ve said in the past seems to get lost in the mists of time”*. Whilst this comment may not respond directly to the detail of the NCS proposals, their words exemplify the lack of trust felt by some long-standing activists. Many of the activists we engaged with have been consulted over the course of 20 years on various health and social care reforms, yet still face social care challenges daily.

The Concept of the National Care Service

Tension between local and national government.

I worked for the local council for over 30 years, and we started off centralized and they thought it would be a good idea to decentralize because [it] was too cumbersome. Too much paperwork and that sort of stuff so they decentralized everything. Spent millions. And about 10 years ago they decided to centralize everything again. ... it was ridiculous. So I don’t know if centralizing everything would actually work. –

Person Living with Dementia

People living with dementia highlighted the tension that the proposed National Care Service has created between national and local government. Understandably, discussion on this subject amongst our groups centred around the prospect of changes resulting in services improving or worsening under increased centralization. As a person living with dementia stated, the NCS will need to *“decide whether they go with local ideas from local authorities or best practice rolled out nationally.”* Positives were identified with both of the strategies. However, some people we engaged with expressed negative associations with local authorities (particularly the power of organisations such as COSLA) to subvert the voices of local service users. This was something our members wish to be avoided at all costs.

Many of the professionals we spoke with had their own concerns with the centralized version of the NCS proposed within the consultation papers. A consistent theme throughout our engagement with professionals was that a *“one-size fits all”* model of care would be to the detriment of the care received by people with dementia and the support provided to unpaid carers in remote or rural communities. One professional shared many of the concerns raised by COSLA and

local councillors in this regard (Anderson, 2021). Those in rural and island communities shared a pervading sentiment that what works in the central belt, may not work in the rest of the country. As one professional put it, “*standardization doesn’t necessarily mean improvement*”. This was echoed by two of our members living with dementia living in remote/rural locations.

The centralisation of the service away from local authorities also risks exacerbating existing challenges in making connections between interrelated and interdependent services such as transport and housing. The *Being Home* report (Brown et al., 2017), whilst focusing on dementia and housing in Scotland, highlighted housing as the missing piece of the integration puzzle. Appropriate housing and relationships between agencies play a key role in facilitating hospital discharge, as well as ensuring a preventative approach to both health and social care. In the majority of cases though, housing departments have no seat at the table on Integration Joint Boards. Our Housing and Home sub-committee in 2019 highlighted some good examples of joined up practice at a local level, but often this was dependent upon individual housing officers and social workers making connections, rather than pre-existing strategic links.

Likewise, integrated transport is a key enabler of independence for many older adults within the community but is rarely considered within health and social care beyond patient transport. The members of both our Housing & Home and Transport & Mobility sub-groups have raised concerns that centralisation of social care away from local authorities could further inhibit strategic connections being made between agencies.

Current system improvement and legislative framework

Can’t they just make what we’ve got work properly? –
Respondent at Engagement Event

Separate to discussions on the detail of the NCS proposals, there was debate over the need for such wholesale reform. One person living with dementia expressed reservations about “*re-inventing the wheel*”. A professional also offered that existing legislation, such as the Self-Directed Support Scotland Act and the Carers Act, should already provide the basis for person-centred care laid out in the Feeley report. The challenge instead, the professional highlighted, was that “*we just don’t use them.*” Again, this emphasises what Feeley described as the “*implementation gap*” (2021).

There was a general theme expressed by some during engagement, which suggested that the current system could be improved by addressing the existing legislative framework and statutory rights for people with dementia and their unpaid carers. Amongst people living with dementia, there was a desire for the Scottish Government to review implementation of existing legislation to improve

care at a local level, such as the delivery and criteria of Self-Directed Support (SDS). The wording of legislation, notably the difference between “should” and “must” was raised consistently. There were even discussions on whether other wording could be used to “*legally compel councils or the local authorities to do what is written*”. There was a fear expressed that local authorities often took on legislation, only to “*mould it to suit their own services and finances*”. Rather than an entirely new system being created, a desire to see local authorities held to account for their existing powers, was prevalent. As one person living with dementia stated, “*if local governments aren’t carrying out the advice of the Scottish Government then they should be penalized. Simple as that*”.

The views expressed by our members, though diverse, emphasise that what is most important to people who use social care in their daily lives is not how it is structured or who is ultimately accountable. What matters to them is that there is accountability. They also care deeply about how they are treated, that they are listened to, and that they can access social care that empowers them to live the lives that they want to lead, in the way that they wish to lead them. This core purpose was well reflected in the Feeley Report (2021) and must not be lost sight of in the process of developing new systems or in debates between existing vested interests. Fundamentally this comes down to a matter of trust. Too many people have lost trust in the systems that exist to support them, and this must be addressed as a matter of urgency.

Fears of a continued postcode lottery

My fear for the NCS is that it becomes another postcode lottery and it repeats the same mistakes that we’ve seen in the system for years. – **Person Living with Dementia**

The desire to find a way to enforce mandatory, equal standards in social care across the country was motivated by an increased understanding among our activists of the ongoing postcode lottery in dementia care and unpaid carer support. As one person with dementia remarked, “*there are some great examples of good service and some appalling examples, and sadly sometimes they’re not that far apart*”. Some members we engaged with felt local authorities were prone to “*wriggle out*” of their statutory duties. For the National Care Service to be successful, trust must be regained by holding all of those involved to account on implementation.

Many of the people we spoke to retain a sense of scepticism over the new service’s ability to deliver on the promise outlined, a feeling underpinned by their experiences of social care to date. It will be an important element of the implementation of any proposals to ensure that this scepticism is overcome, by delivering genuine change for people who use social care in their daily lives.

Positive outlook, but lacking detail

I think that what the document proposes is a very good thing. But what I would like to know, once they gather information, is how they're going to tackle and improve things together. –

Person Living with Dementia

Despite certain levels of scepticism, some contributors did express more positive sentiments on the potential of the National Care Service as a concept. Within our survey, a majority of respondents thought that the NCS would improve day-to-day living for people living with dementia and unpaid carers. In particular, aspirations around human rights and person-centred approaches cited within consultation documents were seen as a step in the right direction and worthy of focus. Others praised the ideals of the service being proposed, with one professional stating it was “quite positive, in its most naïve form” with “a lot of good initiatives” referenced.

Fundamentally, however, contributors were frustrated by a lack of detail contained within consultation documents, with too much reference to the aims and processes involved in the NCS development, rather than the practical means by which this could be achieved. An acknowledgement among some contributors was made that this was perhaps due to the early stage of the service's design and the fact that this is the first round of consultation.

The Scope of the NCS

Worry about the scale of proposed services

The more I read about the NCS, the more concerned I become about it. I think there's some really good things in this, but it's trying to be something to everybody and I just don't think that's going to work particularly well. –

Third Sector Professional

It has been well publicised that the scope of the NCS's responsibilities goes beyond what Derek Feeley suggested in the Independent Review of Adult Social Care (2021). The consultation also expands on what most of our contributors expected in terms of its extension beyond adult social care. It was described as being “a wee bit ambitious” by one of our activists living with dementia, whilst a number of the professionals contributing describe it as a “juggernaut”. Equally, it was questioned how seamlessly different members of staff would be able to be moved from one public service to another, with one professional stating that they “couldn't imagine any GPs would want to leave the NHS”.

The consultation makes a strong logical argument for the extension of the scope of the NCS beyond that envisaged by Feeley. Though there were not strong views as to the inclusion of other areas of social work in the proposals, some of our members were concerned that such a wholesale reform could dilute the impact of the changes that they want to see, simply due to the scale of change being attempted at once.

During our engagement activities, references to previous large-scale reforms in the public sector were never far away. For many of our contributors, these originated from first-hand experience whilst working for public sector organisations at both a national and local level. People living with dementia are not simply defined by their current status, but many of them bring a lifetime of experience, many of whom as public servants and professionals in their own right. The skills and knowledge they bring are still highly valuable to policy development and we were extremely fortunate to be joined at our sessions by people living with dementia who had worked for their local council; in nursing; in social security; in a day centre; in mental health; and as a school teacher respectively. The scale of the proposals being suggested were often viewed through an extremely practical lens, with some of our contributors having experienced previous public reforms that, although ambitious, were often hampered by the realities of disagreement between vested interest, and a lack of funding to make the vision a reality. All were eager that this process not be similarly marred, but nevertheless their experiences had left them sceptical.

Lack of dementia references may mean lack of dementia-specific provision

My worry would be that the more all-encompassing a care system gets, the harder it might be for some services, like services for people with dementia, to argue their corner. –

Person Living with Dementia

A consistent complaint that we heard, especially from people with dementia and unpaid carers, was the lack of direct reference to dementia contained within the consultation papers. The 5 references contained in the 137-page document were considered cursory at best. One person living with dementia, felt that a lack of specific reference to dementia was an intentional move by the Scottish Government to keep dementia “*pretty quiet [...] because if suddenly we become the forefront of financial support, it’s going to swallow half the budget*”. Whilst this view may seem extreme, it’s important to acknowledge how a lack of reference translates to people living with dementia. Inversely, it has been a common theme of our Human Rights of People Living with Dementia sub-group that reference to dementia is absent, often not due to malice but by a failure to consider the unique experience of those affected by dementia.

Although many of our contributors were worried about the lack of appreciation for the unique circumstances of dementia under a “*one banner*” approach to social care, they were still keen to propose solutions that would benefit all service users. In particular, the option to distribute responsibility within the NCS to different thematic groups was raised as a potential way to maintain focus on different conditions/areas without necessarily removing oversight. During the April 2021 Scottish Parliament elections, About Dementia’s manifesto joined Age Scotland’s call for the creation of a Commissioner for Older People, who would have special responsibilities for advancing and safeguarding the rights of people living with dementia. We would recommend a similar creation of responsibility within the National Care Service, although any model would have to understand that those with early onset dementia may not fit under an umbrella of older people. More condition-specific planning may also be a way to adequately provide more tailored care to people at different stages of conditions, with one of our unpaid carers suggesting that there needs to be greater recognition of “*early onset dementia as all services are [currently] geared around older people*”.

Finally, hopes were expressed that the NCS would ultimately lead to a more complete integration of health and social care. Though Scotland has been working towards integration care for some eight years, there has been widespread acknowledgement that this project remains incomplete (Feeley 2021). One of the major tensions in this has been around the balance of power between the two institutions, with integration having tended to favour a more medicalised approach (Caird & French, 2021). This has resulted in the more social emphasis of the third sector and social care having a lesser voice at the table.

This debate was reflected in some of the discussions with our members. Some people living with dementia and unpaid carers expressed a desire to have dementia understood more as a health condition. As one of our contributors stated:

My Alzheimer’s disease is [a] disease, it’s very clear cut. So, if I have care needs as a result of that disease, those are because of an illness. They’re not because of something else, and I think we and the system very quickly lose sight of that. – **Person Living with Dementia**

On the other side of this, another of our members with dementia expressed a desire for a care service “*concentrating on my other problems, not just dementia*”. This social approach has been reflected in the growth of the Dementia Friendly Communities movement in Scotland and beyond (Christie et al., 2021). These locally based community projects have emphasised the extent to which people living with dementia can and do continue to live well with the condition, and contribute towards their communities in a meaningful way. We see clear congruity between these aspirations, and the rights-based aspirations of the National Care Service. However, the potential of this to be realised risks being undermined unless

there is a clear shift of both power and resources from medical to social in the integration project.

Financial Constraints

Finance seems to be above social work. – Former Unpaid Carer of a Person Living with Dementia

Our contributors were aware that budgeting considerations will play a huge part in the final form the proposed National Care Service takes. A concern raised by one professional related to the potential financial oversight that the NCS may have. The professional shared that they felt local authorities currently top up or “*put money in when there’s an underspend to accommodate overspends that are made with social care*”, and questions were asked as to how they would circumvent if this mechanism was removed. This may have been reflective of the particular local authority this professional was from, as this view was not echoed in the experiences of most local authorities.

It was noteworthy that budgets and accounting were a common theme raised by people living with dementia and unpaid carers too. People with lived experience communicated concerns that they felt care plans were dictated by strict budgets within council and local authorities, rather than focusing on person-centred outcomes. Those with direct experience of the system, were under the impression that council staff were instructed to prioritise keeping within budget, instead of granting additional spending for situations that catered to complex requirements. Although this could be a natural result of the increasingly constrained budgets of local authorities (Scottish Government, 2021a), the fact that losses are seemingly being regained from those most in-need, including those with dementia and unpaid carers, is a cause for alarm. This scarcity of access to social care resulting from funding restrictions is reflected in ongoing conversations with our members about access to social care and in particular access to Option 1 and 2 of SDS. This is also evident in recent research conducted by the Scottish Government in partnership with Alzheimer Scotland and Age Scotland into the use of SDS among people living with dementia (Scottish Government, 2021b). In particular, over half of respondents had found it difficult or somewhat difficult to access SDS, and nearly a quarter had never heard of SDS before the survey (see below for more commentary on SDS). The funding of the system is a matter that is yet to be fully addressed, but will nevertheless be key to whether the aspirations of the proposed new systems of personalised, human rights-based and preventative social care can be realised. We urge the Scottish Government not to shy away from this debate, but to embrace it openly in the same spirit in which they have approached the reform agenda.

Improving Care for People

Self-Directed Support (SDS)

Access to SDS should be made a lot simpler and easier. I think that'll make a huge difference. Absolutely massive difference. The fundamental idea is brilliant but it's not [being] used to its potential, and it should be. – Person Living with Dementia

When addressing the consultation documents, many of those involved in our engagement sessions and other research were surprised by the seeming lack of concrete detail on how SDS was going to be improved and expanded. Despite the paper referencing the recently published Framework of Standards (Scottish Government, 2021c) intended to support SDS, many people with dementia and unpaid carers expressed concerns with current eligibility criteria being used at a local level.

Consistent, flexible SDS was cited by our contributors as one of the most effective ways to improve care for people with dementia and support for unpaid carers. Throughout our engagement, people with lived experience pointed to a lack of implementation as one of the key barriers to preventing the success of SDS. Many of the people living with dementia that we speak to have asked the criteria set by local authorities to be addressed. Activists we engage with believe the emphasis on 'critical or substantial needs' in order to access SDS inhibits a preventative approach to social care. Therefore, many people who responded felt NCS proposals failed to give detail as to how identified barriers could be overcome. Nevertheless, the benefits of this form of delivery were recognised as numerous and varied including the potential for a preventative approach to social care as articulated by Feeley (2021). For people with dementia, it was seen as “game-changer” and a “gentle touch” approach that would save national and local authorities “lots of bucks” through lower hospital admissions and crisis interventions brought on by user and carer stress. Further examples of positive potential uses of SDS were mentioned, including using funds to travel to peer support services.

For unpaid carers, the benefits are of equal measure. One unpaid carer who managed to access SDS spoke of the control it allowed them and the benefits of “employing my own staff who got to know my situation”. Equally, the access to SDS allowed this unpaid carer to access a break from direct caring as “I got that time when they [formal carers] were in the house, but I was there too doing other things”. The benefits were not universally acknowledged however, with one carer responding to our survey remarking that it was “not an option unless [you] have support from family who are able to devote a lot of time to sorting and dealing with [it]”. This highlights the ongoing challenge with some of the administration requirements of SDS for those in receipt of Option 1 direct payments. It also

underscores the extent to which the current system has not yet realised the potential of Option 2 packages, which would enable individuals to exercise significant choice and control without being responsible for administering payments or acting as employers. There are some good practice examples of using option 2 that we are aware of from partners working at a local level, and we would hope that a benefit of a centralised approach might be that there would be better mechanisms for sharing and learning from such examples.

For some who had managed to access SDS, the journey had been arduous. One person with dementia articulated *“dealing with a local authority [is] like going into battle”*, with re-assessments of SDS producing anxiety that funding would be removed or reduced. Amongst unpaid carers, it was a similar story for those that eventually qualified, with one unpaid carer stating that it took *“nearly three years”* to get SDS. This process was also described as extremely complicated by said carer and that it was *“like pulling teeth”*, despite the amount of funding in question being relatively small.

In addition to our own engagement, access to SDS was a key theme raised at the Deepness 100/6000 Conference. As part of a workshop on the NCS, attendees living with dementia were asked to create a board which reflected their ideal NCS. All groups who took part championed SDS as an integral part of their imagined NCS model, and the sentiment was [captured effortlessly by one attendee](#), *“We’d like easier access to SDS. We’d like easy access to peer support. Simple easy things!”*.

The benefits and challenges associated with SDS have been themes that we have come across time and time again during the lifespan of the About Dementia project. In our Manifesto, published in the build-up to the Scottish Parliamentary Elections in May 2021, we called for SDS to be made *“available early, and with genuine choice and control”*, with access to all four options for people living with dementia. Equally, we called for *“guaranteed specialist independent advocacy to support access to SDS as part of the National Care Service”* (About Dementia, 2021). We note the precedence given by the Scottish Government in regard to Independent Support and Advocacy within the SDS Framework of Standards, which suggested that *“people are offered independent advice, support and advocacy to have choice and control over their social care and support and to exercise their human rights”* (Scottish Government, 2021c). Advocacy is a highly specialised area of work requiring significant expertise on the part of the advocates. However, people living with dementia may need additional specialist support to enable them to benefit fully from such services. We are aware of a critical lack of dementia specialist independent advocacy in Scotland. This must be addressed, and fully funded if people living with dementia are to be able to fully enjoy the benefits of personalised social care.

If the National Care Service is to take on responsibility for the enforcement of these standards, it will also need to build in a model of independent advocacy provision as a point of necessity. Equally, we have heard impassioned pleas from our contributors, that people with dementia and unpaid carers *“need to be involved in*

discussions on eligibility because that's the crucial part". The recurrence of the theme of eligibility during our engagement went far beyond the references included in the NCS Consultation. Therefore, we would highly recommend that the Scottish Government investigate the eligibility criteria in the design of the NCS.

Skilled, highly trained workforce

If I'm looking for one thing, I'm looking for a skilled, highly trained workforce across health and social care. As a carer, that's what I always wanted. – **Former Unpaid Carer of Person Living with Dementia.**

Recruitment and retention problems in the social care sector continue to grow. Professionals that we spoke to were acutely aware of these challenges, both from first-hand experiences within their own organisations and via conversations with their networks. The mainstream media is beginning to give greater and greater focus to the issue, with the effects of Covid-19 and Brexit being cited as contributing factors for some of the most widespread staff shortages the sector has ever seen (BBC News, 2021).

The impact of staff shortages was something noted by our contributors, with some suggesting this would need to be addressed as a point of priority before any plans for a National Care Service take shape. Indeed, as we outlined the scope of activity proposed to be provided through the NCS, one of our professionals asked "*where are all the staff members coming from to deliver this?*". For another unpaid carer responding to our survey, the key was to conserve staff resources by allocating services "*according to need, rather than location*", with towns with younger demographics having "*very different needs*" to those with a larger percentage of older people. Although such a suggestion may be noteworthy when considering strategies related to staffing, it is also worth pointing out that many people with early-onset dementia may find it difficult to access age-appropriate care in such a scenario.

The Scottish Government have responded to the staffing shortages by making multiple funding commitments to recruitment and retention in health and social care within an overall package of £300 million for this budget year. Measures included a commitment to recruiting 1,000 additional health and care support staff to deal with patient flow and delayed discharge, and the establishment of "*new multi-disciplinary teams*" to support people "*as close to home as possible*". The commitment that grabbed headlines was £48 million in funding to support employers to provide a minimum hourly rate of £10.02 for staff offering direct care within adult social care (Scottish Government, 2021d). Unions, opposition parties, and even some members of the government, have insisted that a £15 an hour wage is the least that is needed to attract and retain staff within the sector (GMB Union, 2020; Scottish Labour, 2021; Scottish Greens 2021). As the Independent

Review of Adult Social Care in Scotland also suggests, the creation of a “*national forum*” to take the lead on “*collective bargaining of terms and conditions*” would also be useful in securing such a wage (Feeley, 2021). Other organisations (including Scottish Care) have highlighted that pay increases are only one factor in addressing staff shortages. Of equal importance is creating a working culture where staff feel valued and where “*parity of access to training and development with the NHS*” is created to allow workforce development (Caird & French, 2021).

Involvement of communities and third sector

It's vital that we make sure that the community and the third sector are properly appreciated in what social care is. Social care isn't just someone going in to provide care at home. It's lunch clubs, it's memory cafes, it's all those things that are happening in our community and I think they really need to be properly valued, which I don't think they are right now. – Third Sector Professional

The strengths of community, peer and third sector support have never been more evident than during the pandemic. Essential social care services stopped or scaled back their support practically overnight whilst in contrast community and third sector support were “*the ones on the ground, supporting people straight away*”, reacting swiftly to fill in the gaps left behind. The power of community, third sector and peer support was heavily praised by the people we engaged with. Many pointed to community-based support as an important mechanism for prevention of crisis, and they were pleased to see this recognition in the NCS Consultation. However, some felt the connection should be emphasised more:

I think we really need to appreciate how vital communities in the third sector are [to] that preventative approach ... often being the first point contact – Third Sector Professional

Professionals who worked in the third sector identified a key benefit their approach being that “*people open up because they know you're not from a statutory organisation*”. In reference to this opinion, it's worth revisiting Feeley's recommendation (Feeley, 2021) that we should not be aiming to formalise or medicalise social care support. It is clear there is a separate and special value to be gained from informal community led approaches.

Nevertheless, third sector professionals communicated an uncertainty about the future of the work they do:

I think there's massive, massive weight on the voluntary sector's shoulders ... sometimes you don't get told what your funding is going to be ... until actually you're halfway through the year. – Third Sector Professional

It is incredibly difficult in this context for third sector organisations to plan and build resilience. The lack of reference to specific funding and support for third sector and community-based approaches was described by one professional as, “a huge issue and not addressed in this at all”.

Similarly, the role of peer support in the form of people with lived experience coming together to support each other (either at a local level or nationally in the case of About Dementia) has been an important theme in our engagement. A key recent example of this was the Deepness 100/6000 conference, which has been described as an example of “*peer support in action*”. Many of the attendees living with dementia took centre stage to share the difference that peer support had made to their lives:

I felt alone in the world and that needed to change. The biggest reward for me is friendship[s] that have grown. The power of friendship can never be underestimated. It is more powerful than any medication in the world. Peer support is like a hug & that hug takes all the pain away. – **Person Living with Dementia at Deepness 100/6000 Conference.**

The same delegate spoke of the advantages they experienced, “*I feel understood, respected & lately I feel more empowered*”. Other conference speakers, all of whom were living with dementia, reflected:

It’s fabulous, it’s cheap, effective and there’s lots of cake. You can laugh, cry and be yourself. But the problem is it happens by chance, and it shouldn’t. – **Person Living with Dementia**

The importance of peer support was also a strong theme in delegates’ depictions of their ‘ideal National Care Service’ (see above) enabling them “*to sail through stormy weather*”. Participants spoke of this giving them “*purpose in life.*” The benefits of this as an approach to both pre and post-diagnostic tool were evident:

It’s about enabling people, acceptance & recognition. Peer support has been a great lifeline. Post-traumatic stress after diagnosis can be converted into post-traumatic growth. – **Person Living with Dementia**

The domino effect of representation throughout the conference was palpable and inspired several attendees to accept their diagnosis: “*After 3 years of dementia, I’ve come to terms with it*”. For this, and many other reasons outlined, we ask that any National Care Service instils peer support as an integral part of support and care. We believe peer support is an effective tool to improve connection, reduce isolation and improve one’s own understanding about the condition they are living with. Another example of effective peer support can be observed from the STAND group in Fife, who were noted in our consultation as a group to look to as a shining example of good practice in this area.

Right to “respite” or breaks from caring

A word that keeps coming to mind is balance. We can't suit all of the people all of the time... Yes, recognize the hours and the input that you're doing, but collaborate and discuss what is best suited to that individual. It won't always be the same. –

Former Unpaid Carer of a Person Living with Dementia

As we are all aware, the Covid-19 Pandemic has brought unprecedented pressures on our social care services. But these pressures have been felt just as strongly (if not arguably more so) by unpaid carers. Crucial services, such as day centres and support groups stopped almost overnight, and in many cases, remain closed to this day due to infection control measures and lack of staff available. Many people living with dementia had their care at home packages reduced, which had a knock-on effect on carers, many of whom were juggling family and/or work responsibilities:

I was also working from home and he couldn't get used to the idea that even though I was in the house I was working. It was 24 hours a day, 7 days a week on duty and it was exhausting –

Current Unpaid Carer of a Person Living with Dementia

Research conducted by Carers UK demonstrates that during the pandemic, unpaid carers saved the Scottish Government £43 million every day (Collie, 2020). However, this figure does not incorporate the millions saved by the hospital admissions and interventions that were avoided thanks to the continuous support given by unpaid carers and supporters since 2020 when the research was conducted.

Unpaid carers, however, need their own support, notably in terms of so-called “respite” or regular breaks from caring. The form that such breaks take within the NCS was one of the significant issues discussed throughout our consultation engagement.

Even before discussing the details of support, the term “respite” was the source of much debate. Many of our contributors, especially professionals, felt the word “respite” had significant negative connotations and that it “*smacked of getting away from some sort of punishment*”. Alternative terms such as “*people having support at home*” and “*holiday break*” were suggested as more appropriate. It was suggested by one professional that there needed to be a less contentious term established with an acknowledgement that “*the person who needs support and the person who gives support in a relationship both need breaks*”. As with the consultation document, for the purposes of this response, the term “*breaks from caring*” will be used to refer to future planning of this service.

One of the more developed parts of the proposals contained within the consultation papers suggests that breaks from caring could be either standardized or personalized. This theme was one of our most engaging posts covered by our 'NCS Twitter Takeover.' The relative anonymity afforded by the platform may have allowed carers to be more frank with their thoughts. One unpaid carer countered our question on the topic by asking "*What's a break?*", exemplifying the lack of support available. Another unpaid supporter had a simple request, "*I'd like to just get more than one meal a day, as at the minute I'm not getting time for that*". Our Twitter interactions also shared the general scepticism that we have experienced throughout our engagement on the NCS:

Fixed entitlement definitely! Not sure how this will be implemented? Can't get assistance as it is. Who would take over, while the unpaid carers take 5 hours off? – **Twitter**

Engagement from an Unpaid Carer

Although some carers did express a preference for standardised care breaks, many felt that by receiving statutory breaks, "*at least it's something that you are entitled to and you [have] the right to claim that*". This quote highlights the compromise that some carers feel they have to make in order to receive any breaks or support. Unpaid carers acknowledged that "*everybody's situation is different*", with some even suggesting that they would be willing to sacrifice some of their own breaks and to "*be on the losing side, as it were, for people that need an awful lot more*". Whilst this illustrates the understanding and compassion displayed by peers, it may also be considered as reflecting an overstretched care system that carers have, unfortunately, grown accustomed to.

The dichotomy presented within the consultation document between a standardized number of hours for all and a more personalized amount for some was considered by some to be a false one. As one of our unpaid carers acknowledged, there is surely room for personalization beyond a right to a basic number of hours enshrined in legislation. The unpaid carer in question suggested that an entitlement to a basic number of hours could be beneficial to immediately gain access to breaks and to simplify the mechanism of assessment, which can be extremely stressful. One unpaid carer also felt that a "*personalized system linked to Self-Directed Support*" would be an effective mechanism for enabling this approach.

Contributors highlighted that the types of breaks from caring offered to unpaid carers should be equally personalized. Many unpaid carers and professionals have had negative experiences accessing previous respite services, with traumatic stories of family members going into hospital or care home settings whilst respite was occurring. Unpaid carers often spoke of "*still being on alert*" when they are on care breaks, and this should be taken into account in any future design for breaks from caring. Those who had used existing "respite" packages also spoke of variable locations at which the person they cared for was to be placed, with one unpaid carer having their relative placed 40 miles away. Concerns were also raised that, in care home and hospital settings, respite services were used as an opportunity to

independently assess people with dementia without their unpaid carers present. Any National Care Service should also have an understanding of the unique circumstances of those living with early-onset dementia. One carer noted *“there is very little for younger people with the disease and even less for their carers”*. The same carer told us that there is no local respite suitable for her husband to attend due to him being aged under 65, and therefore no options for a break. The carer also confided in us that even if it were, she would feel guilty for placing her husband in respite in a care home setting, as it would not be age appropriate.

Breaks from caring took on a number of different forms for the unpaid carers that we spoke to. For some, in-house support was absolutely key, allowing them to get out of the house while knowing that the person they cared for was in a familiar setting. For others, day care services represented a regular break from caring, even if only for a few hours. Peer-support groups and activity clubs designed with dementia in mind were also viewed as providing a break, often with the cared-for individual returning home in a more positive mood than when they had left (Kirrie Connections, n.d.; STAND Kirkcaldy, n.d.; St Andrew’s Church, Carluke, n.d.). However, it is worth noting that whilst many unpaid carers may view day services as providing a break, day services are based upon the requirements of the person living with dementia and not their carer. Relying on day services puts carers in a precarious position, as their only break from caring will be led by what support the person living with dementia is assessed for. Therefore, ‘breaks’ could be easily lost if a person living with dementia exceeds support that is manageable within a day centre setting. We believe that carers should be entitled to their own personalised support, instead of relying on secondary services to gain breaks to fulfil basic needs such as resting or preparing food.

Finally, it was acknowledged that some unpaid carers would prefer not to go away without the person they care for and that retreats where carers were on hand to *“take a bit of the pressure off”* would be ideal in these cases. Our 2021 Manifesto for the Scottish Parliament Elections also highlighted the aspirations that many carers have beyond their caring responsibilities, and the importance of personalisation to enable carers to continue to do the things that are important to them. This could be to engage in a creative outlet, or take part in a physical activity, or even to undertake education or training to support them to re-enter the labour market if they are able to do so in the future. Our proposed ‘Carers Development Fund’ could be one such model that could be enabled through greater provision of support for unpaid family carers, that looks beyond the traditional framework of ‘respite’.

Using data to support care

The amount of time I've spent telling the same story to numerous different agencies including doctors and occupational health is [upmost] in my mind, the story goes on. Each and every one of them should be able to access a level of information. – **Current Unpaid Carer of Person Living with Dementia**

Through our engagement, we were given numerous examples of data-related issues in the current system of adult social care and related health care services. Fundamentally, contributors were in agreement that the current level of information sharing within and between organisation was an ongoing impediment to good care. People with dementia were stunned by the fact that a detailed medical record in one part of the country could not be accessed in another local authority, or even by a different service operating within the same local authority. As one person living with dementia stated:

I've spent hours saying to health professionals "Why aren't you referencing this data?" I've spent hours doing tests but they've gone nowhere. They're not used. – **Person Living with Dementia**

Another person living with dementia found it appalling that “no local authority can access the NHS system to see what's wrong with someone they're bringing into a care home”. Equally, the accuracy of certain records was called into question with examples of healthcare staff “scribbling down a couple of paragraphs” without checking the information with the patient first. One unpaid carer complained about having to send the same power of attorney document to several different healthcare providers, even though some admin staff “don't even know what power of attorney is and what it relates to”.

The fact that so much of the national and local NHS systems are “simply not set up to share information” was seen as having a number of negative effects. For many people with dementia and unpaid carers, it meant repeating assessment processes, described by one carer as “the worst part of caring”. In one case, as many as five different health professionals wanted a “blow by blow” account of a fall that a person living with dementia had had, a particular draining experience for the unpaid carer responsible for relaying this information. Poor data-sharing between mental health and physical health professionals was cited by one unpaid carer as preventing a “joined-up way of working” that would save a lot of time, energy and resources. As one care professional saw it, the lack of availability of information around care plans was particularly detrimental:

You can't provide personalized care or person-centred care without knowing the ins and outs of a person, which is contained within a care plan. – **Care Professional**

Both people with dementia and professionals also identified a lack of communication between local authorities and NHS IT systems as adding to the increasing issue of delayed discharge.

Unsurprisingly, with so many issues arising from poor data-sharing practices, the people living with dementia and unpaid carers that we spoke to had few objections to their data being shared in a more liberal manner if it has the potential to improve quality and integration of care. Many understood that others may have objections on privacy groups, but, as one person with dementia commented “*I couldn’t care less if you put my medical information on the front [page] of the Scotsman*”. For another person living with dementia, a system that “*you can just tap into and get all of a person’s details*” was seen as ideal. One unpaid carer expressed a similar sentiment, stating:

As far as the sharing of data is concerned, I don’t have any issues. I’m pretty sure Tesco know more about me and my doing than anyone in the NHS. And if I don’t have a problem with Tesco knowing about it, why should I have a problem with an entity that’s actually going to help me make my life easier and help the person that I care for? – **Current Unpaid Carer of a Person Living with Dementia**

Despite the desire for the freeing up of relevant patient data, one third sector professional was quick to point out that GDPR and confidentiality issues would still be prevalent in any new system, as “*there will always be at least one person that may cause an issue*”.

One carer, who provided support to their son living with dementia and other complex health conditions, felt strongly that service should allocate time to obtain information themselves when they first meet and interact with a new service user. To this carer, relaying information that other services may already have was not seen as a “*waste of time*” but instead “*really important*” to better understand the person who will be cared for. Whilst some people had concerns about expanding the amount of people or services who had access to sensitive information, for many of our contributors, the proposed plan to free up data records through the NCS proved popular. However, this was very much considered as an ideal in theory, with people living with dementia from public sector backgrounds in particular questioning the feasibility of such plans. One person living with dementia commented that:

Local authorities will not run the same operating systems. Even the NHS boards probably don’t, but the local authorities certainly don’t. So, merging everything into one system would: a) cost too much; b) take too much time; and c) there would be too many errors. So yeah, this is what we need. But by the time it’s set up, we’ll all be dead and buried. – **Person Living with Dementia**

There was further agreement that the job would be simply too large and unwieldy in scale and that you would “*really want someone who knows how to manage the information*” involved in the design. Scepticism on this front was also evident in the wry comment by one person living with dementia who noted that “*banks can sort out their IT systems, but governments can’t because they keep getting shafted by IT companies who are cleverer than they are*”. Professionals agreed (although slightly less directly than this individual) that millions had been needlessly wasted “*trying to merge systems between primary and caring roles*” in the past without success.

For long-term campaigners and professionals working within dementia and social care, the lack of progress in data-sharing was a significant source of frustration. One professional remarked:

I started my nurse training in the 1970s and we were having this conversation then. I can’t believe that with the technology we now have available we can’t make this happen. – Care Professional

For another person living with dementia, there had been a clear lack of accountability in terms of previous promises around data-sharing with nobody going back and asking what had actually been done.

With such fragmentation evident between health and social care, one carer we spoke to had developed her own alternative in the form of a paper record. The unpaid carer in question recommended fervently that others do the same, as, sadly, this was the only reliable way to have a comprehensive record of the care her husband had received. Equally, when it came to other assessment for social care, the handheld record proved “*absolutely invaluable*”. One care professional that we spoke to was also working on an alternative source of digital support, working with a “*Planned Date of Discharge group to try and put together what’s known as a carer’s passport, a one-document-fits-all idea*”.

Complaints and putting things right

It’s not easy. No one wants to accept responsibility and accountability. It’s a battle. And you’ve got so much else to be coping with. It’s just not on. – Former Unpaid Carer of a Person Living with Dementia

Another proposal contained within the consultation paper that proved popular amongst a number of our contributors was the reforming and unifying of the current complaints process. As one unpaid carer put it, “*it is absolutely essential that a National Care Service has a strict complaints policy*”, with users of services being able to access appropriate information regarding the complaints procedure. As one third sector professional put it:

People should be encouraged to give feedback, good and bad, and have a forum to do that. People were talking about Care Opinion being a very effective forum within the NHS. So could that kind of forum be something that's considered for the National Care Service? – **Third Sector Professional**

As is the case with many services discussed in the consultation, the desire for reform originates from perceived ineffectiveness of the current system. In particular, both unpaid carers and professionals that we spoke to cited a prevalent fear of retribution when considering lodging a complaint against a care provider or a particular member of staff. One third sector professional spoke of the current complaints system as “*just really off-putting for people who feel that they need to go down the route*”. Most unpaid carers we spoke to expressed concerns about the possibility that support may be jeopardized if they stuck their head above the parapet. One unpaid carer had had a “*horrible experience with a care company*” after raising concerns with a manager over treatment. Retaliation from the employee in question resulted in a serious complaint being made against the unpaid carer, very nearly taking away their right to take care of their loved one.

As detailed within the consultation papers, currently the SSSC responds to complaints relating to social care staff, whilst the Care Inspectorate manages complaints regarding care services more broadly. However, complaints processes surrounding councils and local authority dealings with social care issues were suggested as being inconsistent by some in our groups and non-existent by others. As there is no single entry point for complaints, under the current complaint's system it would be difficult to complain about the length of time waiting for assessments or care packages or to have recourse if someone has been assessed for a service which does not meet their needs. In addition, many people we engaged with shared experiences in which their concerns about social care were not followed up by social workers, or their details have been lost in the system. People living with dementia and unpaid carers do not currently have a formal option to take complaints, such as those mentioned above, further. One person living with dementia expressed, a particular frustration at the lack of recourse when councils failed to provide statutory services:

If what you end up with is a local authority that say, well the fact is we've run out of cash so we're not going to do this. It's too easy for them at the moment to get away with doing this. –

Person Living with Dementia

High levels of staff turnover within the care sector were also cited as having a detrimental effect on any complaints made. One of our unpaid carers had a minor point of complaint that they hoped to have resolved on behalf of their neighbour who also required support from a care provider. As the unpaid carer stated, “*the problem is that with this particular care company, they're all leaving. The manager, the supervisor, they're all leaving*”. Within such a scenario, there was a clear sense

that complaints were being left in limbo. Even in attempting to complain about the staffing issues themselves, one unpaid carer was unable to make headway:

We had just over 130 different carers in the last year of my husband's life. And I tried to go through the levels to get something done about it. Nobody wanted to know. Nobody was caring. – **Former Unpaid Carer of a Person Living with Dementia**

In the face of such inaction, many of our contributors spoke of their ongoing campaigning for changes to the system and, in essence, politicizing their complaints. One unpaid carer spoke of going directly to her local councillor who followed up a housing issue on their behalf. A former unpaid carer even spoke of sending correspondence to the First Minister with great regularity until some progress was made with their issue. The same former carer felt that, following their husband's death, they were able to be “*the mouthpiece for carers as [they've] nothing to lose now*”. Activism is equally on the rise amongst people living with dementia, as was demonstrated by the recent 100/6000 conference hosted exclusively by and for people living with dementia. Activists with dementia are tired of having their condition used as an excuse against them. As one activist living with dementia put it:

I'm involved in a dispute with a government organization at the moment where they're just saying “he's got dementia, therefore he's not entitled to something”. And I think that kind of thing probably happens to people all the time. – **Person Living with Dementia**

Improving the complaints procedure will go some way to assuaging the growing calls for change amongst people with dementia and similar carer organisations. Another equally effective tactic will be to improve engagement and participation with these growing groups of dedicated activists when considering new service design.

Reformed IJBs and Community Health and Social Care Boards

I've got all the information [on dementia care] at my fingertips and I could give them all the information but nobody's listening. – **Current Unpaid Carer of a Person Living with Dementia**

Much has been made of the commitment to increase meaningful participation for “*people with lived and living experience, and carers*” (Scottish Government, 2021e), by reforming Integration Joint Boards (IJBs) into new Community Health and Social Care Boards (CHSCBs). Amongst those not currently active on IJBs, a clear motivation was expressed to become involved in the new oversight boards. One

person with dementia saw such a position as being a way to hold decision makers to account and “*make sure what has been said has been done*”. Additionally, some felt that the Covid-19 pandemic, and the digital acceleration it had caused, had made it easier for individuals with lived-experience to find time to take up such positions, no longer having to travel to meetings. It is also worth considering that during engagement, some felt former carers would be in a better place to take up such positions than current carers.

Almost unanimously, contributors felt that lived experience members of IJBs should have full voting rights in line with other members. This was certainly the case for one long-term campaigner living with dementia who stated “*I’ve been invited to go on many boards. But I won’t go on any of them unless I’ve got full voting rights*”. However, one third sector professional shared reservations:

You don’t want a huge group because if you have too many voting members, you’re never going to reach a consensus. It’s just going to become a talking shop, which again is no use either. – **Third Sector Professional**

The optimism felt by those seeking to join the rebranded boards was sadly contrasted by the sentiments of those that are currently members. A lack of support for people with dementia and unpaid carers whilst on such boards was a common theme. One person living with dementia described being “*not quite sure what I’m doing there*”, and that administration of the boards “*make[s] it really difficult for you to get involved anyway*”. Unpaid carers faced additional challenges, with one carer stating, “*if I wanted to go and sit on one of these board meetings, I paid someone privately to sit with my husband. To me, it’s not respite, it’s hard work*”. The same carer confided that due to the amount of time required they began to resent accepting the board position. Furthermore, a lack of financial support for legitimate expenses, such as to pay for care while they attended meetings, was confounded by an awareness that most others around the table were in executive positions and on very high salaries.

Professionals agreed that support was inadequate, with one professional going further to suggest, “*this idea of representation has failed completely ... and I don’t think I’m saying that too strongly*”. From our sessions, it’s clear that a significant amount of work must be done, to avoid critiques of tokenism on boards. A proposed means of achieving this was to consult with people with lived experience directly about what might enable them to participate meaningfully. One person living with dementia stated:

If you plunk someone with dementia on a board and then pat them on the head and say “we’ve done it”, then yeah, you might have done, but it’s not real. – **Person Living with Dementia**

Worryingly, we were given more than one example of other board members actively subverting processes to include people with lived experience. This included setting up smaller groups out with official board meetings to dictate policy. As one unpaid carer put it, this all adds to the sense that *“We [are] the outsiders, they don’t really want us there”*. Despite these negative experiences, many of our contributors still saw potential in such roles. Even one unpaid carer who had had such a poor experience was adamant that *“it’s an incredibly valuable role because, quite often when representing unpaid carers, I was the only one around the table who didn’t have a line manager”*, identifying the key strength of impartiality of lived experience board members.

To create real, meaningful participation, our contributors had suggested lived experience representatives needed training in two areas. Firstly, participants wanted technical training to more easily be able to allow them to digest the *“pile of board papers which are complex and full of statistics”*. Secondly, as one unpaid carer put it:

We need training to understand the ways they [the board] do things. We also need to understand the rules and regulations behind why they do what they do. – **Unpaid Carer of a Person Living with Dementia**

It was also recommended that training should be extended to other board members so that they could learn how to suitably engage and take on the ideas of people with lived experience. As one former carer put it:

I think it’s not just the representative that needs to have a bit of training. It’s the other people around the table to understand why you’re there. Because people would talk over me, but I had the confidence to say “Excuse me, I’m not here to rubber stamp what you ‘professionals’ are saying. You’ve asked me here, I’ve got a role to play.” – **Former Unpaid Carer of a Person Living with Dementia**

This theme highlights that a major obstacle to increasing support and improving participation on such boards is the attitudes and actions of board administrators and fellow board members.

Whilst on the subject of personnel and proposed reforms to the IJBs, our contributors were keen to see alternative board structures. One unpaid carer warned of *“regurgitating the IJB people”* and hoped *“that we don’t end up just putting the same people in charge as those who previously were unable to properly implement the old system”*.

For others, changes in the ways lived experience participation was managed was key and many carers pointed to the power of peer support in doing so. An alternative suggestion that garnered some support amongst unpaid carers was to include a substitute system, whereby a pool of unpaid carers took their place on

the board when breaks from caring made this available. The carers we engaged with also suggested a buddy system, whereby individual executive board members were tasked with mentoring an individual with lived experience. Whichever model is used, adequate preparation was seen as key “*because it’s going to flounder from day one unless that work is done previous to being set up*”.

To highlight an example of good practice, one carer spoke positively about their experience as a member of a similar board:

It was quite a unique service. We had a public forum where we actually had someone who was appointed to look after us ... The person that sat on the boards and passed all of our information on. – Unpaid Carer of a Person Living with Dementia

In a similar vein, some attendees highlighted About Dementia as a respectful forum to share their views, suggesting that we could play a role in supporting board level discussions. However, we understand that for some, this suggestion may further distance people with lived experience from board representation.

Finally, for those who felt that integration of lived experience members on such boards would be difficult, external accountability processes were suggested. As a person living with dementia asked:

Why don’t we set up our own monitoring and governing group [...] and keep an eye on what ... they’re going to do with this. And as soon as some local authority or whoever drops the ball, then we create a fuss. – Person Living with Dementia

Alternative Solutions and Other Comments

Given that this response process represents the opening round of consultation, many organisations and individuals are still developing their own ideas on the form that the NCS could or should take. However, some ideas have been offered on both the practical workings of an NCS and alternative arrangements that could improve support for people with dementia and unpaid carers.

Scottish Care have been particularly proactive in this area, notably with their *Time for Change* report, released a month before the government’s consultation process was launched (Caird & French, 2021). Responding to the recommendations contained within Derek Feeley’s *Independent Review of Adult Social Care in Scotland*, the report recommends that rather than a National Care **Service** being created, the adoption of a National Care **Framework** should be considered. This would allow a “*shift away from transactional models of care and support towards collaborative, relational approaches which are developed in true partnership with the people they are designed to support*”. The report suggests that this nominal move

away from service provision would allow the government to concentrate on improving national quality whilst *“maintaining local flexibility and retaining the strength in Scotland with having a diversity of providers”*. To support local service provision within this model, the report suggests promoting local social care leadership through specific programs to improve knowledge and understanding of social care amongst community-based professionals. Another of the report’s recommendations involves a clear cultural move away from *“satisfying the system, health designed approaches and clinicalised social care support”* in favour of a type of care that will *“help people live their life in the way they wish with individual choice and independence”*.

The theme of a human rights-based system of support is woven throughout the Scottish Government’s proposals for the NCS. About Dementia used a human rights-based model to inform our Manifesto, published in the build-up to the 2021 Scottish Parliamentary Elections (About Dementia, 2021). During the development of this manifesto, the publications of the Equality and Human Rights Commission (EHRC) were invaluable (EHRC, 2021). In our minds, suggestions contained within the EHRC’s own consultation response should be considered if a truly human rights-based system is the aim for the NCS. Several suggestions have been alluded to within our own response, including the identifying of significant inequalities relevant to social care, the prioritising of local People-led Panels and the creation of a Commissioner for Social Care.

A sound financial perspective on the NCS and its likely costs will be crucial in initial planning stages immediately following the consultation. In its *Program for Government 2021-2022*, the Scottish Government has committed to backing the NCS with *“at least 25% more investment in social care over this Parliament”* (Scottish Government, 2021f). As the Fraser of Allander Institute (FAI) have pointed out, the UK governments raising of National Insurance Contributions will provide extra funding for both health and social care. In the face of NHS backlogs related to Covid-19, what remains to be seen is how much of this extra funding will be ringfenced specifically for social care and, de facto, the NCS’s development. Adequate funding will be key, with the FAI concluding that *“an underfunded National Care Service is unlikely to do any better than the system that it seeks to replace”* (Cosgrove, 2021).

Recommendations

The evidence we have collected through engagement with people living with dementia, unpaid carers, and professionals working in the third sector, prompts us to make the following recommendations in response to the proposals outlined in the consultation.

1. Our members were largely undecided about the change from local to national accountability proposed for the NCS. Some welcomed the benefits of standardisation that this approach would bring, however others were concerned about the potential loss of locally responsive services. What was clear, however, was that change needs to take place which prioritises the needs of social care users first and foremost. The aspirations of the Feeley review to develop a service that is truly person-centred, preventative and human rights-based, must not be allowed to become lost in a bureaucratic turf war between different public sector agencies.
2. Scotland has been ground-breaking with human rights-based legislation surrounding Self-Directed Support (SDS) and the Carer's Act. However, inconsistent implementation has caused this legislation to fail for the majority of people living with dementia and unpaid carers. It is important that the implementation gap is addressed whilst not weakening the existing legislative framework purely for the sake of change.
3. To rectify the 'postcode lottery', enforcement of mandatory equal standards in social care across Scotland must be a primary outcome of any change that takes place.
4. Our members would welcome greater detail as to how the aspirations of the Feeley review will be operationalised in the new NCS. Core to this will be the decision on funding. For our members to continue effective engagement with the consultation, the discussion of finance and funding must not be put off any further.
5. There has been a significant loss of trust in social care policy and delivery in Scotland that pre-dates the pandemic but has been further exacerbated by its impacts. For some, the promotion of the consultation process did not match the significance of this key public reform. To tackle scepticism, future rounds of consultation must be widely publicised, timely, and meaningfully consult on detail to avoid 'death by consultation'.
6. The consultation process should be adapted to offer varied and creative ways to meaningfully engage. People living with dementia and unpaid carers are experts-by-experience and alternative consultation methods should be explored to tap into their specialised knowledge. The process should strive to be accessible to the widest possible audiences and genuine engagement must be reflected in the implementation of any recommendations.
7. When considering proposals to widen the scope of the NCS beyond the Feeley review, people affected by dementia were concerned that their experiences would be minimised. The benefit of attempting less but doing better should not be overlooked. It is important that the new NCS does not lose sight of the change that needs to happen. Where centralisation takes place, a concerted effort must be made to ensure that strategic links between interconnected and interdependent agencies are not lost on local level.
8. The need for dementia specific and responsive services must not be neglected in the pursuit of generalist approaches to social care.

9. Further integration of health and social care should see a greater shift towards the social over the medical, particularly with respect to realising the aspirations of people who use social care in their daily lives. To achieve a preventative approach to social care, third sector and community responses, including peer support, should be appreciated as an integral part of social care and funded appropriately.
10. We believe that Self-Directed Support (SDS) is the mechanism through which Feeley's aspirations should be realised, a view strongly echoed by our members. The National Care Service should aspire to overcome the inequities that have resulted from the implementation of SDS. Under the NCS, the eligibility criteria must be reviewed to ensure that access is available as widely and as early as possible. The voices of people with lived experience of social care must be at the heart of this conversation.
11. Access to SDS should be underpinned by fully funded and specialist independent advocacy.
12. Carers should be entitled to personalised, responsive and preventative care breaks. This should recognise both the needs of the person caring, and their loved one. To value unpaid carers as equal partners in care, investment must be undertaken to ensure equal access to training. We recommend the creation of a 'Carers Development Fund' to support the aspirations of unpaid carers in establishing a skillset catered to their individual circumstances.
13. We support the aspirations for better data sharing between agencies, which may reduce repeated assessment processes. However, IT systems can only go so far. Any system will need to ensure that the formation of relationships between services and service-users is not lost in the process. Connections built on trust and mutual respect between institutions of health and social care will be vital to making integration a reality.
14. We support the concept of a single point of access for complaints. This should include the right to complain about how information has been collected, the manner in which decisions have been communicated and allow opportunity to complain about service provision quality.
15. We support the inclusion of people with lived experience in the reformed Community Health and Social Care Boards as full voting members. Following a suggestion from carers, we recommend existing board members undertake training to understand and value the inclusion of lived experience. In addition, boards must also consider how they will enable local citizens to carry out this role in a meaningful way, including through financial remuneration, expenses to cover care costs (both to attend and prepare for meetings), and provide opportunities for peer support to develop between members.

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